# Symptom Experience and Self-care among Thai Women with Cervical Cancer

*Bualuang Sumdaengrit, Somchit Hanucharurnkul, Marylin J. Dodd, Sarikapan Wilailak, Thavatchai Vorapongsathorn, Kanaungnit Pongthavornkamol*

**Abstract**: The purposes of this study were to describe the: (a) occurrences, intensity and distress of Thai women's symptoms pre-treatment (T1), during-treatment (T2) and one month post-treatment (T3) for cervical cancer; (b) strategies and effectiveness of self-care behaviors used to relieve the five most frequent, severe and distressing reported symptoms during each period of treatment; and, (c) patterns of change in symptoms the women experienced and their self-care effectiveness from pre- to post-treatment (T1 – T3). One hundred and ninety subjects, recruited from four hospitals, completed three questionnaires, including the: Demographic, Disease and Treatment Questionnaire; Modified Memorial Symptom Assessment Scale; and, Modified Self-Care Diary.

Different symptoms and self-care behaviors occurred during each treatment period. During pre-treatment, vaginal discharge was the most common symptom, while difficulty swallowing was the most intense and distressful symptom. However, during both pre- and post-treatment, mood changes was the symptom that most often required self-care, while "tried to think that whatever will be, will be and do the best you can" and "relaxed by walking, watching TV or listening to music" were the most frequently selected forms of treatment, and "used Dhamma to calm down" was the most effective treatment. The most common self-care performed for vaginal discharge was "frequently cleaned the perineum." During treatment, fatigue was the most frequently occurring symptom, while diarrhea and rectal irritation were the most intense and distressful ones. "Took naps" was the most frequently used and effective strategy for relieving fatigue. After treatment, changes in the skin was the most common symptom, while a problem with sexual interest/activity was the most intense symptom and feeling nervousness was the most distressful symptom. Sleeping difficulty was found to be present during all three treatment periods; with "rested in bed" the most frequently used and "took sleeping pills" the most effective self-care strategies. Changes in symptom experience increased significantly during treatment and decreased during post-treatment, while self-care effectiveness decreased during treatment and increased during post-treatment. The findings suggest health care providers need to assist women in learning to utilize appropriate self-care strategies in accord with their symptom experiences.

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**KeyWords**: Cervical cancer; Symptom experience; Self-care; Thai women

## Introduction

Cancer is reported as the leading cause of death in Thailand, with breast cancer, followed by cervical cancer, being the leading causes of death, specifically, among Thai women.[1] Between 2003 and 2007, the mortality of Thai women due to cervical cancer was 5.2 per 100,000 per year.[1, 2] Over 25 million Thai women, age 15 and over, are at risk of developing cervical cancer, with more than

***Correspondence to: Bualuang Sumdaengrit**, RN, PhD (Candidate) Department of Nursing, Faculty of Medicine, Ramathibodi Hospital, Mahidol University, Thailand. **E-mail:** rabualuang@staff2.mahidol.ac.th or bualuangs@hotmail.com*

***Somchit Hanucharurnkul,** RN, PhD, Professor Emeritus, Department of Nursing, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Thailand.*

***Marylin J. Dodd,** RN, PhD, FAAN, Professor, Department of Physiological Nursing, School of Nursing, University of California at San Francisco, U.S.A.*

***Sarikapan Wilailak,** MD, Professor, Faculty of Medicine Ramathibodi Hospital, Mahidol University, Thailand.*

***Thavatchai Vorapongsathorn**, PhD, Associate Professor, Faculty of Public Health, Mahidol University, Thailand.*

***Kanaungnit Pongthavornkamol**, RN, PhD, Associate Professor, Faculty of Nursing, Mahidol University, Thailand.*

6,000 diagnosed, and over 2,600 dying yearly from the disease.[3,4] By 2010, more than 10,000 Thai women are predicted to be diagnosed yearly with cervical cancer.[1,3]

Unfortunately, the signs and symptoms of cervical cancer may not be noticed until it has advanced and requires intensive treatment. Cervical cancer, as well as treatment for it, are known to cause unpleasant symptoms and precipitate physical, psychological and social changes.[5,6] This is seen especially in advanced stages of cervical cancer when radiotherapy, or a combination of chemotherapy and radiotherapy, are administered. For example, when a large, malignant, cervical tumor is being treated and a cisplatinum-based chemotherapeutic agent is added, as a radiation sensitizer to optimize local response, the agent may cause the woman to experience toxic, urinary, hematological and gastrointestinal symptoms, as well as alopecia and menstrual changes.[7-10]

