RETROSPECTIVE ASSESSMENT ON PSYCHOLOGICAL NEEDS AND NEED FOR HELP POST-DIAGNOSIS: AN EXPERIENCE WITH MALAYSIAN BREAST CANCER SURVIVORS

Nur Haidzat A. W.[a]*, Zubaidah J. O.[b], David J. de L. Horne[c], Aina E. N.[d], Nor Saleha I. T.[e], Normala I.[b], Siti Irma Fadhilah I.[b]

[a]Department of Psychology, International Islamic University Malaysia, P.O. Box 10, 50728, Kuala Lumpur, Malaysia
[b]Department of Psychiatry, Faculty of Medicine and Health Sciences, University Putra Malaysia, 43400, Serdang, Malaysia
[c]Albert Road Clinic, Ramsay Health, Melbourne Victoria, 3004 Australia
[d]Breast and Endocrine Unit, Department of Surgery, Hospital Kuala Lumpur, 50586, Jalan Pahang, Malaysia
[e]Cancer Unit, NCD Section, Disease Control Division, Ministry of Health Malaysia, Putrajaya, Malaysia

Abstract

Breast cancer is becoming a common health problem among Malaysian women. It is undeniably challenging to face the diagnosis, and almost every person experiences distress at any point in time during the cancer journey. However, there is still a lack of evidence to support the importance of screening for psychological distress during this crucial time. This study involved a retrospective assessment using the Emotion Thermometer scale among twenty-one breast cancer survivors who had experienced breast cancer surgeries. They were asked to recall and rate their own emotional and psychological states and indicate problems faced post-diagnosis. In particular, this study aimed to address the questions if emotional and psychological problems exist, and if patients were in need of further assistance.

Keywords: Restrospective assessment, emotion thermometer, distress, need for help, post diagnosis, breast cancer

*Corresponding author.
 E-mail address: haidzatnur@yahoo.com.au

1. Introduction

The prevalence of cancer cases and cancer-related deaths is increasing worldwide. Malaysia is located in Southeast Asia, comprising Peninsular Malaysia and East Malaysia which includes Sabah and Sarawak. In 2017, the Malaysian population was estimated at 32 million with 28.7 million citizens, and the percentage of the major ethnic groups of Bumiputra, Chinese, Indian and Others were 68.8%, 23.2%, 7% and 1 % respectively (Mohd Uzir & Ho, 2017). The National Cancer Registry (NCR) records that from 2007 through 2011, there were a total of 103, 507 new cancer cases diagnosed in Malaysia (Azizah, Nor Saleha, Noor Hashimah, & Mastulu, 2011). The authors note that breast cancer is the commonest form of cancer among Malaysian citizens, and it is anticipated that one in nine women may develop breast cancer or any form of cancer by the age of 75. It was also reported that the lifetime risk for a healthy woman to develop cancer is highest among Chinese with 1 in 22, followed by Indians with 1 in 24, and lowest among Malays with 1 in 35.

However, although Malay women had the lowest incidence of breast cancer, the stage of presentation among this group was more advanced than other races, resulting in the highest rate of mortality (Aina, 2016; Hisham & Yip, 2004; Ibrahim, Dahlui, Aina, & Al-Sadat, 2012; Taib, Akmal, Mohamed, & Yip, 2011; Yip, Taib, & Mohamed, 2006). Moreover, the increasing rate of the onset of the illness at a younger age is of great concern as it indicates that the younger generation may be facing a greater risk of developing cancer with current life challenges such as increase in daily stress, multiple responsibilities, Body Mass Index (BMI) gain, smoking, lifestyle changes and pollution which also, in part, contribute to cancer (Brown et al., 2010; Lim et al., 2007; Suzuki,Tsunoda, Kimura, & Yamauchi, 2017). This information, which is alarming for both the individuals involved and the nation in terms of manpower loss, calls for a focussed and consistent commitment from the government and private sectors in ensuring health promotion and education are on-going and relevant.

Dealing with the cancer diagnosis can be a very stressful experience for anyone. The words/phrases 'stress', 'distress', 'emotional distress', 'psychological distress' have been used interchangeably in research to reiterate the unpleasant experience of cancer patients. Over the years, the openness in discussion about the emotional and psychological distress on patients, family members and psychological toll on health-care systems have led to a wider coverage of the experience of distress. The definition of distress has shifted away from absolute psychiatric interpretation so as to reduce stigma, and aids to validate that distress is normal among persons with cancer. The National Comprehensive Cancer Network (NCCN) is one of the earliest global platforms to communicate scientific information to important stakeholders such as physicians and patients. One of the purposes of NCCN is to engage patients with its established

standards and guidelines of care for treatments. Distress had been defined as "a multifactorial, unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer, its physical symptoms and its treatment. Also, psychological distress is extended from the understanding of experience of common or normal feelings of vulnerability, sadness and fears, to problems that can become disabling such as depression, anxiety, panic, social isolation and spiritual crisis" (NCCN, 2017, p.10). This broad definition appears to capture every aspect that is pivotal in an individual's cancer trajectory and it mirrors a more holistic quality of care for patients.

