



Integrating the Culture and Civilization of the Nusantara:
Perspectives of the Social Sciences and Humanities

PROCEEDING

of the International Conference on
Social Sciences and Humanities

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Foreword by Editor-in-Chief

This version of e-proceedings contains a compilation of 80 selected papers from the International Conference on Social Science and Humanities 2019 (ICOSSH2019) that was held at Universiti Putra Malaysia, Bintulu Campus, Bintulu, Sarawak, Malaysia, on 8 - 9 October 2019. The conference was organized by the Faculty of Social Science and Management, Universiti Putra Malaysia, Bintulu Campus and it was jointly sponsored by Sarawak's Ministry of Culture, Sports and Youth and other private agencies.

This conference covering the fields of Social Sciences and Humanities to scholars, social scientists and academicians facilitate the mutual understanding of fundamentals, theory and applications within the fields of social sciences and humanities such as sociology, anthropology, education, business, management and psychology. The idea behind the organization of the ICOSSH2019 originated at the start of last year following discussions with social scientists and researchers from Malaysia and Indonesia and Brunei as well as from other parts of the world.

The conference featured 70 oral presentations and 10 poster presentations on state-of-the-art social sciences research themes including sociocultural appropriateness of social artifacts, pertinent educational issues and fundamentals of Nusantara paradigms, dichotomous nature of local-global socio-political lenses, and dynamics of unique ethnic-based explorations within Sarawak tribal & communal cultural treasures. All submitted papers are then peer-reviewed, revised according to the reviewers' comments and ultimately 80 papers were accepted for publication in this proceeding. This version of e-proceedings can be viewed or downloaded via <http://icossh2019.upm.edu.my>. We hope that this proceeding will serve as a valuable reference for researchers and social science scholars all over the world.

As the editor-in-chief, I would like to express my utmost gratitude to the fellow review members for their tireless effort in reviewing the submitted papers for this proceeding. I also would like to say special thanks to all the authors for promptly revising their papers according to the proceeding requirements. Special thanks are extended to the organizer of the ICOSSH2019, especially to the Organizing Chair, Dr. Mohamad Maulana Magiman, and Head of Conference Secretariat, Dr Aryaty Alwie.

Thank you

MOHAMAD ABRAR SHAHABUDDIN ADAM ASSAM

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LACK OF *KUDRAT*: A PHYSICAL ILLNESS EXPERIENCE OF YOUNG MALAY BREAST CANCER PATIENTS

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ABSTRACT

This qualitative study aims at exploring the illness experiences of young Malay breast cancer patients in relation to the symptoms they suffered from. Thirteen young Malay breast cancer patients in Kuala Lumpur and several selected areas of Selangor were selected through purposive snowballing technique. In relation to this, an ethnographic fieldwork employing a qualitative approach was conducted for approximately 10 months. A series of in-depth interviews, phone and online interviews guided by semi-structured interview schedule and participant observation were carried out among the informants of this study. This is imperative particularly to make sense the meaning of illness as perceived by the Malay informants. Data obtained from the fieldwork was analysed thematically to gain understanding of the stories conveyed by informants. Codes were then generated in relation to the study's objective. It is evident from the present study that young Malay informants had described their illness experiences in terms of physical dimension. As such they perceived having *semput*, *tak boleh makan* and *tak boleh pergi kerja* as the ingredients of lack of *kudrat*. This study holds an important implication in contributing to the existing corpus of knowledge as far as medical anthropology is concerned. It is also significant for health care providers and support networks in better understanding breast cancer patients' conditions, medical problems, psychosocial needs and quality of life in coping with cancer.

Key terms: kudrat, illness, Malay, breast cancer

INTRODUCTION

Background Information

The notion of illness experienced can be discussed in relation to symptoms experienced by patients. Suchman (1965) distinguishes three aspects of symptoms experienced by patients, namely physical, cognitive and emotional illness experiences. The physical experience refers to pain, discomfort and change of appearance or debility. The cognitive experience of illness refers to the interpretation and the meaning of symptoms described by those experiencing the illness and finally the emotional aspect of symptom refers to fear or anxiety that accompanies both the physical and cognitive experiences of illness. In relation to this, Skott (2008) in his study of cancer patients in Sweden has associated symptoms with illness experience.

The study reports that these cancer patients noticed physical, cognitive and emotional changes in their bodies such as clumsiness, breathlessness, poor balancing and staggering that consequently hinder many of their daily activities. They were not able to see, speak normally, read, write or listen to the radio. In addition, they were also unable to walk and lift their feet properly like before. These lead to frustration amongst cancer patients in dealing with their daily lives. Thus, the symptoms suffered, could be defined as unwanted, abnormal bodily changes that often result from the disease.