Given that treatment of cervical cancer involves both inpatient chemotherapy administration and outpatient radiotherapy,[11] even those who have ready access to a cervical cancer center often have to assess and care for themselves at home. This is especially true in Thailand, where cervical cancer treatment centers are available only at the National Cancer Institute of Thailand, university hospitals and hospitals located in major cities. Thus, while receiving treatment, women from rural areas often are separated from their family, which causes them to experience additional anxiety and distress. So as not to have to be admitted to the hospital while receiving treatment, many temporarily stay with relatives or in cancer hostels. However, once the treatment is completed and they are discharged, they still have to manage, at home, the changeable and unpredictable symptoms that may persist.[12]

Therefore, health care providers need to provide appropriate information regarding the type of symptoms women may experience, as well as how intense and/or distressing the symptoms may be. In addition, women need to have knowledge regarding which self-care behaviors to use for given symptoms. Those who have experienced cervical cancer may be the best source of information regarding experienced symptoms, as well as effective self- care behaviors.

## Conceptual Framework and Review of Literature

The Symptom Management Model (SMM),[13,14] which is composed of three interrelated dimensions (symptom experience, management strategies and outcomes) was used to guide this study. However, this study focused only on symptom experience and symptom management strategies. Symptom experience refers to one's: perception of discomfort or abnormal changes; evaluation of symptom intensity; and, response to distressful symptoms. On the other hand, symptom management strategies refer to the self-care behaviors an individual uses to relieve symptoms, and are determined by the strategy and its effectiveness, given the symptoms.

Symptoms associated with radiotherapy alone, including sleep difficulty, fatigue, diarrhea, anorexia, nausea, urinary frequency, dysuria, vaginal discharge and peritoneal irritation, have been investigated through use of self-reports and interviews via cross-sectional and longitudinal designs.[12,15-17] However, symptom occurrence and intensity, both during and after radiotherapy treatment for cervical cancer, have been found to differ, compared to Western countries, in Thailand.[12,17] Furthermore, no studies related to symptom experience, at pre-treatment among women with cervical cancer, could be located in either Thai or English language publications.

Currently, the treatment of choice for cervical cancer is a combination of chemotherapy

and radiotherapy.[7] Adverse effects of this combination include: nausea, vomiting, alopecia, anemia, leucopenia, fever, diarrhea, mucositis, renal toxicities, encephalopathy, granulocytopenia and thrombocytopenia. Although the toxicity of combining chemotherapy and radiotherapy has been systematically reviewed,[8-10] the acute and chronic toxicity levels have been limited to assessment by physicians using World Health Organization (WHO) criteria. However, the gold standard for assessing symptom experience is based on the perception of the individual experiencing the symptom.[14]

As individuals obtain the capacity for self-care, they utilize their abilities to seek ways to minimize the degree of intensity and distress caused by unpleasant symptoms.[18] Self-care has been recognized to be learned, goal-oriented activities, actions or behaviors that have purpose, are sequential and patterned, and exist in real life situations to self regulate the environment that affects one's health and life.[18] Prior research has found such behavior among women undergoing treatment for cervical cancer. A strategy used by Western women to reduce fatigue is "increasing rest with an afternoon nap,"[17] while "increasing rest during the day and going to bed early" often is used by Thai women for the same purpose.[12]

Although actions appear to be the same both in Western countries and Thailand, no studies, regarding self-care during radiotherapy treatment, could be located that addressed self-care during pre- or post- radiotherapy treatment for cervical cancer in Western countries or in Thailand. Since it is believed that self-care behaviors are dynamic and may change over time, data are needed regarding Thai women's symptoms and self-care, before and after radiotherapy treatment, for cervical cancer. Thus, the purposes of this study were to describe the: (a) occurrences, intensity and distress of Thai women's symptoms pre-treatment (T1), during treatment (T2) and one month post-treatment (T3) for cervical cancer; (b) strategies and effectiveness of self-care behaviors used to relieve the five most frequent, severe and distressing reported symptoms during each period of treatment; and, (c) pattern of change in symptoms the women experienced and their self-care effectiveness from pre- to post-treatment (T1 – T3).

