I-ROLE 2023
International Conference of Research on Language Education

ADVICE AND INFORMATION SHARING: A NETNOGRAPHIC STUDY ON FACEBOOK CANCER SUPPORT GROUPS

Wan Nur Asyura Wan Adnan (a)*
*Corresponding author

(a) Universiti Teknologi Malaysia, Kuala Lumpur, Malaysia, asyura.kl@utm.my

Abstract

This study explores health information sharing and seeking on Facebook Cancer Support Groups in Malaysia. Given the extent to which internet has changed human interaction in online social spheres, individuals with illnesses have also moved to online spheres to seek and offer health-related advice and information. Previous studies on online cancer support group mostly focused on the psychosocial supports and emotional coping among cancer patients. Empirical studies on the exchange and patterns of health advice and information on online cancer support groups are still scarce. Using netnographic approach, some interesting findings were discovered. Facebook cancer support groups in Malaysia are not merely a platform for psychosocial support and cancer treatment-related information, but they have become a platform to debunk cancer myth and misleading information related to treatment and supplements. These support groups are also an avenue that creates awareness among their members on the importance of getting early screening and medical treatment from medical professionals. The findings draw an important implication on the importance of health-related online community as the platform to create awareness and debunk misleading health-related advice and information.

Keywords: Advice and information sharing, cancer support group, online support group, netnography

1. Introduction

Cancer diagnosis can be overwhelming for many people as individuals affected by cancer have to deal with emotional, mental and physical challenges upon the diagnosis. In the past, before the advent of internet and other communication technology, cancer patients typically sought emotional and psychosocial support from local community, hospital information centres, and cancer-related organisation. Although the conventional cancer support group still exists, cancer patients have also looked for support on online platform. Given the anonymity and convenience that online support group offers, online cancer support group has gained attention in recent decades. Nonetheless, in an online platform such as social media, cancer support group is a closed group and can only be accessed by registered members. This has led to the issues of information accuracy which could contribute to misleading health information and other consequences.

Another issue of information accuracy has been discussed with reference to health information and sharing on internet. The advent of internet has contributed to an array of health information available on many online platforms such as websites, online health communities, blogs and social media. Online health information is not only shared by medical professionals but lay people which includes individuals with illnesses who share health-related information (Kington et al., 2021). This situation has aroused concerns surrounding the accuracy and reliability of health information offered by lay people (Dalmer, 2017; Samy et al., 2020). In the context of cancer patients, misleading health information especially on treatment and medication could lead to fatal consequences (Wan Adnan et al., 2019).

In Malaysia, one of the challenges to get early cancer treatment is due to people's beliefs in alternative treatment or reliance on herbal supplement (Zulkipli et al., 2018), lack of awareness of getting cancer screening and fatalistic views on cancer (Lee et al., 2019). Therefore, it is deemed important to explore information offered in Malaysian online cancer support group especially on social media. This study aimed at exploring information shared on Malaysian cancer support groups on Facebook using netnography approach. Specifically, it aimed at answering these two research questions: (i) What are the predominant themes of health advice and information found on Malaysian cancer support groups; and (ii) What are the strategies used by the members when offering health-related advice and information?

1.1. Advice and information giving in online community

Information giving refers to an act of giving a statement that helps people to make sense of their situations and assists them in dealing with challenges that they face. Advice giving is commonly referred as an act of giving a statement that "describes, recommends or forward preferred course of action". Advice also refers to "opinions or counsels given by the people who perceives themselves as knowledgeable and/or the advice seeker may think they are credible, trustworthy and reliable" (DeCapua & Dunham, 1993, p. 519; Heritage & Sefi, 1992, p. 368). This study focuses on health-related advice and information giving in Facebook cancer support group with an aim to explore how this online community give and solicit advice and information related to cancer.

