Illness Experience Sharing on Personal Blogs: A Case Study of Malaysian Breast Cancer Survivors

Wan Nur Asyura Wan Adnan

asyura.kl@utm.my
Language Academy,
Faculty of Social Sciences and Humanities,
Universiti Teknologi Malaysia

Noor Aireen Ibrahim

naireen@utm.my
Language Academy,
Faculty of Social Sciences and Humanities,
Universiti Teknologi Malaysia

Nur‘ain Balqis Haladin

nurainbalqis@utm.my
Language Academy,
Faculty of Social Sciences and Humanities,
Universiti Teknologi Malaysia

Wan Farah Wani Wan Fakhruddin

wanfarah@utm.my
Language Academy,
Faculty of Social Sciences and Humanities,
Universiti Teknologi Malaysia

ABSTRACT

Illness experience which was very much a private matter is now increasingly becoming a shared public experience on different public spaces including social media, and other interactive online platform such as personal blogs. Past research has shown that sharing illness experience provides emotional support which surpasses traditional face to face support. In addition, studies also suggest that online sharing of illness experience can be both therapeutic as well as beneficial for cancer patients. Thus, exploring cancer discourse on media is important in enhancing understanding of the nature and characteristics of cancer discourse as constructed on social media. This is especially important in breast cancer illness, in the Malaysian context in which survival rate remains low due to lack of awareness and reluctance to perform screening. Hence, a total of three personal blogs written by breast cancer survivors from Malaysia were examined in this study. Taking a discourse analytic perspective, this study explored the positions taken by bloggers when constructing their illness experience and how these positions are realised through the different discursive strategies and linguistic devices. The findings provide insights into how breast cancer patients position themselves when they share their illness experience online. Understanding this new form of illness sharing provides an avenue to better understand breast cancer patients’ journey and their struggles, and the different roles relevant parties can play in their own health care management and information.

Keywords: subject position; illness experience; breast cancer bloggers; social media; breast cancer discourse
INTRODUCTION

Illness experience is pervasive across all cultures and societies and has been considered entirely a private matter until very recently (Ziebland & Wyke, 2012). With the development of interactive online platforms on the Internet, illness has shifted from the personal to the public domain (Conrad, Bandini, & Vasquez, 2016). Online platforms which began with chat rooms, support groups, and the more recent social media platforms such as forums, blogs, Twitter, Facebook; and video sharing websites such as YouTube has paved the way for individuals with illness to share information, experience, and advocacy. With these online platforms, communication has increased and brought new challenges for online interaction. It is likely that the transformation of illness from a largely private to an increasingly public experience is a revolutionary change that is here to stay (Conrad et al., 2016).

Essentially, seven health domains motivate internet use for peer-to-peer connections including obtaining information, feeling supported, maintaining relationship, affecting behaviour, and experiencing health services (Ziebland & Wyke, 2012). Hence, people with chronic illness and disability (or sometimes their caregivers) are among the largest users of Internet health sites, with one in four Internet users with a chronic condition are reported going online to seek health information (Benetoli, Chen & Aslani, 2017; Fox, 2011). The efficacy of the Internet as a knowledge driven interactive venue for various diseases has transformed the nature of illness experience. It can be said that all forms of illness or medical condition can be openly accessed, at multiple online sites to any interested individual. For instance, a patient’s personal experience of chronic disease such as cancer can be easily found on forums, social media and personal blogs. Without a doubt, illness in the cyber age has shifted from a private to a public experience.

Breast cancer-related discourse is also part of the growing research on online health discourse (e.g. O’Hanlon, 2019; Kressler, 2014; Bender, Jimenez-Marroquin & Jadad, 2011). Online resources are now established as a primary route to health information and support. In the past, authoritative health information was based on scientific information, often presented as evidence-based “facts and figures,” rather than on patients’ experiences. When health problems are commonly experienced (such as winter colds and flu or headaches), people have their own embodied experience to draw on when deciding whether and how to act (self-management, decisions to consult, and so on) (Dingwall, 2001; Leventhal, Brisette, & Leventhal, 2003).

Media representations in relation to cancer discourse are important because representations shape people’s beliefs on health and illness, demonstrate the associated behaviours and shared experiences of cancer patients (Macdonald et al., 2018; Castillo, Godoy-Izquierdo, Vázquez, & Godoy, 2011; Hodgetts & Chamberlain, 2006; Lyons, 2000). Thus, exploring media and its association with illness discourse (i.e. cancer) is a worthy attempt in enhancing understanding of the nature and characteristics of cancer discourse as constructed on social media. Lyons (2000, p. 353) identified the role of media as enabling “the construction of identity through meanings that are embedded within dominant representations of health, illness and disease”. A recent study on media representation of breast cancer by McGannon, Berry, Rogers and Spence (2016) explored the Canadian newspaper and its implication on women’s identity construction. Taking an eclectic critical discourse approach, they identified two prevailing discourse of breast cancer in the Canadian media – a discourse of biomedicine and a discourse of healthism. In addition, two subject positions were mobilised by the media when representing breast cancer (henceforth BC) patients namely as breast cancer survivor, the good consumer and the medical expert.

Unlike studies on media representation of breast cancer, the current study examines breast cancer discourse from the patient’s perspective derived from personal blogs which has
a unique feature that of being unsolicited and interactive. The significance of examining online illness narratives, as is the focus of the current study, lies in the global implication it has on the work of healthcare professionals. Never has illness narratives and experience been shared more extensively, more vividly and in such detail than in social media platforms, particularly in blogs. Patients, like the personal bloggers examined in this study, articulate their illness journey – detailing the highs and lows, the failures and successes as well as aspects of the journey that may be improved. Access to patients experience about their life during treatment provides rich information which guide healthcare professionals’ practices in improving patient’s care.