## Method

***Design and setting:*** A prospective, descriptive design was used to obtain data pre-, during, and 1 month post-treatment for cervical cancer. A convenience sample of 205 women, with cervical cancer, was recruited from four hospitals (one university; two military; and one governed by the Thai National Cancer Institute), which represented the types of hospitals providing treatment for cervical cancer in Thailand. Data were gathered May 2006-July 2007. Approval to conduct the study, prior to data collection, was granted by the Institutional Review Board of Mahidol University and each respective hospital.

Subjects received one of two frequently prescribed treatment regimens provided by radiologists and gynecologists in Thailand. One treatment regimen consisted of 4,500 – 5,000 cGy fractionalized radiotherapy and 1,500 – 2,500 cGy of brachytherapy. The other treatment regimen involved two 2-day cycles of a combination of radiotherapy (6,000 to 7,500cGy) and chemotherapy (cisplatinum 75 mg/m$^2$/cycle) over a four week span. To increase their radiosensitivity, the first two-day cycle of chemotherapy (cisplatinum 75 mg/m$^2$/cycle) was given after 7-10 daily doses of radiation had been received, then the second two-day cycle was started four weeks after completion of the first two-day cycle of chemotherapy. In addition, all subjects were assessed weekly regarding their treatment response, and attended a

nurse run group to learn about the side effects of their treatment, as well as how to relieve them.

***Sample:*** Two hundred five subjects was determined, through power analysis, to be required, based on the number of subjects in a prior longitudinal study (with a 25% attrition rate), [19,20] using symptom severity criteria.[12,17] One week prior to commencement of data collection, the primary investigator (PI) reviewed each potential subject's chart, while she was being seen by her physician in her respective gynecological-oncology clinic, to determine if she met the inclusion criteria. The inclusion criteria included females who were: 20 year of age or older; newly diagnosed with cervical cancer; receiving standard care provided by radiologists and gynecologists; determined to have European Cooperative Oncology Group (ECOG)[21] scores less than or equal to two (ambulatory, capable of all self-care, unable to carry out work activities, up and about more than 50% of waking hours); able to speak Thai; and, willing to participate. Those meeting these criteria were informed about: the purposes of the study; what would be involved by being in the study; confidentiality and anonymity; and, the ability to withdraw from the study, at any time, without negative repercussions. Those consenting to participate signed a consent form. Although 205 women initially were approached, 15 (7.31%) refused to participate due to being overwhelmed and too fatigued. Thus, a convenience sample of 190 was obtained.

Participants were 25-79 years of age (mean = 52.1), with 0-20 years of education (mean = 6.75) and monthly incomes of 1,200 -100,000 baht (median and mode = 10,000 baht; 30 baht = 1 USD). The majority: were married or had partners (n = 134; 70.5%); owned their own home (n = 110; 57.9%); and, had family caregivers (n = 182; 95.8%). Over half were diagnosed with Stage II (n = 107; 56.3%) or Stage III (n = 67; 35.3%) cervical cancer and were receiving radiotherapy alone (n = 64; 33.7%) or in combination with chemotherapy (n = 126; 66.3%). Most (n = 183; 96.3%) had some form of universal health coverage [30 Baht (n = 80; 42.1%), government (n = 58; 30.5%) or social insurance (n = 45; 23.7%)], with only 3.7% (n = 70) using personal finances for treatment expenses.

***Instruments:*** Three self-report instruments were used to collect data. They were the: Demographic, Disease and Treatment questionnaire; Modified Memorial Symptom Assessment Scale (MMSAS); and, Modified Self Care Diary (MSCD).

The PI designed, Demographic, Disease and Treatment Questionnaire was created to obtain general information about each participant's: age, years of education, marital status, financial status, family caregiver and living arrangements. In addition, each woman's medical chart was reviewed to obtain information about her stage of cancer and treatment.