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. It is not surprising that the number of internet users who seek for health information continue to increase (Jia et al., 2021). The percentage of people who use social media to seek for health-related information and advice from peer patients are projected to grow significantly (Chen & Wang, 2021). In similar direction, Tonsaker et al. (2014) argue that the Internet has become the most favoured source of health information for many people instead of seeking information directly from the medical professionals or doctors. This trend is an important indicator that many people around the world rely on online health-related information and advice.

Understanding the strategies of advice and information giving is also important as advice and information in online community is a form to understand social support and explore the reasons and sociolinguistic cues behind why certain advice strategies are employed (Kouper, 2010).

There has been limited empirical documentation on the how Malaysians use online health-related information especially pertaining to cancer and there remain concerns on the current state of health-related information and advice available in Malaysia especially on social media. Hence, this study provides an observational view of advice and information sharing behaviour on online cancer support community.

2. Research Methods

2.1. Research design

This study is a qualitative study that used a netnographic approach to discover health advice and information sharing on two Malaysian Facebook Cancer Support Groups. Netnography is an ethnographic approach to study online communities and social interactions between them (Kozinets, 2010). When studying an online community, netnographers completely immerse themselves in the online community which require no offline interaction at all (Kozinets, 2010). Netnography also requires "a 'significant' amount of data collection "originates in and manifests through the data shared freely on the internet" (Kozinets, 2015, p. 79).

2.2. Data collection

The primary method of data collection in a netnographic study is participant observation in which the researcher enrolled herself as the member of two Facebook cancer support groups. There are referred to as Facebook cancer support group 1 (FBSCG 1) and Facebook cancer support group 2 (FBCSG 2). For FBSG 1, there are about 20,000 group members and for FBSCG 2, there are about 30,000 group members as of January 2023. The members of these support group are not only among the cancer patients, but also cancer survivors, their family members and caretakers.

During the data collection period, the researcher observed and participated in the discussion and interaction in the two groups for two years. To date, the researcher has been the member of these two groups for three years. Researcher's field note was also used to document the observation of the data.

During the observation, the researcher specifically focused on the exchange of health-related advice and information on the two Facebook cancer support groups. Field notes of the observation were

924

recorded in a Word processor and transferred to Atlas.ti software as an early preparation for the data analysis stage.

In terms of the participant's consent, the Institutional Review Board for the Social and Behavioral Sciences (IRB-SBS) (2023) outlines that "the observation of public behaviour (including audio and visual recordings) can be exempted if one of the following are adhered: (i) the information of the observation does not reveal the identity of the participants or can be ascertained with certain descriptions or identifiers that will point to the participants; (ii) the disclosure of the participants do not risk, harm, damage or become the participants' liability on their career, education or reputation; (iii) if the participants are identifiable, appropriate measures to maintain their privacy and confidentiality should be taken. Following the IRB-SBS guidelines, this study chooses to protect participants' anonymity and real names and any other personal identifiers such as age, specific location, real names, and hospitals were altered.

2.3. Data analysis

Since the focus of the study is to explore health advice and information giving in two Facebook cancer support group, the data was analysed with the aim to answer these two research questions – RQ1: What are the predominant themes of health advice and information found on Malaysian cancer support groups; RQ2: What are the strategies used by the members when offering health-related advice and information?

To find the answer to RQ1, the data was analysed using thematic analysis (Braun & Clarke, 2006) in order to find recurring and prominent themes throughout the data. In response to the identified themes, the data was analysed by adapting Hinkel's (1997) and Kouper (2010) Taxonomy of Advice to understand the strategies used by the members when sharing health-related advice and information as in Table 1.

Table 1. Taxonomy of advice (Hinkel, 1997; Kouper, 2010)

Category	Description
Direct advice	Advice or information where the speaker attempts to cause the addressee to do something i.e. including imperatives and the modal verb should as in "You should…".
Hedged advice	Advice or information contains explicit hedges, hedging devices, or softeners of various types, e.g., expressions like "I think," "it seems that," or questions like "Why don't you," "Aren't you," or modal verbs other than "should".
Indirect advice	Advice or information that has no explicit or hedged advice but has enough information to act on it.
Description of personal experience	Advice or information that has no explicit, hedged advice, or indirect advice but has an account of how the person dealt with the situation an advice seeker described.