This paper, therefore, is to build on the existing literature on illness narrative by contributing to the knowledge of illness narrative shared on social media platforms. In particular, this study aims to elucidate the illness experience of BC patients who have survived treatment by analysing (i) the dominant position taken by the BC bloggers when narrating their illness experience, (ii) the discursive strategies they draw on when taking on the particular position and (iii) the linguistic features used to achieve these discursive strategies. In brief, the overarching research question that guides this study is as follows: What is the dominant position taken by Malaysian BC bloggers when sharing their illness experience and how is this position constructed through the different discursive strategies and linguistic devices?

**LITERATURE REVIEW**

**ONLINE ILLNESS EXPERIENCE**

In the past, people communicated their illness experience, be it the pain and struggle, through written means. Expressing emotions or traumatic experiences verbally or in written form have been shown to have therapeutic benefits for the individual (Pennebaker & Seagal, 1999; Frank, 1995; Sandelowski, 1991; Kleinman, 1988). Health and illness related expressive writing has been well-researched in the past decade (e.g. Kaptein, Hughes, Murray & Smyth 2018; Mugerwa & Holden, 2012). With the advent of the Internet, and notably with social media platforms, a wider reach has been initiated which transcends educational achievement, race and ethnicity, and level of health care access (Giustini, Ali, Fraser & Kamel Boulos 2018; Welch et al., 2016; Chou et al., 2011). Individual can express their emotional experiences of pain and illness to a larger audience from different parts of the globe in real time. Pain and illness experience are not only shared with family, friends and unknown people, the readers are also able to comment on the shared experience. This level of experience sharing is not only possible on social media platforms such as Facebook, blogs and Instagram, but has become a daily occurrence (Schildhauer, 2015).

Learning about other patients’ experiences has the potential to affect decision making, one’s sense of isolation or support, and adjustment to the illness or health condition. Support from online communities, websites, blogs which is available anywhere and at any time both supplement and at times surpass the traditional face-to-face support groups. Traditional forms of contact and support are limited to certain hours of the day, week, or month; some face-to-face support groups meet less than once a month and may require considerable travel and effort. An undeniably transformational feature of the Internet is that contact and support are now available at any hour of the day or night and that individuals with access to the internet at home have a range of resources for private and anonymous communications with others in real time (Wong & Cheung, 2019; Benetoli et al., 2017; O’Neill, Ziebland, Valderas & Lupiáñez-Villanueva, 2014; Ziebland & Wyke, 2012).
A growing body of research points to the importance of storytelling as a cancer communication tool. Through various storytelling contexts; including support groups, patient testimonials, medical encounters, and communication interventions; personal cancer stories have positive health impact for readers and storytellers alike (Lulu & Alkaff, 2019; Cepeda et al. 2008; Charon & Wyer, 2008; Kreuter et al., 2007). Survivors’ stories have been used as a vehicle for modelling coping skills, providing social and emotional support, and sharing information and resources (Kreuter et al., 2007). Recently, cancer communication efforts have begun to adapt narratives as a tool for changing health behaviour. For example, Kreuter and colleagues have demonstrated that effective use of BC survivors’ narratives increased mammography uptake among African American women (Kreuter et al., 2007). Equally, Kressler (2014) and McQueen, Kreuter, Kalesan and Alcaraz (2011) found that BC survivors’ narratives makes them credible and effective messengers of information conveyed through their personal illness stories. In this way, narrative communication is seen as offering unique advantages over traditional expository or didactic communication in the context of promoting desirable health behaviours.

Narrative writing has a long history of being self-initiated and directed. Recently, narrative as a directed activity, guided in part by health care professionals, has been shown to be an effective therapeutic intervention. By using online narrative tools such as blogs, patients and families may find a new way to bridge the divide between the sick and the healthy. Specifically, blogs allow patients to articulate illness narrative through online interaction with others—family, friends, and other patients with similar health concerns. Although illness blogs share similarities with traditional forms of illness narrative, blog features, in particular the ease of sharing or commenting, are unlike earlier narrative forms. Hence, the goal of this study is to explore the use of personal blogs as a means of communicating illness experience and the strategies BC patients use to position themselves in their blog postings.

PATIENT DISCOURSE

The term patient carries strong association with medicine and health as the term is only assigned to an individual receiving some form of medical treatment or care. A person is labelled a patient only in a medical setting. Likewise, studies on patient discourse have predominantly focused on institutionalised setting, especially, patient-doctor communication (Wodak, 2006). Current research on patient discourse has now shifted its focus to online platforms, authentic interaction among patients, the role of technology in patient-provider communication and health narratives (Hamilton & Chou, 2014). With this recent trend, the focus on BC patient discourse on online platform is both timely and significant.