The Memorial Symptom Assessment Scale (MSAS)[22] is a three-scaled, validated, multidimensional symptom assessment instrument that measures one's rate, intensity and distress associated with 32 highly prevalent symptoms. In addition, open-ended questions are provided for symptoms not listed. The MSAS has been used widely to assess symptom experience among cancer patients, is in the public domain and is open to use via registration at http://www.mywhatever.com/cifwriter/content/41/pe1262.html.[23]

In this study, the PI, after review of the literature, modified the MSAS by adding 4 prevalent symptoms (vaginal discharge, headache, rectal irritation and fever) found among cervical cancer patients receiving treatment. By so doing, this brought the list of symptoms to a total of 36. To

determine the level of symptom occurrence, subjects were asked to respond "yes" or "no" as to whether they experienced the particular symptom. Subjects then were asked to respond on a 4-point Likert-like scale, ranging from "1= slight to 4 = very intense," as to the level of intensity of each symptom being experienced. In addition, they indicated how much distress they experienced, from each of the symptoms, by responding on a 5-point Likert-like scale, which ranged from "0 = not at all to 4 = very much." Overall symptom occurrence, intensity and distress were calculated by summing and averaging the scores of each of the three scales. In addition, subjects were asked to identify and rank, in order of self-care behavior required, the top five symptoms they had experienced.

The Self Care Diary (SCD)[24] is designed to investigate the incidence and intensity of cancer treatment symptoms, as well as identify symptom related self-care activities used. Subjects were asked to indicate five of the listed symptoms for which they performed self-care during the past week, select which of the listed self-care activities they used to manage each respective symptom, and indicate how effective each of the selected activities were on a 5-point, Likert-like, scale (0 = used, but no relief, to 4 = used, was completely relieved). The scores of self-care effectiveness, for each self-care activity, were summed and averaged to reflect the overall effectiveness of the subject's self-care behaviors (the higher the score, the higher the effectiveness). The strength of utilizing a closed-ended approach, to obtain data on symptom related self-care behaviors, is that it assists women to recognize or recall, from an existing list, the self-care behaviors they use. In this study, the SCD was modified, whereby one ("eyes have been more sensitive to light") of the original 15 self-care activities was removed due to rarely being involved in cervical cancer and not included in the MSAS. In addition, 7 symptoms (vaginal discharge, fever, urination difficulties, itchy skin at treatment site, drowsiness, shortness of breath, and mood changes) were added, after review of the literature, bringing the modified instrument's symptom list to 21. Permission to modify and translate, from English to Thai, both the MSAS and SCD was granted by the authors of the original instruments. The PI initially translated both instruments into Thai, which then were back-translated to English by a Thai nursing faculty who received her doctorate in America. Each new English version was compared with its respective original, to ensure meanings were not lost in translation.

Content of the modified versions of the MSAS and SCD was validated, for use with cervical cancer patients, by five bilingual Thai experts (one gynecologic-oncology physician, three advanced practice oncology nurses, and one ontological nursing instructor). The item-level content validity index (I-CVI)[25] was found to be 0.94 for the modified SCD and 1.00 for the modified MSAS, while the scale-level content validity index (S-CVI)[25] for the modified SCD was found to be 0.92 and 1.00 for the modified MSAS.

Reliability of symptom occurrence, intensity and distress was determined among 20 subjects during treatment, via three days of test-retest , and found to be 0.78, 0.89 and 0 .91, respectively. These values are consistent with prior one day MSAS test-retest reliabilities.[26] Self-care effectiveness of the MSAS test-retest reliability was determined to be 0.86. Due to the fact one's symptoms may change over time, especially if self-care is ineffective, the stability of the two instruments was tested via three days of test-retest. The test-retest reliabilities of symptom occurrence among all subjects were: 0.45 (T1-T2); 0.48 (T2-T3) and, 0.36 (T1-T3). The overall test-retest reliabilities for symptom intensity were: 0.51(T1-T2); 0.50

(T2-T3); and, 0.31 (T1-T3). The overall test-retest reliabilities for symptom distress were: 0.51 (T1-T2); 0.49 (T2-T3); and, 0.32 (T1-T3). With respect to self-care effectiveness, the test-retest reliabilities among all subjects were: 0.39 (T1-T2); 0.38 (T2-T3); and, 0.45 (T1-T3). These test-retest reliabilities were low to moderate, most likely, because the test-retest period was lengthy, approximately one month.