3. Findings

Overall, the data offers a dynamic glimpse of findings with regards to advice and information giving on Malaysian Facebook cancer support groups. However, the analysis of the study only focused on

health-related advice and information in the two groups. In this paper, the findings are presented by integrating both RQ 1 and RQ 2 under each theme.

3.1. Predominant themes of health-related advice and information and advice strategies

In general, Malaysian Facebook Cancer Support groups are the platform where cancer support is given and sought by their members. In terms of advice, the data offers a dynamic glimpse of findings with regards to advice and information giving on Malaysian Facebook cancer support groups. However, the analysis of the study only focused on health-related advice and information in the two groups. The data analysis showed that the two most predominant themes of advice and information given in the Facebook Cancer Support groups are (i) treatment-related advice and information and (ii) non-medical but health-related advice and information.

3.1.1. Treatment-related advice and information

Under treatment-related advice and information, the two Facebook cancer support group members exchange advice and information on the different types of treatment available to treat different types of cancer among their members. For example, a group member solicited advice and information on other possible treatment apart from whole breast removal as in the excerpt from Facebook Support Group 2 (FBSG 2) as presented in Table 2:

Table 2. Sample of excerpts for treatment-related advice and their strategies

Sample of excerpt (Advice and information solicitor)	Sample of excerpt (Advice and information givers)	Advice strategies used by the advice givers
The specialist from Hospital A suggested to go for whole breast removal but other specialist from Hospital B suggested that my mother should undergo six chemo sessions, 18 radiotherapy sessions, with 6 cycles. Please suggest to me what are other possible treatment given my mother's situation (FBSG2)	I am a multiple myeloma patient and *had the same situation as your mom*. *I had targeted chemotherapy* and I did not have to go for radiotherapy or other invasive solution. You *should* discuss with your mom's specialists. They will help.	(i) Description of personal experience (ii) Direct advice
I am currently undergoing the 9th day of radiotherapy. Met my onco(logist) just now, and my HB (hemoglobin) has dropped from 9.7 to 8.7 and have started to consume iron tablet. If my Hb continues to drop, my onco suggested that I should go for blood transfusion. Please share tips on maintaining good HB count while undergoing radiotherapy? I have a total of 25 times of radiotherapy and still have a long way to go (crying emoji). (FBSG 1)	Response 1: To ensure that the iron tablet is week absorbed, take the tablet with empty stomach (1/2 hour before or 1 hour after your meal) and consume the tablet along with orange juice or any juice with high Vitamin C. Response 2: When you are about to take the tablet (1 hour before), try to avoid caffeinated drinks and any drinks with milk. Better to take along the tablet with Vit C. Take at least 3 protein meals. Each protein meal should be equivalent to 2 eggs, 1 drumstick, 2 match box-sized meat, 2 small mackerel, or 1 small block of fish. If not, take along with supplement such as Ensure, Nutren, Optimum etc.	Indirect advice (no explicit or hedge advice but contain information at large as in Response 1 and 2)

There are also many other instances of treatment-related advice and information for cancer such as medications for certain types of cancer, the latest technology in cancer treatment, and post-treatment care. For treatment-related advice and information strategies, under the comment sections of each Facebook post, the most predominant patterns of advice and information strategies were direct advice (e.g. "You *should* just rest at home after the treatment"), description of personal experience (e.g. "I am a multiple myeloma patient and *had the same situation as your mom. I had targeted chemotherapy*…") and indirect advice.

