

Information Giving in Malaysian Breast Cancer Survivors' Blogs: A Thematic Analysis

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Abstract: Communicating online has become an essential human activity. This includes exchanging information and sharing experience related to health and illness in an online platform such as social media, forums and blogs. Breast cancer survivors' blog is one of the growing sources of information which internet users sought. Past studies suggest that different kind of breast cancer information is shared through blogs from jargon-packed medical information written by professionals to lay medical information written by breast cancer survivors. Notwithstanding, little is known about what kind of information available in Malaysian breast cancer survivors' blogs. The purpose of this paper is to examine the information provided by Malaysian breast cancer survivors through their blogs using thematic analysis. The data was drawn from three Malaysian breast cancer survivors' blogs with a total of 240 blog postings. Atlas.ti software was used to analyse the data. The analysis yielded two main themes: Medical information giving related to breast cancer and non-medical information giving related to breast cancer. It is assumed that non-medical information related to breast cancer is the most predominant information throughout Malaysian breast cancer survivors' blogs. It is also learned that information provided by Malaysian breast cancer survivors is not meant to challenge professional knowledge or assume an expert roles but it serves as an avenue to share experience, knowledge and raise awareness on breast cancer. The findings of this study provide an indication of the potential role of blogs as one of the platforms to disseminate health information in Malaysia.

Keywords: information giving, breast cancer experience, breast cancer survivors' blogs, health communication

Introduction

The advent of Internet allows more individuals to seek and exchange health information online especially among those who have the same health concern. In the case of breast cancer, internet has been used by breast cancer patients and survivors as a medium to provide information on their cancer experience (Foley et al. 2015) and find cancer-related information. Previous studies (e.g. Thielst , 2007; Kim, 2009) suggest that blogs have become a well-known health communication media among cancer patients, their families and health care professionals. Blogs which discuss a person experience with a health problem are among the most popular type of health-related blogs (Miller and Ole, 2010). It is also learned that the highest number of bloggers in health-related blogs is the female breast cancer patients or survivors (Quinn et al, 2013). Considering the load of breast cancer information disseminated through blogs, analysing the content of these blogs justifies the potential of blogs as a health promotion tool.

Ideally, information giving in health context is divided into two types, namely, expert and lay information. According to Schildhauer (2015), lay information is based on a person's personal experience to which it is disseminated at individual and at a more general level. In contrast, expert knowledge refers to knowledge based on professionals or experts decisions. As Nordin (2000) posits, expert knowledge is related to medical professional experts' knowledge and personal evaluation which is based on their medical knowledge.

Breast cancer patients/survivors blogs are classified as personal blogs which suggests that it is written and managed by patients who are considered as laymen with lay knowledge. It is evident in past studies that personal illness blogs provide construction and dissemination of lay theories (Schildhauer, 2015). This sparks a few arguments on the credentials of information given by a lay person through personal blogs. Although there have been a few studies on information giving in breast cancer blogs, little is known about the information available in Malaysian breast cancer blogs.

This study seeks to shed some light on information giving in Malaysian breast cancer survivors' blogs. It is important to evaluate the content of these blogs as people continue to seek medical

information and solicit health advice online. Therefore, this study is developed to analyse the information provided by Malaysian breast cancer survivors through their blogs using thematic analysis.

Literature Review

Despite the booming of other forms of social media such as Facebook, Twitter and Instagram, internet users continue to opt for blogging for online communication (Gualtieri and Akhtar, 2013). It is estimated that about 19 million people around the world have blogs with almost 181 million blogs existed. It is also learned that blogs have become a well-known health communication media among cancer patients, their families and even for health care professionals (Thielst, 2007). Miller and Ole (2010) reveal that blogs which discuss a person's experience with a health problem are among the most popular type of health-related blogs with as many as 24,000 health related blogs indexed by Technorati with the major proportion of the blogs are on cancer. Female breast cancer patients/survivors are identified as the highest number of health-related bloggers (Quinn et al. 2013). As such, breast cancer blogs are seen as a very important source of information.

Previous studies such as Ventola (2014) and Laranjo (2015) have also reported that communication through online platform can influence a person's health decision and behaviour. Since internet provides an endless boundary of communication, people share different kind of information which includes health-related information based on their own personal experience. The information provided by laymen is much easier to comprehend since it is written in laymen's terms (Rudd et al. 2004). Although these types of information can be helpful, there is a possibility of the information being inaccurate, incomplete or misleading (Ancker et al. 2009). Crocco et al. (2002) report that there have been a few incidents of medical injury linked to online health information. In the same vein, Esquivel et al. (2006) assert that false and misleading information was identified in an unmoderated breast cancer email list and was immediately corrected by the receivers. This suggests that the impact of misleading information could be harmful.

In the context of breast cancer information online, there have been relatively a few studies on breast cancer information provided through blogs in Malaysia. Therefore, this study endeavours to identify breast cancer information given by Malaysian breast cancer survivors through their blogs.

Methodology

Research Design

This study is descriptive in nature, thus a qualitative paradigm fits in the most as the study intends to explore the information provided by breast cancer survivors through their blogs. To achieve the objective of the study, thematic analysis was employed. The potential ethical issues that might result from the work were also addressed. To further safeguard, some of the personal information that are possibly confidential from the researcher's perspectives were not revealed including participants' real names and blogs' address.