***Procedure:*** Data were collected, in a quiet and private location at each hospital, during the week before each subject began treatment (T1), between the 3rd and 4th week of treatment (T2), and one month after completion of treatment (T3). During T1, subjects were asked to complete the Demographic, Disease and Treatment Questionnaire, the modified MSAS and the modified SCD, in that order. During T2 and T3, administration of only the modified MSAS and modified SCD (in that order) was carried out.

The PI remained available, at all times, in case anyone needed assistance or clarification regarding the questionnaire items, and read questionnaire items to 49 subjects who had visual impairment. It took 45 to 60 minutes to complete all questionnaires during each data collection session. Upon retrieval of the completed questionnaires, code numbers were applied for identification.

## Results

***Symptom Experience:*** Subjects reported the occurrence of 36 different symptoms at each measurement period. The mean and standard deviation of symptom occurrences at T1, T2 and T3 were 6.94 (SD = 5.09), 11.34 (SD = 6.35) and 6.18 (SD = 4.21), respectively, with a range of 0-33. As shown in **Table 1**, the top five symptoms differed during each data collection period. Vaginal discharge, worrying, difficulty sleeping, constipation and weight loss were most common symptoms noted at T1, while fatigue, poor appetite, rectal irritation , diarrhea and weight loss were prevalent at T2. During T3, changes in skin, difficulty sleeping, sweating, worrying and feeling irritable were the most often experienced symptoms.

The mean and standard deviation of symptom intensity at T1, T2 and T3 were13.13 *(SD = 10.09),* 20.54 *(SD = 13.11)* and 9.98 *(SD = 7.64)*, respectively, with a range of 1-71. As shown in **Table 2**, the most intense symptoms differed over the measurement periods. The most intense symptom, at T1, T2, and T3 respectively, was difficulty swallowing, diarrhea and problems with sexual interest/activity.

The mean and standard deviation of symptom distress at T1, T2 and T3 were 10.39 *(SD = 10.17)*, 16.00 *(SD = 12.84)* and 6.71*(SD = 6.66)*, respectively, with a range 0-67. As shown in **Table 2**, the greatest symptom distress, at T1, T2 and T3 respectively, was difficulty swallowing, rectal irritation and feeling nervous.

***Self Care Behaviors:*** As shown in **Table 3**, the most frequent behavior for difficulty sleeping was "rested in bed," while the most effective strategy was "took sleeping pills." With respect to mood changes, the most frequent behavior was "tried to think that whatever will be will be and do the best you can", while the most effective strategy was "used Dhamma to calm down."

"Took naps" was the most frequent self-care behavior, as well as most effective for dealing with fatigue. For vaginal discharge, the most frequent self-care behavior was "frequently cleaned perineum area," although "used vaginal suppository" (used by 3 subjects) was the most effective.

The mean and standard deviation of self-care effectiveness measured at T1, T2 and T3 were 2.82 *(SD = .88)*, 2.45 *(SD = .89)* and 2.95 *(SD = .95)*, respectively, with a range of 0-4. The five