According to Fabrega (1973), symptoms are one of the components of illness that deal with bodily sensation and abnormality such as pain in specific locations as well as nausea and vomiting that vary in their intensity and effects. His emphasis is given to physiological symptoms in order to reflect illness severity. For example, Fabrega and Zucker (1977) in their comparative study on illness episodes among the Ladino and Indigena women in Mexico, have shown that there is a linear relationship between symptoms and illness severity. This indicates that the increased symptoms signify the increased illness severity and seriousness. Generally, it was observed in the study that women were reported to having more symptoms of all types related to emotions, role functions, work, general physiological and pain symptoms during their illness episodes; they judged their illness to be more life-threatening.

Furthermore, Fabrega and Zucker (1979) define symptoms as total constitute disruptions to an individual. These disruptions are often negatively valued by individuals as it signals a need to seek treatment or corrective action. Thus, these symptoms signal to the individuals as to what is going wrong with their body. For example, among the Malays, the loss of *semangat* (vital force) and the presence of 'poisonous' blood accompanied by depression, auditory hallucinations, insomnia and confusion are among the symptoms of *gila merian* or postpartum depression. The Malays believe that an illness is caused by an excessive 'poisonous' blood accumulated during child-birth. In relation to this, mothers are prescribed by the *bomoh* to consume herbal decoctions, undergo the traditional *berdiang* (roasting of the mother) or *bertungku* to remove the excessive 'poisonous' blood in the body (Chen, 1970).

Wong et al. (2014) in their study in Kuala Lumpur, Malaysia observe that *lelah* or breathlessness was prevalent in most of the complaints forwarded by Chronic Obstructive Pulmonary (COPD) patients and reported by doctors upon their admission to a hospital. They found that due to poor knowledge of COPD, the symptom was mislabeled as asthma by patients and doctors prior to the diagnosis of their illness. They also observe that the suffering from *lelah* had left several implications on patients' lifestyle, management and adaptation towards the disease. These include psychosocial limitations such as fearful of being alone at home, worry that help could not arrive in a timely manner, avoiding crowded places for believing this could exaggerate the symptom, and less participation in family gathering. Additionally, patients reported several physical limitations in relation to the symptom of *lelah* suffered like becoming helpless and having to depend on caregivers to move about, limiting the amount of food taken and avoiding cold beverages and fruits like watermelon.

Having said all these, this study aims at exploring the exploring the illness experiences of young Malay breast cancer patients in relation to the symptoms they suffered from.

METHODOLOGY

Study Area and Population

Ethnographic fieldwork was carried for approximately ten months among young Malay breast cancer patients in Klang Valley and several selected areas of Selangor,

located in the central region of Peninsular Malaysia. The study areas were selected mainly due to the higher incidences of breast cancer reported. The actual locations of the study were kept confidential to protect the privacy and confidentiality of the informants.

Sampling

Thirteen young Malay breast cancer patients between the ages of 29 and 48 years old were selected for this study through purposive snowballing technique. Several criteria were laid down and carefully determined prior to embarking on the selection of potential informants. The criteria of potential informants include 1) must be women of Malay ethnicity 2) must be of young age defined in the study which is within the range of 25 to 49 years old 3) must be breast cancer patients or survivors as the study itself was carried out specifically to study the illness experiences of breast cancer patients or survivors and 4) must have undergone a series of treatments at least for a period of six months before the selection was carried out.

Data Collection Procedure

The data collection consisted of ethnographic qualitative methods i.e. in-depth interviews and participant observation. Prior to the interview, potential informants were contacted via phone call to seek their consent for participation in the study. A series of in-depth interviews were conducted with informants in order to identify the various factors associated with the onset of their breast cancer symptoms. Several interview techniques were included such as face-to-face interviews, phone interviews and online interviews. The interview sessions were held informally in a semi-structured way, but guided by the interview schedule. Informants' demographic and health profiles and factors associated with the onset of their breast cancer symptoms were covered in the interview schedule. Each interview lasted from around 45 minutes to one and half hours. In the case where face-to-face interviews with informants was not possible due to several limitations such as time and health factors, the interview sessions would be held either through phone interview or online interview. In order to observe several situations described by the informants throughout the interview sessions, participant observation was carried out. In several occasions, the researcher had the opportunity to participate in several events such as accompanying informants for an appointment in the hospital, visiting them when they were admitted to the hospital and attending funerals when informants passed away. All data obtained and events observed and participated were recorded in fieldwork diary

Data Analysis

Thematic content analysis technique was used to analyse the data obtained from the field. The researcher began the analysis by reading and rereading the field notes and online scripts to gain understanding of the stories conveyed by informants. Codes were then generated in relation to the study's objective. With the subsequent field notes, codes were added or dropped and the coding list was recoded whenever necessary. When the coding was completed, the codes that have common elements were merged and themes or categories that are explanatory to the relevant issues highlighted in the study were formed. All the themes or categories developed from field notes were compared in order to derive to the final themes or categories. The final sets of themes or categories later became the findings of the study.