Emotional distress is part of psychological health because human behaviours are better understood with the reciprocal interaction of thoughts, emotions, and behaviours. In critical situations, emotional stability and overall psychological states can be at stake. It is well documented that a person may be suffering from emotional distress due to cancer diagnosis at any juncture of the journey. In general, when a person is in distress, the psychological states can be presented explicitly through thinking patterns, feelings as well as behaviours or actions. To a certain degree, the signs of distress can be detected through physical symptoms, as when the body is trying to cope with the physiological changes and its process. However, be it cognitive, emotional, behavioural or physical symptoms related to psychological distress, it is often overlooked. Although it is generally assumed that not every patient needs supportive care, it is part of the concern for psychosocial care to identify those who may be experiencing elevated distress during meeting the physician to confirm the diagnosis.

2. Problem Statement

The acquisition for psychological assistance or any help to deal with the problems may go unnoticed, as screening for signs of psychological distress is still scarce in our current practice. Although this is the case, there is still a lack of empirical evidence to underscore the importance of screening for psychological distress. Therefore, this study aimed to address the issue of presence of emotional and psychological distress post-diagnosis, and if, at all, patients required help in dealing with this distress.

3. Research Questions

This study aimed to answer two questions related to the:

a) patients' recall of experiencing distress when they learnt of the diagnosis of cancer.

b) patients' attempt/need to seek for help and/or if they faced problems during the diagnosis.

4. Methodology

4.1. Participants

A total of twenty-one survivors from the Breast Cancer Welfare Association (BCWA), National Cancer Society Malaysia (NCSM), and on-going treatment patients at the Oncology Clinic and Day Care Centre, Specialist Complex and Ambulatory Care Centre (SCACC) in the General Hospital of Kuala Lumpur (HKL) participated in this study by filling up the Emotion Thermometer (ET) questionnaire.

4.2. Sampling

The study employed purposive sampling as it called for a voluntary participation among the survivors who fulfilled certain criteria. The criteria set to ensure patients possessed similar characteristics with the actual patients for future experiments. The inclusion criteria were female, aged between 18 and 65 at the year of surgery, literate, and diagnosed with breast cancer stage one (I) through three (III). Patients aged above 65 with underlying psychiatric or neurological illness or diagnosed with advanced staging, were excluded from the study. This study is a subset of another study which was held between April and September 2015 at the recruitment sites. It reports a retrospective assessment where patients who participated this study have had mastectomy or related breast surgeries such as Breast Conserving Surgeries (BCS) or extensive axillary clearance from the year 2011 until 2015. Advertisement leaflets about the research were emailed to the potential patients, and hard copies were distributed at the clinic. Those interested in participating in the study contacted the person in charge at the recruitment sites, and consent was obtained before joining the study.

4.3. Measure

The Emotion Thermometer (ET) was used as a scale for self-report in the present study. ET has a simple and rapid tool for detection and monitory of emotional disorders in the field of Psycho-Oncology. The scale, developed by Mitchell (2010), has five thermometers which are *Distress*, *Anxiety*, *Depression*, *Anger* and *Need Help*. These thermometers look-alike are formatted as a scale ranging from zero represents 'Nothing at all' through ten represents 'Very high', which describes the degree of the specific emotional states in the past week. It comes together with a problem checklist of thirty-three items organized under five specific domains namely *Emotional*, *Family*, *Practical*, *Spiritual* or *Religion Concerns*, and *Physical*, and consists of problems commonly experienced by cancer patients.

In this study, patients were asked to recall their emotional states during disclosure of diagnosis and rate the items independently. The information on the scale was partly used as a basis for respondent validation where information about need for 'Help' was sought. The most recent validation study of ET amongst Singaporean cancer patients by Beck, Tan, Lum, Lim and Krishna (2016) has been used as the closest reference for local context whereby cut-off points of three is used for *Depression*, and four for *Distress*, *Anxiety*, *Anger* and *Need Help* as a standard reference in the present study.

Last but not least, this study aimed to report the internal consistency (Cronbach's alpha) for the thermometers, as it reflects the agreement and responsiveness of the scale when it is used in a clinical sample.