**Table 1** Symptom occurrence pre-treatment, during treatment and post-treatment (n=190)

| Symptoms | Pre-treatment | | During treatment | | Post-treatment | |
|---|---|---|---|---|---|---|
| | N | % | N | % | N | % |
| 1.Difficulty concentrating | 31 | 16.30 | 25 | 13.20 | 11 | 05.80 |
| 2.Pain | 63 | 33.20 | 67 | 35.30 | 48 | 25.30 |
| 3.Fatigue | 61 | 32.10 | **134**[1] | **70.50** | 58 | 30.50 |
| 4.Cough | 19 | 10.00 | 31 | 16.30 | 14 | 07.40 |
| 5.Feeling nervous | 50 | 26.30 | 61 | 32.10 | 35 | 18.40 |
| 6.Dry mouth | 36 | 18.90 | 85 | 44.70 | 32 | 16.80 |
| 7.Nausea | 20 | 10.50 | 95 | 50.00 | 12 | 06.30 |
| 8.Feeling drowsy | 29 | 15.30 | 69 | 36.30 | 43 | 22.60 |
| 9.Numbness/tingling in hands/feet | 46 | 24.20 | 38 | 20.00 | 48 | 25.30 |
| 10.Difficulty sleeping | **96**[3] | **50.50** | 98 | 51.60 | **77**[2] | **40.50** |
| 11.Feeling bloated | 57 | 30.00 | 93 | 48.90 | 57 | 30.00 |
| 12.Problems with urination | 17 | 08.90 | 75 | 39.50 | 21 | 11.10 |
| 13.Headache | 37 | 19.50 | 42 | 22.10 | 19 | 10.00 |
| 14.Fever | 18 | 09.50 | 26 | 13.70 | 5 | 02.60 |
| 15.Vaginal discharge | **113**[1] | **59.50** | 77 | 40.50 | 55 | 28.90 |
| 16. Rectal irritation | 11 | 5.80 | **114**[3] | **60.00** | 41 | 21.60 |
| 17. Vomiting | 9 | 4.70 | 37 | 19.50 | 5 | 02.60 |
| 18. Shortness of breath | 25 | 13.20 | 44 | 23.20 | 12 | 06.30 |
| 19. Diarrhea | 7 | 3.70 | **103**[4] | **54.20** | 9 | 04.70 |
| 20. Feeling sad | 67 | 35.30 | 54 | 28.40 | 25 | 13.20 |
| 21. Sweating | 31 | 16.30 | 53 | 27.90 | **73**[3] | **38.20** |
| 22. Worrying | **97**[2] | **51.10** | 69 | 36.30 | **70**[4] | **36.80** |
| 23. Problems with sexual interest or activity | 5 | 2.60 | 5 | 02.60 | 9 | 04.70 |
| 24. Itching | 22 | 11.60 | 92 | 48.40 | 23 | 12.10 |
| 25. Poor appetite | 49 | 25.80 | **129**[2] | **67.90** | 40 | 21.10 |
| 26. Dizziness | 47 | 24.70 | 68 | 35.80 | 34 | 17.90 |
| 27. Difficulty swallowing | 7 | 3.70 | 14 | 07.40 | 6 | 03.20 |
| 28. Feeling irritable | 58 | 30.50 | 66 | 34.70 | **63**[5] | **33.20** |
| 29. Mouth sores | 3 | 1.60 | 9 | 04.70 | 2 | 01.10 |
| 30. Change in the way food tastes | 11 | 05.80 | 50 | 26.30 | 3 | 01.60 |
| 31. Weight loss | **70**[5] | **36.80** | **101**[5] | **53.20** | 30 | 15.80 |
| 32. Hair loss | 6 | 3.20 | 29 | 15.30 | 26 | 13.70 |
| 33. Constipation | **76**[4] | **40.00** | 36 | 18.90 | 43 | 22.60 |
| 34. Swelling of arms or legs | 3 | 01.60 | 8 | 04.20 | 2 | 01.10 |
| 35. "I don't like myself" | 14 | 07.40 | 20 | 10.50 | 7 | 03.70 |
| 36.Changes in skin | 7 | 03.70 | 38 | 20.00 | **117**[1] | **61.60** |

*Note:* Top five most frequently occurring symptoms are **bolded**

**Table 2** Intensity and distress of five top symptoms pre-treatment, during treatment and post-treatment (n=190)

post-treatment (n=190)

| Symptom | Pre-treatment | Mean (*SD*) (range 1-4) | During treatment | Mean(*SD*) (range 1-4) | Post-treatment | Mean (*SD*) (range 1-4) |
|---|---|---|---|---|---|---|
| **Intensity** | **1.Difficulty swallowing** | **2.43*(1.14)*** | **1.Diarrhea** | **2.28 *(1.09)*** | **1.Problems with sexual interest/ activity** | **2.86 *(1.34)*** |
| | 2.Rectal irritation | 2.25 *(1.14)* | 2. Rectal irritation | 2.25 *(1.08)* | 2.Sweating | 2.05 *(1.05)* |
| | 3. Sweating | 2.20 *(1.13)* | 3.Difficulty swallowing | 2.20 *(.86)* | 3.Changes in skin | 1.85 *(.93)* |
| | 4.Vaginal discharge | 2.13 *(1.14)* | 4.Difficulty sleeping | 2.14 *(1.01)* | 4.Fatigue | 1.81 *(.79)* |
| | 5.Difficulty sleeping | 2.11 *(.92)* | 5. Change in the way food tastes | 2.13 *(1.12)* | 5.Difficulty sleeping | 1.80 *(.87)* |
| **Symptom** | **Pre-treatment** | **Mean (*SD*) (range 0-4)** | **During treatment** | **Mean(*SD*) (range 0-4)** | **Post-treatment** | **Mean (*SD*) (range 0-4)** |
| **Distress** | **1. Difficulty swallowing** | **2.00 *(1.16)*** | **1.Rectal irritation** | **1.97 *(1.26)*** | **1. Feeling nervous** | **1.63 *(1.03)*** |
| | 2. Rectal irritation | 2.00 *(1.49)* | 2.Diarrhea | 1.96 *(1.23)* | 2.Problems with sexual interest/ activity | 1.57*(1.62)* |
| | 3."I don't like myself" | 1.92 *(1.38)* | 3.Difficulty swallowing | 1.86 *(1.03)* | 3. Pain | 1.48 *(1.03)* |
| | 4. Difficulty sleeping | 1.85 *(1.25)* | 4.Pain | 1.83 *(1.25)* | 4. Sweating | 1.47 *(1.13)* |
| | 5. Pain | 1.84 *(1.23)* | 5. Problem with urination | 1.76 *(1.22)* | 5. Rectal irritation | 1.42 *(1.00)* |