Selection of Blogs and Sampling Procedure

An extensive search was conducted to select personal-journal blogs of Malaysian breast cancer survivors who share their journey and experience of cancer through their blogs. The criteria of blog inclusion are, (i) first person narrative, (ii) written in English, (iii) set as publicly available, (iv) share information on their experience coping with a physical or mental health condition as breast cancer survivors and (v) actively written for at least a year. These criteria have led to the selection of three Malaysian blogs with a total of 240 blog postings.

Data Analysis

As this study takes an exploratory approach on the data, the analysis commenced with the reading of the blog posts and coding of the related cues simultaneously which suggests that codes were derived

from the data. As suggested by Guest et al. (2012), in any exploratory approach to qualitative data analysis, specific codes or analytic categories are not predetermined and usually the codes derived from the data. To ease the process of data analysis, *Atlas.ti 8* was used.

Results and Discussion

Data analysis on breast cancer survivors' blogs yielded two main themes of information giving in Malaysian breast cancer blogs which are medical information and non-medical information. Two of the most significant medical information in Malaysian breast cancer survivors' blogs were (i) diagnosis-related information, and (ii) treatment-related information. For non-medical information, two most predominant information identified were (i) information on cancer support and (ii) information on non-medical alternative treatment. Table 1 shows the occurrence of information giving themes in Malaysian breast cancer survivors' blogs. The occurrence was based on a count of single word/phrase frequencies in the blog postings.

Table 1 The occurrence of information giving themes in Malaysian breast cancer survivors' blogs

Blog	Medical information	Non-medical information
Blog 1	303	510
Blog 2	160	344
Blog 3	298	476
Total of occurrence	761	1,330

Based on the occurrence of the themes, it is identified that non-medical information giving is the most predominant talk throughout breast cancer survivors' blogs. The discussion further elaborates the subthemes of medical and non-medical information giving in Malaysian breast cancer survivors' blogs.

Medical Information Giving

Diagnosis-Related Information

As breast cancer survivors write blogs on their battle with breast cancer, most of the information related to diagnosis is based on their experience. This includes information on how they first discovered breast cancer, biopsy process and their breast cancer types and grades identified after the biopsy procedure. However, it is learned that most of these information are written in layman's terms and if medical jargon is used, the blogger usually explained it using non-medical terms. This finding supported previous research showing that information provided by patients/survivors is likely to be written in common terms, rather than in medical jargon (Ancker and Kaufman, 2007). The excerpt below is one of the diagnosis-related information found in the blogs:

To perform biopsy, doctor injected me for the 'bius' on the breast of course. After that, he asked for 7 size blade from the nurse!! OMG!! Why do I have to listen to that?!! Yeah, he made incision (a small cut on the breast). Of coz I can't feel anything. (Blog 1)

Treatment-Related Information

Some the information related to treatment found in Malaysian breast cancer survivors' blogs are on chemotherapy which includes types of drugs and its side effects, mastectomy, lumpectomy and oxygen-therapy as shown in the excerpt below:

Mastectomy - means removing the whole breast, including the nipple, followed by chemo and radiotherapy. A year after, breast reconstruction, taking tissues from the "spare tyre" at the abdomen. Sounds good eh as I could have a flat tummy. But I can't bear the thought of having one breast only for the entire year! (Blog 1)

As evident in the blogs, most of the treatment-related information are explained using common terms. The information provided also are based on breast cancer survivors' experience and some are based on their readings from books. As posited by Kim (2009), most of the medical information shared in blogs are specific to personalised disease matters, and mostly based on the blogger's own experience with the illness. Interestingly, no misleading information was found in these three blogs although Ancker et al. (2009) report on the tendency of misleading information provided by laymen.

Non-Medical Information Giving

Information on Cancer Support

One of the most significant non-medical information found in Malaysian breast cancer blogs was information related to cancer support. It is inevitable, cancer support is important to any breast cancer patients or survivors. Some of the cancer support information that were found in breast cancer blogs were particularly on family, friends, workplace and healthcare providers support as evident in the excerpt below:

And I am very speechless when the HR assures me that the company/company insurance will take care of all the costs and I'll be on paid MC for 6 months.. (Blog 3)

This finding concurs with Posma et al. (2009) as they argue that women with breast cancer want practical and explicit information and ongoing support.

Information on Non-Medical Alternative Treatment

Another predominant non-medical information provided by Malaysian breast cancer survivors was non-medical alternative treatment which includes herb-based diets and herbal supplements. However, there was one blogger talked about she sought for a traditional medicine practitioner's treatment, but she claimed that there is no guarantee of full healing for breast cancer patients when they opted for alternative treatment and modern medicine intervention is needed.

Though I went for an alternative treatment, I still seek the conventional (modern medicine) method. During an appointment with the surgeon, he advised for another round of chemo to shrink the lump before having a mastectomy. (Blog 1)

This finding parallels studies by Parsa et al (2006) as they posit that seeking alternative traditional treatments to heal illnesses is quite strong in Asian culture including Malaysia. Therefore, an information on non-medical alternative treatment can be found in all three Malaysian blogs.

Conclusion

This study reveals that non-medical information is the most predominant information found in Malaysian breast cancer survivors' blogs. Although their blogs provide breast cancer information, no evidence of misleading information was found. The information provided by Malaysian breast cancer survivors also are mostly based on their own experience of battling with the cancer. It is also learned that the information is not meant to challenge professional knowledge or assume an expert roles but it

serves as an avenue to share experience, knowledge and raise awareness on breast cancer. The findings of this study provide an indication of the potential role of breast cancer survivors' blogs to offer and guide readers to information that are not provided by healthcare providers.

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