5. Data Analyses

All data entry and analysis for quantitative data was done using Statistical Package for Social Sciences (SPSS) version 22. Descriptive statistics were reported for patients' characteristics on age, race, stage of cancer, family history on cancer, types of surgery, pain score before and after surgery, and days of hospitalization. The means and standard deviations scores of *Distress*, *Anxiety*, *Depression*, *Anger*, *Help* thermometers were calculated. Also, the percentages were also reported for patients' expressions on two items: *'Are you already getting 'Help' for problems indicated on thermometers?'* and *'Do you want further 'Help' for the problems?'*.

6. Results and Discussion

Table 1. Demographic Characteristics of Participants (n = 21)

Characteristic		n	%	M	SD
Age	0-40	3	14.29		
	41-55	10	47.62		
	56-65	8	38.10		
	Overall	21	100.0	51.52	9.51
Marital Status	Married	15	71.4		
	Single	6	28.6		
Race	Malay	6	28.6		
	Chinese	10	47.6		
	Indian	4	19.0		
	Others	1	4.8		
Stage	I	4	19.0		
	II	10	47.6		
	III	7	33.4		

Family History of Cancer	Yes	9	57.1		
	None	12	42.9		
Type of Surgery	Mastectomy	16	76.2		
	BCS	4	19.0		
	AC	1	4.8		
Pre-operation Pain Score	Min=0, Max=10			2.76 (3)	3.36
Post-operation Pain Score	Min=0, Max=10			4.76 (5)	2.91
Days of Hospitalization	Min=2, Max=19			5.95 (6)	
	7 days of less	18	85.7		
	8 days onwards	3	14.3		

Abbreviations: Mastectomy, Breast Conserving Surgery (BCS), Axillary Clearance (AC), Standard Deviation (*SD*), Mean (*M*), Minimum (Min), Maximum (Max)

Table 1 shows the characteristics of the patients who participated in this study. Twenty-one female patients with breast cancer participated in this study. The mean age of the patients was almost 52 years old, and the highest range of age is between 41 and 55 (47.62%). Fifteen (71.4%) of them are married and the majority have children while six (28.6%) are single. Half the patients were ten Chinese (47.6%) followed by six Malays (28.6%), four Indians (19%), and one of aborigine ethnicity. The highest number of patients at stage II, were ten (47.6%), followed by four (19%) with stage I, and seven (33.4%) with stage III. None of the patients were at stage zero (0) with invasive or pre-cancerous stage or stage IV as the present study focussed its scope to match the characteristics of patients who benefit from the psychological intervention provided at the hospital. There were nine (57.1%) patients with a family history of cancer while twelve (42.9%) patients had no history of cancer in the family. The majority of patients, sixteen (76.2%) had undergone mastectomy while four (19%) had BCS with axillary clearance, and only one patient underwent axillary clearance.

Pain score is based on a ten-point Numerical Rating Scale (NRS) where zero represents 'No pain sensation' while ten represents 'Worst pain imaginable'. The interpretation of pain severity also based on the *Three-Step Analgesic Ladder* by the World Health Organization (WHO) whereby 'mild' is indicated by score of four or below, 'moderate' by pain score of five through six, while 'severe' by pain score of seven through ten (Clinical Practice Guideline (CPG), 2010). Overall, the average scores for pre-operative pain score and post-operative pain scores are three and five, respectively. Based on the mean scores, patients experienced mild pain before undergoing an operation and a mean score of five showed that patients experienced moderate pain.

The pain scores may vary if observed just for mastectomy as the procedure is more extensive than BCS. Based on sixteen patients who had undergone mastectomy, it was observed that the mean scores for pre-operative and post-operative pain scores were three and

four, respectively. The pre-operative mean scores reflected that patients reported more pain before undergoing mastectomy than BCS, whereas the post-operative pain scores remain similar for the two procedures. Although the sample is not equivalent for an ideal comparison, it does give a heads-up about patients' emotional experiences based on risks and outcomes of surgeries. Based on the mean score for hospitalization, most patients (85.7%) were hospitalized for seven days or less.