The use of direct advice and an account of personal experience when offering treatment-related advice and information suggested that advice givers also demonstrate their credibility when offering advice. Some group members used scientific terms with the use laymen's explanation in the response. The seamless interweaving between personal experience and scientific discourse shows that a lay person has indeed acquired credibility as experiential expert (Schildhauer, 2015) but they do not show any evidence of assuming medical professionals' roles (Turnbull, 2016). Health-related advice and information in Malaysian Facebook cancer support groups are mostly offered by lay people with experiential cancer knowledge, as Myskja (2007, p. 1) described "lay people with particular knowledge based on tradition and experience" and "lay people who represent an alternative perspective to expert views because they are non-experts". On the other hand, the use of indirect advice by the support group members were delivered with straightforward responses and their advice does not impose on the advice seekers in mitigating their advice.

3.1.2. Non-medical but health-related advice and information

Interestingly, the thematic analysis revealed that non-medical but health-related advice and information is another predominant information found in the Malaysian Facebook cancer support groups. This include the advice and information related to complementary and alternative medicine such as the use of herbs with precaution to treat cancer as in Table 3.

Table 3. Sample of excerpts for non-medical but health-related advice and their strategies

Sample of excerpt (Advice and information solicitor)	Sample of excerpt (Advice and information givers)	Advice strategies used by the advice givers
My mom recently got diagnosed with breast cancer. I read a lot about supplement and herbs for cancer patients. Can someone suggest what is the best supplement or herbs for breast cancer. Is it dangerous to consume drugs and herbs at the same time? (FBSG1)	Response 1: *Reminder to cancer patients. Avoid* taking these three supplements – ginseng, spirulina and Sabah Snake Grass leaves as these sources contain high amount of oestrogen. Oestrogen speeds up cancer development. The Malays commonly suggests Snake Grass as the supplement for cancer, but factually, snake grass is a herb taken as to prevent cancer not curing cancer. This advice was given by Prof NI of Hospital K, a breast surgeon. Response 2: (in response to the misleading product seller) Mr HD, please leave this group! We don't welcome any 'trash product' seller here. You have been influencing people with your *misleading information*. You even gave *wrong facts* – cancer cells are not dead cells as you claimed. Go and get your facts right! Don't mess with us!	Direct advice

When offering non-medical but health-related advice and information, it is frequent that group members used direct advice strategies. The support group members were found to advise the advice seekers to first consult their medical professionals when deciding on any complementary and alternative medicine (CAM), so that the CAM will not interfere or affect the modern medical treatment. Another interesting observation was the two Facebook support group members collectively debunk the myth of misleading advice and information on the overclaimed products or supplements that were claimed as able to cure cancer by some group members. Direct advice is always straightforward and it is easier for the message to get to the receiver. In non-medical but health-related advice and information, the strategy was providing information with facts and provide warning of consequences which also echoes Kouper's (2010) study.

This is an important indicator that Malaysian Facebook Cancer Support groups act as a source of providing credible information and a platform to create awareness among cancer patients, their family members and caretakers on the use of unverified supplements or products promoted by Malaysian public. As part of health-related online community, this study realises that giving solicited or unsolicited health advice comes with consequences, which points to the need for health-related online community to be responsible with the advice we provide and ensure that we do not give misleading advice.

4. Conclusion

Advice and information giving in health-related online community entails many effects to their community members. In the context of Malaysian Facebook Cancer Support groups, health-related advice and information offered are believed to be useful to their members and it is rather interesting to observe the exchange of advice and information in these groups which is also an important indicator of the function of online cancer support group in creating awareness on cancer and correcting misleading cancer-related information among Malaysians. Taking this thought further, future research can look into many other interesting facets of Facebook cancer support group in terms of advice and information on different support offered and can be extended to other cancer support group on social media platform.

References

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77-101. https://10.1191/1478088706qp063oa

Chen, J., & Wang, Y. (2021). Social media use for health purposes: Systematic Review. *Journal of Medical Internet Research*, *23*(5), e17917. https://doi.org/10.2196/17917

Dalmer, N. K. (2017). Questioning reliability assessments of health information on social media. *Journal of the Medical Library Association*, *105*(1), 61–68. https://doi.org/10.5195/jmla.2017.108

DeCapua, A., & Dunham, J. F. (1993). Strategies in the discourse of advice. *Journal of Pragmatics*, *20*, 519–531.

