

Online Health Information Seeking Behaviors Among Malaysian Breast Cancer Patients, Survivors And Caretakers: A Content Analysis

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Abstract

Exploring online health information seeking behaviour (HISB) among Malaysian breast cancer patients, survivors and caretakers is crucial in understanding the ways these people used, communicated and disseminated online health information related to breast cancer. HISB has been explored and approached from different viewpoints which include extensive studies on online platform. Nonetheless, such expositions are considered inadequate as studies on cancer related online HISB are still scarce especially among Malaysians. The methodology used in this study is qualitative content analysis. Adapting the Health Information National Trends Survey (HINTS) 2021, the data was collected from 113 respondents via Survey Monkey platform. The users' online health information searching behaviour with regards to cancer information were also investigated. Using content analysis to analyse the data, we identified three overarching themes in relation to online cancer-related information seeking behaviours among them. Three major themes identified are (i) internet as the primary source of cancer-related information, (ii) experience of seeking cancer-related information online and (iii) issue with seeking and sharing online cancer-related information. The findings of this study are of significance for the healthcare practitioners, public health experts and health communication researchers. Future studies should consider exploring how online health information seeking behaviour among these groups can contribute to engaging them to choose credible online

cancer-related information and how these behaviours can help Malaysian health practitioners to offer, disseminate and fulfil the health information needs of these groups.

Keywords: Health Information Sharing Behaviour; Online Health Information; Breast Cancer Information; Content Analysis

Introduction

The advancement of internet has changed the way people seek health-related information and advice. This is due to the fact that health-related information online is easier to access compared to the conventional way of seeking health-related information and advice which are either through medical professionals or books. However, a person needs to carefully choose source of health-related information and advice posted online as there is tendency of misleading information and advice (Wang et al., 2019).

With abundant of misleading information available on internet, internet users can easily find unvetted health-related information and advice. For cancer patients, misleading information on treatment and medication may lead to fatal consequence (Wan Adnan et al., 2019). Therefore, identifying online health-information seeking behaviour may offer deeper understanding on the patterns of information searching which will lead to ways to reduce the tendency of getting the wrong information. This research is a part of a broader study of online information seeking behaviour of breast cancer in Malaysia conducted from 2019 to 2022. In this paper, we aimed at answering the following research questions – What are the online health information seeking behaviour among Malaysian breast cancer patients, survivors and caretakers with regard to cancer information?.

Health Information Seeking Behaviour

The advent of internet has tremendously changed the human behaviour of seeking information. With continuous development of internet and its technology, a person is now able to find any information in just a few seconds through online search engine. This has also affected the way people seek health-related information. The number of internet users who seek for health information continue to increase (Bastani et al., 2022). The percentage of people who use social media to seek for health-related information and advice from peer patients are projected to grow significantly. Internet has become the most favoured source of health information for many people instead of seeking information directly from the medical professionals or doctors (Hesse, Moser & Rutten, 2010). This trend is an important indication that many people around the world rely on online health-related information and advice.

The health information seeking behaviour is defined as an activity with the purpose of obtaining information on health treatments, alternative medicine, nutrition and physical exercise (Niederdeppe et al., 2007). The aim of seeking and receiving health information among individuals are linked to an effort to reduce the uncertainty related to health status and to develop confidence on health-related issues (Chu et al., 2017). These activities include seeking health-related information on remedy for illness, looking for possible diagnosis and searching for ways to prevent an illness from becoming worst (Tan & Goonawardene, 2017). Social media has propelled information seeking behaviour to another level due to the interactive features of social media which allow frequent and user-friendly online activities, thus attracting more users to discuss health-related issues (Zhou & Zhang, 2017). Access to social network through modern devices like smartphones or tablets, provide easier access to any online information. With the abundance of health-related resources available online, one

in four internet users will discover the people with the same disease in order to exchange information and opinions (Fox, 2011).

The shift in the fundamental health information seeking behaviour marks an important view that doctors and medical professionals have less control on health information relayed to their patients. Patients now have more control over the information that relate specifically to their disease. At the same time, it arises various questions and views on the use of online platform as a source of health information and advice. Although health literacy is believed to be a crucial factor in determining the behaviour, one of the recent studies in Malaysia (e.g. Nor Intan Shamimi & Nurul' Aini, 2018) assert that youngsters (at tertiary level) who frequently engaged in health-related discussions had better online health literacy and were more likely to perceive intention to seek and evaluate health information.