FINDINGS

From the data obtained, several informants had associated their breast cancer illness with lack of *kudrat* (one's physical agility). The lack of *kudrat* includes physical movement, pattern of food consumption and work performance after they had been diagnosed with breast cancer symptoms.

Physical movement

Several informants encountered physical behavioural limitation particularly in performing their daily routines and activities. They frequently suffered *semput* or *penat* (easily getting tired due to shortness of breath) symptoms in carrying out their household duties. Prior to breast cancer, they could perform many duties such as cooking, walking in the orchard, cleaning household compound, playing with their children and doing laundry. However, after they had breast cancer symptoms, they believed the symptoms had *makan diri* (gradually killing themselves i.e. their energy or stamina) that eventually made them *tidak sihat* (becoming ill). One of the informants aged 41 described her symptom of *penat* as an ingredient of *sakit* (illness). The symptoms suffered had substantially resulted in some physical behavioural limitation to her. She narrated as follow:

She began to notice her limited physical movement; she could hardly climb the stairs in her office after her breast cancer symptoms worsened. She was informed by the doctor that the cancer cells in her breast had spread to her lung. As a result, she suffered from symptom of 'penat' even for a short distance of walking from the bed to the washroom. She added that her condition had becoming more severe a few weeks before being admitted to the hospital.

Pattern of food consumption

Good health refers to one's ability to enjoy good diet. This involves the pattern of food consumption. It was observed in this study that informants associated good health with *boleh makan* i.e. one's ability to consume food without restriction or having *pantang larang*. At the expense of their good health, they enjoyed eating whatever food served before them. The food served could be oily, contained artificial flavour, with high amount of sugar, salt and MSG that could jeopardise their good health. This is common for career women in particular for they are busy and tight with their working schedule. Thus, they have limited time to cook for themselves and family, and would resort to eating outside. However, things changed after having breast cancer. During interview session, one of the informants aged 35 narrated to me as follows:

She knew for certain that eating outside was considered as unhealthy pattern of diet. The choice and food preparation could be unhealthy too. She continued enjoying the food partly due to her busy and tight working schedule. She never bothered whether the choices of food were healthy or not. She described the choices of her food were 'sedap tapi tak sihat' (delicious but unhealthy) for it was oily and contained high amounts of salt, sugar and MSG. The habit continued until she was diagnosed with breast cancer. Since then, her awareness about

the importance of a healthy diet and its relation to her health developed. She started to cook her daily meals. In relation to that, she hired a maid to help her prepare ingredients for her to cook. She added that she would ensure that the meals prepared would contain all groups of food with suggested amount per serving as recommended by the doctor.

The forgoing case highlights that the concept of *boleh makan* is very much related to one's awareness about one's health status.

Work performance

In addition, several informants believed that one's health status is measured through his or her ability to carry out duties at work. They were informed by their employers that they are entitled to paid cancer leave up to two years upon recommendation from the doctor. One of the informants aged 36 for instance, had considered *boleh pergi kerja* as good health. She narrated to me below:

She believed 'sihat' as 'boleh pergi kerja' or returning to work after nearly a year being on medical leave. It was an indicator that she is surviving from cancer. She had to wait for five years for her to be declared as a cancer survivor.

DISCUSSION

The *boleh makan* concept refers to the following features i.e. having *selera makan* (appetite) and *boleh rasa makanan* (able to enjoy the taste of food). These features were absent once they were diagnosed with breast cancer. Several informants had associated *tidak ada selera makan* (loss of appetite) as a result of chemotherapy treatment received for their breast cancer symptoms. Most of the informants strongly believed that the killing of breast cancer cells through chemotherapy in particular, had inadvertently affected their appetite towards food. Similarly, *tidak boleh rasa makanan* (taste of food becomes bland) was mentioned by several other informants as one of the side effects of chemotherapy they suffered after receiving the treatment. They strongly believed that the drug used in the treatment to kill cancer cells in their breast areas had changed their taste buds, causing the food they consumed to taste bland or have a metal-like taste.

They described *boleh pergi kerja* or ability to go to work as they used to before they were diagnosed with breast cancer as a sign of good health. Instead, *tidak boleh pergi kerja* or inability to go to work due to illness was perceived as an ingredient for *sakit* for they were not fit enough to carry out duties at work accordingly. On this account, informants were exempted from performing their role as workers and were given sick leave.

CONCLUSION

Lack of *kudrat* is another common physical symptom of chronic illness suffered by young Malay breast cancer patients.

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