Heritage, J., & Sefi, S. (1992). Dilemmas of advice: Aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. In P. Drew & J. Heritage (Eds.), *Talk at work: Interaction in institutional settings*. Cambridge University Press.

Hinkel, E. (1997). Appropriateness of advice: DCT and multiple choice data. *Applied Linguistics*, *18*(1), 1–26. https://doi.org/10.1093/applin/18.1.1

Jia, X., Pang, Y., & Liu, L. S. (2021). Online health information seeking behavior: A systematic review. *Healthcare*, *9*(12), 1740. https://doi.org/10.3390/healthcare9121740

Kington, R. S., Arnesen, S., Chou, W. S., Curry, S. J., Lazer, D., & Villarruel, A. M. (2021). Identifying credible sources of health information in social media: Principles and attributes. *NAM Perspectives*, *2021*, 10.31478/202107a. https://doi.org/10.31478/202107a

Kouper, I. (2010). The pragmatics of peer advice in a LiveJournal community. *Language@Internet*, *7*, 1. http://nbn-resolving.de/urn:nbn:de:0009-7-24642

Kozinets, R. V. (2010). *Netnography. Doing ethnographic research online*. Sage.

Kozinets, R. V. (2015). *Netnography: Redefined* (2nd ed.). Sage.

Lee, M.-S., 'Azmiyaty Amar Ma' ruf, C., Nadhirah Izhar, D. P., Nafisah Ishak, S., Wan Jamaluddin, W. S., Ya'acob, S. N. M., & Kamaluddin, M. N. (2019). Awareness on breast cancer screening in Malaysia: a cross sectional study. *BioMedicine, 9*(3), 18. https://doi.org/10.1051/bmdcn/2019090318

Myskja, B. K. (2007). Lay expertise: Why involve the public in biobank governance? *Genomics, Society and Policy*, *3*(1), 1-16. https://doi.org/ 10.1186/1746-5354-3-1-1

Samy, M., Abdelmalak, R., Ahmed, A., & Kelada, M. (2020). Social media as a source of medical information during COVID-19. *Medical Education Online*, *25*(1), 1791467, https://10.1080/10872981.2020.1791467

Schildhauer, P. (2015). I'm not an expert: Lay knowledge, its construction and dissemination in personal weblogs. In M. Bondi, S. Cacchiani, & D. Mazzi (Eds.), *Knowledge dissemination in and through the media: Recontextualizing and reconceptualizing expert discourse* (pp. 264-289). Cambridge Scholars Publishing.

Tonsaker, T., Bartlett, G., & Trpkov, C. (2014). Health information on the Internet: Gold mine or minefield? *Canadian Family Physician Medecin De Famille Canadien*, *60*(5), 407–408.

Turnbull, S. (2016). Defining and achieving good governance. In Aras, G., & Ingley, C. (Eds.) *Corporate behavior and sustainability: Doing well by being good.* Ashgate Gower Publishers. http://doi.org/10.2139/ssrn. 2571724

Wan Adnan, W. N. A., Ibrahim, N. A., Haladin, N. a. B., & Wan Fakhruddin, W. F. W. (2019). Illness Experience Sharing on Personal Blogs: A Case Study of Malaysian Breast Cancer Survivors. *GEMA Online® Journal of Language Studies, 19*(4), 28-47. https://doi.org/10.17576/gema-2019-1904-02

Zulkipli, A. F., Islam, T., Mohd Taib, N. A., Dahlui, M., Bhoo-Pathy, N., Al-Sadat, N., Abdul Majid, H., Hussain, S., & MyBCC Study Group. (2018). Use of complementary and alternative medicine among newly diagnosed breast cancer patients in Malaysia: An early report from the MYBCC study. *Integrative Cancer Therapies*, *17*(2), 312–321. https://doi.org/10.1177/1534735417745248