In relation to the current study, the exploration of online cancer-related information seeking behaviour will help to unravel how these behaviours can enhance patient and caretaker's involvement with medical decision-making and improve medical professionals' communication with patients and caretakers (Rutten et al., 2019).

Methodology

Adapting the Health Information National Trends Survey (HINTS) 2021, the data was collected from 113 respondents via Survey Monkey platform. The Health Information National Trends Survey (HINTS) was developed by the National Cancer Institute (NCI), the United States with the aim of identifying public's knowledge of, attitudes toward, and use of cancer-and health-related information (NCI, 2021). The participants were recruited from local cancer support groups on Facebook. The participants were only selected among Malaysian breast cancer patients, survivors or caretakers.

As this study is a qualitative study, the survey was analysed using content analysis by Burnard (1991). Content analysis was used as the analytical tool to analyse the survey's open-ended questions with the purpose to code these responses into a meaningful set of categories (Lavrakas, 2008). Using content analysis as a research method requires adherence to specific research process. Fundamentally, there are three main processes involve which are (i) planning, (ii) data collection and (iii) data analysis. The results are presented in the form of frequency for participants' demographic characteristics. Other items from the survey are presented in themes as to enable the interpretation of the results (Burnard, 1991). Although we included the frequency count of the demographic characteristics, this study is still considered as qualitative content analysis as the purpose is to understand the magnitude of a phenomena clearly (Berg & Lune, 2012).

To ensure the quality and trustworthiness of the data analysis, two intercoders were asked to conduct the analysis separately, compare results and come out with the consensus. To present the results of the study, the analysed data is presented as *themes* with the rationale that they are able to unravel the underlying meaning on an interpretative latent level of analysis (Graneheim & Lundman, 2004).

Result

113 participants completed the survey questionnaire via Survey Monkey. Table 1 shows the demographic characteristics of the participants.

Table 1: Demographic characteristics of the participants

Characteristics	Description
Age	19 – 63 years old (average – 45.3 years old)
Gender	%
male	2.5
female	97.5
Participant category	%
breast cancer patient	84.8
breast cancer survivor	10.1
cancer caregiver	5.1
Educational level	%
high school	27.8
college degree	50.6
postgraduate degree	12.8
others	8.8
Access to internet	%
yes	100
no	0

The participants of this study ranged from 19 to 63 years old with an average age of 45.3 years old. 97.5% of them are female. Breast cancer patient made up the highest category of participants, followed by survivors and caregivers. In terms of education background, 50.6% of the participants have college degree. All participants are identified to have access to internet.

Our data analysis from the online survey led to the identification of three major themes that lead us to understand online health information seeking behaviour among Malaysian breast cancer patients, survivors and caretakers with regard to cancer information. These key themes and findings are presented in the discussion section.

Theme 1: Internet as the primary source of cancer-related information

Theme 2: Experience of seeking cancer-related information online

Theme 3: Issue with seeking and sharing online cancer-related information

Discussion

Theme 1: Internet as the primary source of cancer-related information

Although this study explores online cancer-related information, in one of the survey items, the primary source of cancer-related information was sought. Our data analysis revealed that the internet is the primary source of health information among Malaysian breast cancer patients, survivors and caretakers. Apart from the internet, other cancer-related information is sought from medical professionals, cancer-related organisations and medical brochures. Since the internet is the primary source of cancer-related information, 92.1 percent of our participants used Internet search engines such as Google, Bing, Microsoft Edge and Safari

when they looked for cancer-related information online. Our participants reported it is easy to get cancer-related information that they wanted online compared to other information sources with social media as one of the most sought sources. The existence of social media has propelled information seeking behaviour to another level due to the interactive features of social media which attract more users to discuss health-related issues (Zhou & Zhang, 2017; Choudhury et al., 2014) and exchange health information and advice (Samy et al., 2020). This finding in particular suggests that vast amount of breast cancer-related information is available online. The data analysis also revealed that our participants agree that online cancer-related information is trustworthy if it is written by medical professionals, breast cancer survivors/patients themselves, government health agencies and cancer-related organisations.