Patient discourse is characterised by distinctive linguistic features that differentiate it from other types of discourse. For example, patient discourse centres around medical-related information but at the same time it is embedded with the personal experience of the patient. Different groups of patients who have different illnesses have been identified to use different linguistic features and these features provide a speech profile for a specific group (Cortes, 2013). Thus, enabling a solid description of the linguistic features of each group of patients which suggests BC patient talk has its own unique characteristics. Through investigating actual BC patient discourse, which is focus of the current study, insights into important characteristics of breast cancer discourse in personal blogs can be identified.
BREAST CANCER IN MALAYSIA

Every year, around 5000 Malaysian women are diagnosed with cancer (NCSM, 2015). It is also identified that only 49% survived during the five-year survival rate of cancer in Malaysia (Yip, Pathy & Teo, 2014). One of the factors that contributed to the low survival rate in Malaysia is breast cancer is often detected at the late stage (Yip et al., 2014). The main determinant of survival in breast cancer is early detection, which in turn is dependent on disease awareness and screening uptake. However, breast cancer awareness among Malaysian women remains poor and very few attend regular mammography screening or perform breast self-examination. In fact, many studies have shown that symptom recognition remains an important public health issue in Malaysia (e.g. Kanaga, Nithiya & Shatirah, 2011; Parsa, Kandiah, Mohd Zulkefli & Rahman, 2008) highlighting the need to disseminate breast cancer related information and advice.

Personal blogs can be used to disseminate breast cancer-related information. With the increase in people's dependency on the internet for health-related information and advice, it is important to examine breast cancer-related information online. In fact, studies (e.g. Kimiafar, Sarbaz, Sales, Esmaeli & Ghazvini, 2016) have shown that one of the factors which contribute to breast cancer awareness and knowledge is meeting the information needs of BC patients. Yet research on BC patients in Malaysia has shown that information obtained online fail to meet the patient’s informational needs (Raja, Siti Meriam, Rohaizak, Subahan & Nabishah, 2016). Thus, it is important to explore social media platforms such as BC personal blogs as a source to disseminate health-related information.

METHODOLOGY

DATA COLLECTION PROCEDURE

The main focus of this study is to examine how Malaysian BC patients position themselves when sharing their illness experience through their personal blogs. The data consists of three personal blogs written by BC patients who have successfully undergone treatment. Hence, they will be referred to as survivors. Although there are many web-based social networking platforms such as forums, Facebook and Instagram, personal blogs provide rich data to examine illness experience sharing due to the length of postings made.

Embarking on the data searching process, seven common search terms were used in the selection of suitable Malaysian BC blogs for the current study. These terms are some of the most common search terms related to breast cancer as suggested by Google. The terms used were breast cancer, cancer experience, diagnosed with cancer, cancer nightmare, dealing with cancer, depression due to cancer and I have cancer. The search focused on the two most popular blog-hosting websites used by Malaysians which are blogspot.com and wordpress.com.

Later, more specific search phrases such as cancer, breast cancer in Malaysia, breast cancer blogs in Malaysia, I have breast cancer, I was diagnosed with breast cancer, breast cancer nightmare, breast cancer journey and my experience of breast cancer were used. In addition, the word Malaysia was added to each phrase in order to enable the search engine to capture only Malaysian blogs. Guided by past media and social media research (e.g. O’Hanlon, 2019; Macdonald et al., 2018; Chou et al., 2011) and the particular aim of the current study, the researcher developed six selection criteria to guide the blog selection process: i) Location of the bloggers – Malaysia; ii) Types of narrative – first-person narrative, iii) Language – predominantly written in English with minimal use of Malay language; iv) Focus of the blogs – experience coping with the physical and psychological effects of breast cancer.
cancer iv) Blog privacy setting – publicly available; v) Blog posting – actively written for at least a year and contain an adequate amount of information on BC survivors’ experience with a minimum of thirty blog postings and; vi) Blog hits – more than 5,000 hits.

Apart from the selection criteria, the time frame for the data collection was also determined which began from October 2016 to October 2017. The 12-month period was necessary to ensure adequate data was gathered for analysis. The selection criteria have led to the identification of three BC survivor blogs from Malaysia with 238 blog posts retrieved during the data collection. Table 1 provides a profile of the selected BC bloggers for this study.

TABLE 1. Profile of the Malaysian BC bloggers

<table>
<thead>
<tr>
<th>Blogger’s code and background</th>
<th>Medical history</th>
<th>Motivation to blog</th>
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<tbody>
<tr>
<td>MB 1 (Malay, in her 40s)</td>
<td>MB1 was diagnosed after the biopsy on a lump near the armpit confirmed that it’s cancerous. MB1 underwent four cycles of chemo before surgery to remove the lump. 3 years after the treatment, she was diagnosed with Stage 4. She started on IV cycle of chemo before surgery. She, then, went to China for Cryoablation treatment and Iodine Seeding. Now, MB1 is cancer free.</td>
<td>MB1 started blogging to share her journey in battling cancer. She admits that she doesn't write to influence anybody to follow her treatment regime.</td>
</tr>
<tr>
<td>MB 2 (Sabahan Dusun, in her 30s)</td>
<td>MB2 was first diagnosed with breast cancer in 2011 with BCRA-2. MB2 discovered a lump on her breast after a self-examination. She had chemotherapy, radiotherapy, surgery and mastectomy to treat her cancer.</td>
<td>MB2’s sole motivation to blog is to share her breast cancer journey.</td>
</tr>
<tr>
<td>MB 3 (Malay, in her 40s)</td>
<td>MB3 was first diagnosed with breast cancer in March 2009. She underwent chemotherapy after surgery followed by radiation and hormonal therapies.</td>
<td>MB3 started her blog as a personal journal while undergoing adjuvant treatment for breast cancer. Writing about her experience is her way of coping and accepting the challenges in managing the side-effects of cancer. She wishes to share and to draw on the experience of others.</td>
</tr>
</tbody>
</table>
DATA ANALYSIS

This study draws on the definition of subject positions by Davies and Harré’s (1990) and Edley (2001). A subject position is a discourse construction of “people in interaction using language to negotiate positions for themselves” (Davies & Harré, 1990, p.46). Edley (2001) defines it as the identities made relevant by specific ways of talking. In this study, the patient position taken by the bloggers is signalled by the following medical related topics such as patient roles, medical experience, challenges of post-treatment management and medical test results. The first step to approach the data is to commence with a close reading of the blog postings to identify the dominant patterns throughout the data. At this stage, the researcher made field notes in order to understand the nature of BC bloggers’ discourse. To identify these patterns, a thematic analysis was conducted to identify patterns and themes across the data set (Maguire & Delahunt, 2017; Braun & Clarke, 2006).