Table 2. Responses to Emotion Thermometers and Problem-Checklist (n = 21)

Response	*M*	*SD*	*n*	%
Distress	5.29	2.91		
Anxiety	6.14	2.73		
Depression	5.43	2.66		
Anger	3.52	2.77		
Help	4.67	3.04		
Often ticked concerns or problems				
Worry			19	90.5
Depression			18	85.7
Fear			20	95.2
Pain			9	42.9
Sleep			16	76.2
Appetite			13	61.9
Breathing			20	95.2
Item 6: Are you getting help?				
Yes			12	57.1
No			9	42.9
Item 7: Do you need further help?				
Yes			17	81
No			4	19

We also had the patients fill in the ET before joining a prior research endeavour. The questionnaire calls for retrospective psychological experience and quest for help during post-diagnosis. It provided an objective evaluation of patients' self-report about distress, and the interpretation for each thermometer relies on cut-off score set earlier. On another note, Mitchell (2010) pointed out the clinical interpretation cut-off scores of zero through three is low while four through ten is high on any thermometer. Table 6.2 above shows the responses to the ET. Overall, the mean scores of *Distress* (5), *Anxiety*, (6), and *Depression* (5) thermometers indicated patients' psychological states were affected. Specifically, *Anger* thermometer is almost four which reflected anger is part of the total emotional experience, and may relate to denial thinking and feeling of shock during disclosure of diagnosis. It reflects patients had experienced overall psychological distress, and it is suggestive that such high

scores should be followed up with enquiries. These are available in two questions just below the thermometers; *if patients are already getting some form of 'Help' for the problems and/or if more 'Help' is needed*. Also, it may also be useful to ask concurrently, when it is likely that patients would be in need of such help. This may be crucial as it allows for a space to build rapport between physician and patient to explore the specific needs of the patients and resources available to support the patients. With better alliance, patients may feel comfortable to open up about their underlying worries and concerns related to psychosocial and/or treatment(s).

Pertaining to stage of illness and distress, the number of patients at stage I and II doubled compared to patients at stage III. Hence this result may imply that most patients feel distressed, regardless of the staging of diagnosis. Based on predisposition factor of getting the illness, nine patients with no family history (42.9%) may have experienced distrust over the cancer diagnosis which resulted in heightened psychological distress. Whereas, the twelve (57.1%) who had a family history of cancer, may have expected that they would develop cancer, thus reducing the psychological distress. Finally, equally importantly, is the mean score for *Help* (4) thermometer which echoes the need for patients to combat distress, anxiety and depressive symptoms.

In addition, based on the often-ticked concerns at the problem checklist, seven items (> 40%) were observed to be pertinent in this sample. The item 'Fear' and 'Breathing' ranked highest in percentage. This may be explained by the presence of 'Worry' and 'Depression', where both were also cited frequently during the pre-operative phase. The physical symptoms found to be related to patients' psychological distress were 'Pain', 'Sleeping', 'Appetite' and 'Breathing' problems. Particularly, breathing problem was attributed to feeling anxious and scared of treatment(s), rather than respiratory or cardiology problems.

Items number six and seven asked specifically if patients are getting any 'Help' for the problems cited in the problem checklist (with multiple domains) and almost half reported that they received no help (42.9%). The last item asked for if they need further help, and seventeen patients (81%) admitted they do need further help, and this accounts for most patients who have received some help. This information indicated that patients are seeking for help post-diagnosis and there should be clear help-seeking strategies to provide the help these patients' needs. It is important for patients to understand how to cope with challenges, for family and close friends to observe unusual emotional reactions of patients, and for doctors to detect symptoms as well as suggest psychological screening and rapid intervention for patients.

Finally, the Cronbach's alpha for ET based on the five thermometers is .884. This scale sustains the internal consistency of more than .7, and therefore, it can be considered reliable

and acceptable for clinical sample. However, it should also be noted that this study has its limitations. Firstly, it employed a relatively small sample size and secondly, the patients involved were of specific criteria due to the needs of the study. Thirdly, bias related to true recall of events and experiences and the misinterpretation of the life events may occur as the study included a retrospective approach. Hence, the results presented should be interpreted with caution.

7. Conclusion and Implications

In conclusion, this study has demonstrated that overall, the emotional and psychological health of patients was affected right after or post-diagnosis. The information related to need for 'Help' through the thermometer and specific items in the ET revealed that the majority of patients did need further assistance for the cited problems. It is also worth noting that of thirty-three listed problems, three *Emotional* problems namely '*Worry*', '*Depression*' and '*Fear*' were cited with high percentages, more often than other problems. The psychological distress as manifested through the cited problems would not merely be linked to or caused by physical pain, but is understandably linked to the abdication of their roles and responsibilities due to the illness.

Having said that, to a certain extent, the research findings reiterate the pressing need for patients to undergo a diagnostic screening for emotional and psychological distress not only to ensure that needful actions are implemented, but also, to carefully plan for an effective intervention, and understanding the best time to support the newly diagnosed as well as on-going treatment patients. In other words, mandating a screening tool for psychological distress would make a difference to the mental health and overall well-being of breast cancer sufferers. The recognition of psychological distress through the screening tool and subsequent interventions would clear the way for these patients to deal with the illness in a holistic manner. One way or the other, this initiative will go a long way to improve the quality of services provided at hospitals.

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