*Note:* The most intense and distressful symptoms are **bolded**

**Table 3** Description of symptoms specified for self-care activities (n=190)

| Symptoms | Pre-treatment | | During treatment | | Post-treatment | |
|---|---|---|---|---|---|---|
| | Freq. (%) n (%) | Self- care effectiveness X (SD) | Freq. (%) n (%) | Self-care effectiveness X (SD) | Freq. (%) n (%) | Self-care effectiveness X (SD) |
| **1. Difficulty sleeping** | | | | | | |
| *1.1. Rested in bed* | *82 (92.10)* | *2.41(1.25)* | *62(92.50)* | *2.23(1.15)* | *48(96.00)* | *2.60(1.25)* |
| 1.2. Prayed or meditated | 66 (74.20) | 2.45(1.18) | 50(74.60) | 2.22(1.34) | 35(70.00) | 2.77(1.24) |
| 1.3. Read, watched TV or listened to music | 64 (71.90) | 2.41(1.11) | 48(71.60) | 2.02(1.18) | 39(78.00) | 2.64(1.04) |
| 1.4. Tried not to think about it | 60 (67.40) | 2.27(1.23) | 44(65.70) | 2.11(1.08) | 30(60.00) | 2.43(1.07) |
| 1.5. Got some exercise (during daytime) | 36 (40.40) | 1.83(1.18) | 38(56.70) | 1.97(1.20) | 25(50.00) | 2.40(1.19) |
| 1.6. **Took sleeping pills** | 14 (15.70) | **3.36(0.93)** | 25(37.30) | **3.16(0.90)** | 18(36.00) | **3.28(1.02)** |
| **2. Mood changing** | n (%) | | | | n (%) | |
| 2.1. *Tried to think that whatever will be, will be and do the best you can* | 97 (95.10) | 2.84(1.05) | | | 44(81.50) | 2.70(1.11) |
| 2.2. *Relaxed by walking, watching TV or listening to music* | 97 (95.10) | 2.641.02) | | | 50(92.60) | 2.80(1.03) |
| 2.3. Socialized with others, found some hobbies to keep busy and keep my mind off it | 83 (81.40) | 2.80(1.06) | | | 36(66.70) | 2.86(1.07) |
| 2.4. **Used Dhamma to calm down (e.g. meditated, read Dhamma's book or made merit)** | 82 (80.40) | **2.91(1.15)** | | | 34(63.00) | **3.03(1.03)** |
| 2.5. Accepted the illness and searched for good thing from the illness | 81 (79.40) | 2.54(1.13) | | | 34(63.00) | 2.44(0.99) |
| 2.6. Tried not to think about it | 77 (74.50) | 2.26(1.06) | | | 35(64.80) | 2.60(1.14) |
| 2.7. Tried to find a more appropriate way to do things | 71 (70.60) | 2.49(1.16) | | | 30(55.60) | 2.60(1.00) |
| 2.8. Searched for information about the illness | 65 (63.70) | 2.49(1.12) | | | 2444.40 () | 2.13(0.90) |
| 2.9. Talked with close friends | 65 (63.70) | 2.46(1.10) | | | 31(57.40) | 2.58(0.92) |
| 2.10. Talked with husband | 58 (56.90) | 2.79(1.12) | | | 24(44.40) | 2.38(0.97) |
| 2.11. Talked with health care providers | 38 (36.30) | 2.74(1.08) | | | 23(46.20) | 2.43(0.99) |
| 2.12. Tried to stay alone | 24 (21.60) | 1.88(1.15) | | | 13(24.10) | 2.85(1.34) |
| 2.13. Shouted or cried | 21 (19.60) | 2.24(1.14) | | | 02(03.70) | 2.00(0.00) |