The findings of the thematic analysis showed that BC survivors offer different categories of breast cancer-related information and advice. Hence, the subsequent reading and coding of the related cues were conducted simultaneously to ensure the codes were derived from the data. To ease the data analysis process, Atlas.ti 8 was used to facilitate the management of 238 blog postings. The qualitative analysis software provided a workbench to analyse the large quantities of textual data examined in this study. The thematic analysis on BC survivors’ blogs yielded two main themes of information giving in the Malaysian BC blogs which are medical information and non-medical information with the latter constituting a greater portion of the blog postings. The occurrence was based on a count of single word/phrase frequencies in the blog postings.

Two of the most significant medical information in the Malaysian BC survivors’ blogs were diagnosis-related, and treatment-related information. For the non-medical information, two predominant information identified were information on cancer support and information on non-medical complementary or alternative treatment. The findings suggest that the personal BC blogs analysed in this study were laden with medical related information and advice and can serve as an avenue to share experience, knowledge and raise awareness on breast cancer. As such, an analytical focus on the medical-related information in subsequent analysis will provide a better understanding of BC bloggers’ discourse and how medical information and advice is embedded in the illness narrative.

A person who is involved in a social interaction is constituted through different discursive strategies in which they participate (Davies & Harré, 1990). When an individual position himself/herself in a discourse, that positioning is achieved through the discursive components which refers to as discursive strategy in this study. In this context, strategy means “a more or less accurate and more or less intentional plan of practices (including discursive practices) adopted to achieve certain aim” (Wodak & Reisigl, 2015, p. 585). The discursive strategies within the discourse can be linked to the acts of positionings (Thurnherr, Rudolf von Rohr & Locher, 2016). When analysing the discursive strategies, the focus is given to the different discursive devices used to attain different subject positions. Since discursive device is a smaller unit of analysis, the discursive strategy is the synthesis of the ‘full picture’ of these devices. The combination of different discursive devices is employed to create different discursive strategies. We attend to these strategies with a focus on the ways in which discursive strategies are used by the bloggers to position themselves when offering breast cancer-related information and advice. To illustrate the identification of discursive strategy, take Excerpt 1 as example.
Excerpt 1
(MB3, P24-7-8)

The Onco Nurse was ready to explain to me again, the full procedure when we were just about to begin Round 2, an hour after the Emend dose. As in cycle 1, I was given a shot of a pre-chemo medication, 2 shots via the temporary port (there is a medical term for this, but I didn't take it down so have completely forgotten by now) that they had installed on a good vein on the back of my palm. One of them made me tingle all over, as it did the last time, just for a few seconds. Then the chemo proper took place.

Based on Excerpt 1, to identify the discursive strategy used, the researcher first determined the focus of the specific excerpt. In this case, the overall narrative is centered on the blogger’s account of her chemotherapy session. The excerpt provides a rich description of the experience, from the Oncology Nurse attending to her to the tingling sensation of the pre-chemo medication. Several discursive devices are in play in Extract 1, for example the use of the personal pronoun I (I was given… and I didn’t take it down) and the use of descriptive words (…tingle all over) provide the bloggers with vivid description of her personal (as indicated by the use of the pronouns) experience undergoing chemotherapy treatment. Clearly, the discourse is centered on the blogger’s vivid description of her personal experience undergoing a chemotherapy treatment. Thus, the discursive strategy can be identified as drawing from the patient’s own experience or referred to as drawing from own experience.

Breast cancer discourse in the current study is not merely a description of real events or attitudes as emphasis is given to specific language features of the discourse with a focus on “orientation to action and the resource in which they are constructed” (Hepburn, 2000, p. 607). This approach to language is the characteristics of discourse analysis (Potter & Wetherell, 1987). There are different levels where language can be approached as constructive and action oriented. In relation to this study, the analysis of language will depict how BC bloggers use language to achieve the discursive strategies when taking on the patient positions.

FINDINGS AND DISCUSSION

THE DISCURSIVE STRATEGIES AND LINGUISTIC FEATURES USED WHEN CONSTRUCTING THE PATIENT POSITION

Based on the data analysis, the prevalent position taken by BC bloggers when offering advice and information through their blogs is as patients. The term patient in this position carries a strong association with medicine and health, as the term patient is in itself a medical term. As such, the discourse of the patient position in the current study is characterised by the following medical related topics; the patient roles, medical experience at a medical setting, challenges of post-treatment management and medical test results. In fact, adopting the patient position has been shown to be common during active treatment with surrounding discourse heavily centred around the disease (Deimling, Bowman & Wagner, 2007). Therefore, medical terms and contexts are regularly referred to in this position. This can be seen from the following data extracts:

Excerpt 2
(MB2, P1-8)

So, last Friday I went for a Breast Ultrasound at National Cancer Society Malaysia. (I was informed that Mammogram is only recommended for ladies above 35 years old.) My appointment was at 11am. Been called by a lady doctor for a manual check and been waited
until 12.30pm for my turn for the ultrasound! That means the appointment made was useless. It took only 15 minutes to finish the process. It’s like what pregnant mommies go for the baby ultrasound, but only at different area.