Our participants were also identified to use the internet to look for both medical and non-medical related information on breast cancer. For medical-related information, our participants looked up for the interpretation of medical results, breast cancer symptoms and recurrence symptoms, breast cancer patient diets, ways to reduce chemotherapy effect, and types of cancer treatment. For non-medical related information, participants use internet to look for Malaysian medical experts in oncology, treatment costs, complementary and alternative treatment, vitamins for cancer patients, and online support group for cancer patients. These results corroborate the findings of Wan Adnan and Ibrahim (2017) who explored breast cancer survivor blogs as source of information for breast cancer patients.

Theme 2: Experience of seeking cancer-related information online

Our results indicate that seeking online cancer-related information has always been a positive experience among our participants, which outweighs the negative experience. We investigated whether or not they needed a lot of effort in order to find information related to breast cancer to which majority of our participants disagree. In fact, when they sought for cancer information online, they did not have any difficulty in getting the exact information they were looking for.

Another important finding of this study is cancer patients, survivors and caretakers are also concerned on the accuracy of medical-related information online in which they will trust online source written by medical professionals, organisation or experienced patients more than any other source. This finding also accords with Samy et al. (2020) where they argue that there are concerns surrounding the accuracy of information and reliability of health information available online. In the case of information shared by cancer survivors, past studies report that chronic illness patients are able to use complex medical-related terminologies correctly especially when describing their specific illness situation on diagnosis, treatment and disease management during patient-to-patient interactions (Fage-Butler & Jense, 2016). Fage-Butler and Jense (2016) also contend that information provided by lay people online are not meant to challenge professional knowledge or assume roles as an expert, but it serves as an avenue to share experience and knowledge, guidelines for future actions, raise awareness on the condition or situation and provide support to those with the same situation.

Theme 3: Issue with seeking and sharing online cancer-related information

Although majority of our participants earlier reported that it is easy to obtain breast cancer-related information they want, 13 percent of the participants mentioned that some cancer-related information are difficult to obtain. The information includes how to choose which

doctors are the best to do breast cancer operation (general surgeon/breast and endocrine surgeon), post treatment care (e.g. post mastectomy care), institutional support system for patients and detailed and patient-friendly information of the drugs prescribed for breast cancer patients. From the analysis, we deduce that given the vast information available on internet, some information can only be sought from the specific person or source (e.g. pharmacists are able to explain the drugs prescription and post mastectomy care can be shared by cancer survivors/patients who had undergone mastectomy successfully).

Another important finding is Malaysian breast cancer patients, survivors and caretakers showed concerns surrounding online information on complementary and alternative treatment (CAM). What is interesting about this finding is, some participants believed that CAM works wonder to treat cancer and some participants totally defied the idea of treating breast cancer using CAM. Our findings identified that a number of participants who looked for CAM information online, read CAM research articles published in well-known journals which suggest some participants used scientific explanation before making decision to take up any treatment type. Our findings explain further Zulkpli et al's (2018) findings as they identified that a number of Malaysian breast cancer patients in their study opted for the CAM treatment (especially dietary supplement) before seeking medical professional treatment.

Conclusion

The study aims at exploring online health information seeking behaviours among Malaysian breast cancer patients, survivors and caretakers with regards to cancer-related online information searching. The study fills in the knowledge gap related to online health information seeking behaviours among Malaysian breast cancer patients, survivors and caretakers as there has been a scarcity in the research area.

This study has identified three main themes in the behaviour of seeking online health information with regards to breast cancer – internet as the primary source of cancer-related information, experience of seeking cancer-related information online and issue with seeking and sharing online cancer-related information. Taken together, these findings suggest that internet can be a useful information source for breast cancer patients, survivors and care takers. Nonetheless, the unvetted information may lead to the danger of misinformation, hence it calls for medical professionals, public health related agencies, or breast cancer advocates' roles to create awareness among public to be able to discern between reliable and unvalidated breast cancer information available online.

Although small sample size in this study is sufficient to achieve theme saturation in qualitative study, a larger sample would contribute to a better understanding of online health information seeking behaviour and enable better exploration of participants' experiences. We also propose that future studies should look into how online health information seeking behaviour among these groups can contribute to engaging them to choose credible online cancer-related information and how these behaviours can help Malaysian health practitioners to offer, disseminate and fulfil the health information needs of these groups.

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