Excerpt 3

( MB2, P2-4)

I went to a 24 Hour Mediviron clinic nearby for some antibiotics. The Doctor prescribed some antibiotics but urged me to consult a Breast Specialist as the abscess needed to be drained a.s.a.p. I completed the 3-day course of antibiotic and made an appointment to see a Breast Specialist. A small surgical procedure was carried out to drain out the abscess and a small tissue sample was taken for investigation. The analysis of the sample indicated some abnormal cells and growths in the ducts which may require further investigation given my profile: A golden girl, post-menopausal and non-childbearing. I agreed to a mammogram once the surgery incision heals. The result of the mammogram about month later prompted an Ultrasound scan to be done. Some highly suspicious looking mass were noted, indicative of malignancy. The Surgeon reassured me that 95% of such cases were benign. I would however need to have the lumped checked and removed as a precaution before it could become cancerous. We fixed a date for surgery.

Excerpt 4

( MB3, P24-7-8)

The Onco Nurse was ready to explain to me again, the full procedure when we were just about to begin Round 2, an hour after the Emend dose. As in cycle 1, I was given a shot of a pre-chemo medication, 2 shots via the temporary port (there is a medical term for this, but I didn't take it down so have completely forgotten by now) that they had installed on a good vein on the back of my palm. One of them made me tingle all over, as it did the last time, just for a few seconds. Then the chemo proper took place.

From these data excerpts, it is clear that the focus of the discourse is the bloggers’ experience going through different breast cancer diagnosis and treatment procedures. For example; going for a mammogram screening in Extract 2; a surgical procedure to obtain sample for further investigation in Extract 3 and a chemotherapy session in Extract 4. In each of these three extracts, the patient position taken up by the BC bloggers is essential as being patients warrant them an identity to share information and advice related to breast cancer. The patient status – a status only awarded to individuals who have been registered to receive treatment for a particular illness – in some ways provide the individual with a credible position of one whose narrative is of a lived experience which was perhaps even life-threatening. This is what Clark and Mishler (1992, pg. 352) refers to as “a momentary shift in the social alignment in which the patients assume authority”. Their personal experience as BC patients allows them to produce personal stories of illness which can increase self-awareness and also promote active coping (Turkle, 1999). The discursive strategies within the discourse can be linked to the acts of positionings (Thurnherr et al., 2016). A person involved in a social interaction is constituted through the different discursive strategies in which they employ (Davies & Harré, 1990). Returning to excerpt 2, 3 and 4, the topics are all medical related with the bloggers positioning themselves as the patient in these illness narratives.

Much of the narrative in the patient position is accomplished through a recognizable discursive strategy. In the case of BC survivors in this study, the prevalent discursive strategy taken in the illness narrative is drawing from their personal experience of their illness journey. Hence, the discursive strategy taken in the patient position is drawing from own experience. In fact, three discursive strategies employed by BC bloggers emerged from the
analysis of the postings in the Malaysian BC personal blogs: (a) drawing from own experience, (b) drawing from other’s experience and (c) borrowing the voice of professionals. Table 2 shows the occurrence of these discursive strategies in the patient position found on the personal blogs.

### TABLE 2. Discursive strategies employed by BC bloggers when sharing their illness experience

<table>
<thead>
<tr>
<th>Discursive strategies for the patient position (n=246)</th>
<th>Drawing from own experience</th>
<th>Drawing from other’s experience</th>
<th>Borrowing the voice of professionals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>207 (84.1%)</td>
<td>28 (11.4%)</td>
<td>11 (4.5%)</td>
</tr>
</tbody>
</table>

The figures in Table 2 shows that the Malaysian bloggers draw on their own experience the most (84.1%), followed by drawing on other’s experience (11.4%) and borrowing the voice of professionals (4.5%). The most frequent discursive strategy found in the patient position is, drawing from own experience. Excerpt 5 illustrates how the blogger narrate the chemotherapy process by drawing from her own experience.

**Excerpt 5**

*(MB3, P24-7-8)*

The Onco Nurse was ready to explain to me again, the full procedure when we were just about to begin Round 2, an hour after the Emend dose. As in cycle 1, I was given a shot of a pre-chemo medication. 2 shots via the temporary port (there is a medical term for this, but I didn't take it down so have completely forgotten by now) that they had installed on a good vein on the back of my palm. One of them made me tingle all over, as it did the last time, just for a few seconds. Then the chemo proper took place.

**Drawing from her own experience** strategy is used as BC bloggers construct their credibility to write blogs based on the knowledge acquired from their illness experiences. Arksey (1994) argues that patients possessed medical knowledge as lay persons with practical experience and insider knowledge. Drawing from own experience when offering information and advice clearly demonstrates the claim made by Arksey. Similarly, Frank (1995) claims that through the discursive construction of illness and healing, a person is able to provide a frame of reference where he/she will be able to experience herself, her identity and body. In fact, drawing from one’s experience is one of the characteristics of personal illness narratives found in the blog postings. The data also revealed that drawing from own experience is the most frequent strategy used by the BC bloggers when taking on the patient position.

Discursive strategies are achieved through the use of specific discursive devices. In this study, the term discursive devices or resources describe the specific linguistic units which serve to fulfil a strategy. The analysis is presented by demonstrating the discursive devices employed to show how these devices work together to fulfil different discursive strategies. For example, when drawing from own experience, one of the discursive devices used is the first-person personal pronouns (e.g. I, me, my experience, etc – excerpt 5). The use of pronouns helps to position the bloggers and establish their identity while foregrounding the personal level of the illness narrative.

The bloggers use the following linguistic devices to draw on their own experience - (a) the use of first-person personal pronouns (e.g. I had my chemo..., my treatment regime...); (b) the use of abstract and emotive words such as feel relieved, afraid or worse) and; (c) the use of chronological structure to describe an event (i.e. A happens first, then B takes its place). The following section will illustrate how the strategy drawing on own
experience is achieved through the use of the three prominent discursive devices mentioned earlier.

DRAWING FROM THEIR OWN EXPERIENCE VIA THE USE OF FIRST-PERSON PERSONAL PRONOUNS

The first linguistic device used by BC bloggers when drawing from their own experience is the use of first-person personal pronouns (e.g. I had my chemo..., my treatment regime...). The following excerpts are taken from the first few entries in the personal blogs in which the bloggers’ narrate their experience of breast cancer detection and diagnosis.

Excerpt 6
(MB 1, P1-4)
I’ve been having this lump for quite some time now; I can’t really remember from when. I thought it was just a milk gland and as I was busy, I kept on postponing seeing my GP about it. It was two weeks ago that I went for my pap smear and I requested the nurse to do a breast screening as I suspect there was a lump. She immediately referred me to the breast institute for further investigation. On March 3, 20XX, I had a thorough check up by the specialist at the institute including mammogram, ultrasound and as well as biopsy where they poked long needle to get some samples from the lump.

Excerpt 7
(MB2, P1-8)
So, last Friday I went for a Breast Ultrasound at National Cancer Society Malaysia. (I was informed that Mammogram is only recommended for ladies above 35 years old.) My appointment was at 11am. Been called by a lady doctor for a manual check and waited until 12.30pm for my turn for the ultrasound!...It took only 15 minutes to finish the process. It's like when pregnant mommies go for the baby ultrasound. Only at different parts of the body!

Excerpt 8
(MB3, P2-4)
I went to a 24 Hour Mediviron clinic nearby for some antibiotics. The Doctor prescribed some antibiotics but urged me to consult a Breast Specialist as the abscess needed to be drained a.s.a.p. I completed the 3-day course of antibiotic and made an appointment to see a Breast Specialist. A small surgical procedure was carried out to drain out the abscess and a small tissue sample was taken for investigation. The analysis of the sample indicated some abnormal cells and growths in the ducts which may require further investigation given my profile: A golden girl, post-menopausal and non-childbearing. I agreed to a mammogram once the surgery incision heals. The result of the mammogram about month later prompted an Ultrasound scan to be done. Some highly suspicious looking mass were noted, indicative of malignancy. The Surgeon reassured me that 95% of such cases were benign. I would however need to have the lumped checked and removed as a precaution before it could become cancerous. We fixed a date for surgery.

All the above excerpts share one common characteristics – to reiterate; the frequent use of first-person personal pronoun or first-person personal possessive pronoun. The bloggers draw on their own personal illness experience when they first initiated the discussion of cancer in their blogs (e.g. I’ve been having this lump...; Last week I was diagnosed with breast cancer; When I think of it, I had the symptoms four years before surgery). The use of first-person personal pronouns can be linked to a high level of ‘involvement’ of the author/narrator which reflect the intimate nature of the BC personal blogs.
When the patient position is constructed, bloggers tend to immerse themselves in the stories to create a sense of personal identity and to foreground the personal level of the cancer experience. The use of first-person personal pronouns demonstrate that a narrator is an experiencing agentic person (Ringer, 2013) and that the speech characterises the narrator’s own voice or opinion (Kettendörfer, 2014). Hence, the use of personal pronouns can be linked to a person’s psychological state, cognitive processes and inner emotions. It is evident throughout the discourse that when BC bloggers take on the patient position, they either use the first or third-person personal pronouns.

**DRAWING FROM OWN EXPERIENCE VIA THE USE OF ABSTRACT AND EMOTIVE WORDS**

Overall, the BC bloggers’ accounts of illness are laden with emotional talk as the bloggers are documenting an important event in their life into perspectives. Past research (e.g. Kreuter et al. 2007; Cepeda et al. 2008, Charon & Wyer, 2008) have shown that cancer narratives are filled with personal stories filled by descriptions of feelings and emotions. Similarly, the analysis also revealed that when the bloggers provide information and advice online, they take on the patient position by drawing from their own experience using emotive words. Emotive words relate to any language function and meaning that have to do with the feelings of the speaker, both superordinate (e.g. feeling, mood) and specific (e.g. anger, remorse, relieved) (The Concise Oxford Dictionary of Linguistics, 2014; Stubbs, 2014). The following extracts illustrate the use of abstract and emotive words when BC survivors draw on their own experience to provide breast cancer-related information and advice.

**Excerpt 9**
*(MB1, P96-2)*

The last cryoablation and immunotherapy done in China in December 2014, must have not killed all the cancer cells. By end of 2015, I experienced series of bleeding again. Feeling trauma that it might bleed anytime, anywhere, I then decided to go for Microwave Ablation (MWA). With cryoablation, the tumor is frozen, on the contrary, with MWA, the tumor is heated.

**Excerpt 10**
*(MB2, P15-4)*

Since I got to know that I have cancer, I feel helpless. I don’t feel like life is worth living as I keep on thinking about the worst thing that could happen to me. But, when I think of how lucky I am to have my mother, husband and children beside me, I should always be grateful.

In Excerpt 9, MB 1 used emotive words such as trauma for a non-invasive procedure, suggesting fear which led her to opt for another treatment procedure – Microwave Ablation in China. According to MB 1, the procedure to stop the hormones was actually good to avoid cancer recurrence but there were side effects. Other abstract and emotive words such as feels worse, do not feel life is worth living, and I am proud are used by MB 2 and MB 3, which constructed their cancer journey as a journey full of emotions.

**DRAWING FROM OWN EXPERIENCE VIA THE USE OF CHRONOLOGICAL STRUCTURE TO DESCRIBE AN EVENT**

Another linguistic feature used in drawing from own experience is the use of chronological structure to describe events (i.e. A happens first, then B takes its place). The chronological structure is used when BC bloggers described the chemotherapy process, there were sequence of events used in their account. They first explained that they had to undergo a series of tests
which included heart, blood and liver tests to identify their current health condition before commencing chemotherapy. The following are the extracts that show how BC bloggers draw from their own experience using chronological structure to describe an event.

Excerpt 11


_I had my first chemo last Tuesday._ These are some snapshots on how it's done. It's not that bad. _The drugs are injected into the vein._ One good thing being in the cold weather, _when the nurse poked the needle, it's not that painful at all._ I'm wearing a cold cap to help reduce hair loss. It reminds me of the Combat movie when I was little, hence I name this cold cap "topi combat". _It is worn 15 minutes before the treatment, and it has to be changed every 45 minutes throughout the treatment._ For the whole two-hour duration, my husband has got to run upstairs to get the cold cap from the freezer. _These are the drugs that got into my vein._ The red coloured one is Doxorubicin; two tubes of it. In between the nurse injected in the anti-sickness medication. Then, only the big bag of Cyclophosphamide is _dripped into the vein._ Surprisingly, I don't feel hot at all. With the saline (salt water) and those much drugs that got into my vein, the one thing that I need was to pee.

Excerpt 12


_A month after the major surgery, which was somewhere in January, I had an appointment with the Oncologist._ The Oncologist consulted the following: 1. 6 cycles of Chemotherapy; or 2. Continue with new medicine. The current Tamoxifen pills are no longer effective. However, in order to prescribe me with new pills, I have to be induced-menopause first! _What is the process to be induced menopause? A. First, need to undergo minor operation to remove the 'egg' (immediate & can start with new pills asap); or B. Radiotherapy 4x. Blood test after 1 or 2 months to monitor 'egg'. If confirmed menopause, then only will start with new pills._

Each excerpt shows the chronological sequence of treatment-related information. For example, MB 1 explained the chemotherapy process she underwent. Similarly, MB 2 talked about a treatment process. The analysis also showed that they used a lot of sequence connectors such as _then, after_, and _finally_ which characterizes the chronological structure when describing an event. In this case, it is the bloggers’ account of their illness experience. Apart from drawing from their own illness experience, BC bloggers also draw from other’s experience when taking on the patient position. It is interesting to note that learning from the experience of others is essential for BC patients. Previous studies have shown how survivors’ stories have been used as a model for coping skills, providing social and emotional support, and sharing information and resources (Kreuter et al., 2007)

**LINGUISTIC DEVICES USED WHEN DRAWING FROM OTHER’S EXPERIENCE**

The analysis also revealed that BC bloggers draw from other’s experience when they provide information and advice on cancer. Other’s experience in this context refers to the cancer experience of their family members, close friends and acquaintances. The linguistic devices used when they draw from other’s experience is the third person pronouns such as _he, she, it, his, hers and their_.

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DRAWING FROM OTHER’S EXPERIENCE VIA THE USE OF THIRD PERSON PERSONAL PRONOUNS

The linguistic strategy used when drawing from other person’s experience is the third person personal pronouns which includes, he, she, it, his, hers, him, her, they, them, and their-. The following excerpts are some examples of drawing from other’s experience.

Excerpt 13
(MB1, P21-1)

My kind of treatment is kind of unique too. Usually when one is diagnosed, the immediate reaction is to be under the knife, followed by chemo and radiation. At least that was what my sister-in-law (BC survivor) did when she was diagnosed 12 years back. She had total mastectomy including some of her glands. When it was sent for biopsy, her glands were not affected at all. What a waste...

Excerpt 14
(MB3, P13)

I’ve been trying to nudge my sister in that direction as well since she’s not yet tried to attack the challenge with that weapon, but her oncologist hasn’t been particularly encouraging about it (I’m not a fan of his for many reasons, this being one). Every journal report I’ve read on the procedure seems to support the conclusion that it’s quite effective specifically with regard to controlling liver mets, although of course it’s always that delicate balance between treatment and causing some new problem to treat. Ugh. Another option I’ve discussed with my oncologist is chemoembolization. Again, her oncologist is resistant to the idea, but mine has had fantastic success with treating one affected lobe at a time and has kept several of his patients with diffuse liver mets either disease-stable or disease-free for years.

In Excerpt 13, MB 1 provided information related to available treatment options while implicitly suggesting treatment options depend on the discretion of the oncologist treating the patient. Likewise, MB 3, in Excerpt 14, talked about her sister’s cancer experience, in particular, her sister’s treatment decision and how different oncologists have differing opinions on a patient’s treatment. The bloggers draw on the cancer experience of others which in this case refer to their own family member’s. Therefore, it is interesting that as well as drawing from their own experience, BC survivors draw from the experience of others when sharing their illness narrative.

LINGUISTIC DEVICES: BORROWING THE VOICE OF MEDICAL PROFESSIONALS

The second discursive strategy used in the patient position involves borrowing the voice of medical professionals. In this context, medical professionals include oncologists, medical scientists and other medical professionals such as nurses, radiologists and psychiatrists. When taking on the patient position, BC bloggers in this study also borrow the voice of the medical professionals when offering breast cancer information. This strategy succeeds to establish two communicative tasks. The first is to further assert the blogger’s patient position as it distances the patient position from the experts or professionals. At the same time, borrowing the voice of medical professionals emphasizes the expert knowledge held by medical professionals.

BORROWING THE VOICE OF PROFESSIONALS VIA THE USE OF REPORTING VERBS

The linguistic device used when borrowing the voice of professionals are reporting verbs. Reporting verbs are used to show that a particular discourse is constructed based on what
others have written or said. These verbs are signalled by words and phrases such as the doctor said and according to my oncologist. This also includes verbs like warn and explain. The use of these verbs can be clearly discerned from the following data extracts:

Excerpt 15
(MB1, P14-3)
These are the drugs that got into my vein. The red coloured one is Doxorubicin; two tubes of it. In between the nurse injected in the anti-sickness medication. Then only the big bag of Cyclophosphamid is dripped into the vein. Surprisingly, I don't feel hot at all. With the saline (salt water) and those much drugs that got into my vein, the one thing that I need was to pee. Luckily the nurse warned me that my urine might be pinkish. True enough, I had a pink urine!

Excerpt 16
(MB2, P20)
I cannot get a mammogram again this time because I was still breastfeeding. So, the doctor suggested that I get an ultrasound because it can pick up images even with dense breasts. But she also said that she would recommend waiting about 2-3 months before getting the ultrasound, hoping that if it's milk related, the lump will just clear itself. From what she said, getting the ultrasound was more to ease my mind that it's nothing more than just milk.

MB 1, in Excerpt 15, shared information on the chemo drugs she received. She quoted the nurse who mentioned the aftereffects of the chemo drugs as it is evident through the use of the word warn. Here, MB1 is clearly constructing the patient position when sharing information about mammogram and ultrasound scanning decisions. Similarly, in Excerpt 16, MB 2 quoted the doctor she consulted when explaining about the pre-ultrasound session.

The BC bloggers were found to construct the patient position when giving information and advice by borrowing the voice of professionals. This discursive strategy is achieved through reporting verbs to maintain the authenticity of the information by borrowing the ‘actual’ voice of the professionals. It is interesting to note here that the use of reporting verbs when quoting medical professionals clearly indicate that the information or advice shared is not the blogger’s. Instead, such strategies highlight that the information and advice are given by the medical professionals. It is important to note that the bloggers often borrow the voice of professionals when offering important health information and advice. This is important as it clearly suggest that the bloggers do not take on the expert position but instead borrow the voice of medical experts when sharing important health information and advice.

CONCLUSION

Overall, the findings from this study have contributed to the existing body of knowledge on the discourse of BC survivors through blogs, the position they take when offering breast cancer-related information and advice and how the positioning is achieved through different discursive strategies and linguistic devices. The findings of this study make an important contribution to the field of discourse, social media and health communication studies. The current study offers some important insights into the discourse of BC bloggers based on the different positions they take when sharing their illness narrative. This includes the features, characteristics and discursive construction of the Malaysian BC bloggers. In addition, the findings of this study have contributed to the scarcity of research related to BC patient
discourse especially in Malaysia. It is interesting to note that although BC patients have the practical experience and insider’s knowledge (Arksey, 1994), they do not cross the line that delineates between patient and health expert. This is clearly shown from the patient position taken by the bloggers in their postings – they do not overstep the patient and physician boundary.

Considering the importance of information and advice from BC bloggers who are lay people, the positions taken up by BC survivors entail different information and advice given, it appears plausible to examine the positioning of BC bloggers when offering information and advice regarding this genre. The uniqueness of this study lies in the fact that this study, unlike previous studies, focus on how medical related information and advice is embedded in the illness narrative of these bloggers. Since the focus of this study is on the bloggers’ positionings when constructing breast cancer-related information and advice, the findings contribute to improving the information needs of BC patients.

Social media platforms are an important social space in which more and more people are sharing their illness experience, sometimes even in real time. It is important for healthcare providers to attend to these illness narratives very little can be expressed or observed during clinical visits or hospital stay. Access to patients experience about their life during treatment provides rich information which guide healthcare professional practices in improving patient’s care. Research on illness narrative on social media such as personal blogs helps to support efforts towards raising the volume of the patient’s voice in health care. This has important implications on improving communication between patients, their family members, friends and healthcare providers.

REFERENCES


ABOUT THE AUTHORS

Wan Nur Asyura Wan Adnan is a Language Instructor at Language Academy, Faculty of Social Sciences and Humanities, Universiti Teknologi Malaysia. Her research interests include Health Communication and Media Discourse. She has published several papers on breast cancer discourse and breast cancer survivor blogs.

Noor Aireen Ibrahim is a Senior Lecturer at Language Academy, Faculty of Social Sciences and Humanities, Universiti Teknologi Malaysia. Her interest lies in discourse-driven research in the areas of Health and Media. She is currently investigating and supervising research on communication in the intensive care, media construction of mental illness, HIV related communication challenges; nurse communication; and media construction of trust on the web.

Nur'ain Balqis Haladin is a Senior Lecturer at Language Academy, Universiti Teknologi Malaysia. She has conducted research and published several papers on Advice and Information Giving in HIV Counselling.

Wan Farah Wani Wan Fakhruddin is a Senior Lecturer at Language Academy, Faculty of Social Sciences and Humanities, Universiti Teknologi Malaysia. Her research interests and publications are in the area of Systemic Functional Linguistics (SFL) and Genre Analysis.