| **3. Fatigue** | | | n (%) | | n (%) | |
| *3.1. **Took naps*** | | | ***86(93.50)*** | ***2.59(1.10)*** | ***43(97.70)*** | ***2.58(1.18)*** |
| 3.2. Drank large amounts of nutritious liquid | | | 74(80.40) | 2.36(1.02) | 28(63.60) | 2.64(1.13) |
| 3.3. Got fresh air | | | 73(79.30) | 2.14(1.03) | 39(88.60) | 2.38(1.12) |
| 3.4. Watched TV or listened to music | | | 63(68.50) | 2.03(0.97) | 31(70.50) | 2.16(1.04) |
| 3.5. Went to bed earlier than usual | | | 60(65.20) | 2.12(1.01) | 28(63.60) | 1.93(0.81) |
| 3.6. Kept busy to get my mind off it | | | 59(64.10) | 2.17(1.10) | 36(81.80) | 2.39(1.20) |
| 3.7. Stopped working/doing activities | | | 54(58.70) | 2.39(1.20) | 13(29.50) | 2.15(0.90) |
| 3.8. Told myself not to worry | | | 46(50.00) | 2.02(1.06) | 22(50.00) | 1.95(1.05) |
| 3.9. Prayed or meditated | | | 42(45.70) | 2.10(1.32) | 18(40.90) | 2.61(1.34) |
| 3.10. Got more exercise | | | 40(43.50) | 1.95(1.01) | 28(63.60) | 1.89(0.96) |
| 3.11. Got up later than usual | | | 29(31.50) | 2.03(0.57) | 20(45.50) | 2.30(0.66) |
| 3.12. Took multivitamins daily | | | 29(31.50) | 2.00(1.19) | 4(09.10) | 2.00(0.82) |
| 3.13. Listened to Dhamma's cassette tape | | | 16(17.40) | 2.25(1.24) | 10(22.70) | 2.30(1.42) |
| **4. Vaginal discharge** | n (%) | | | | n (%) | |
| *4.1. Frequently cleaned perineum* | *95 (97.90)* | *3.26(1.01)* | | | *43(97.70)* | *3.65(0.78)* |
| 4.2. Frequently changed pad | 84 (86.50) | 3.19(1.07) | | | 23(52.30) | 3.69(0.99) |
| 4.3. Stayed away from other people | 03 (03.10) | 2.67(1.53) | | | - | - |
| 4.4. **Used vaginal suppository** | 03 (03.10) | **3.33(1.16)** | | | - | - |

***Note**:* SD = standard deviation; most frequently used self-care activities are *italicized*; most effective self-care activities used are **bolded**

**Table 4** Effects of time on changes of the symptom occurrence, intensity and distress, and self-care effectiveness (n=190)

| Variables | Estimate | *SE* | df | t | Sig. | 95% Confidence Interval | |
|---|---|---|---|---|---|---|---|
| | | | | | | Lower Bound | Upper Bound |
| **Symptom occurrences** | | | | | | | |
| Intercept | 6.937 | .379 | 475.009 | 18.313 | .000 | 6.193 | 7.681 |
| Time (week) | 1.563 | .136 | 360.708 | 11.455 | .000 | 1.295 | 1.832 |
| Time$^2$ (week$^2$) | -.116 | .009 | 315.454 | -13.274 | .000 | -.133 | -.098 |
| **Symptom intensity** | | | | | | | |
| Intercept | 13.137 | .759 | 466.831 | 17.297 | .000 | 11.645 | 14.630 |
| Time (week) | 2.683 | .267 | 362.771 | 10.044 | .000 | 2.158 | 3.219 |
| Time$^2$ (week$^2$) | -.208 | .017 | 318.710 | -12.280 | .000 | -.242 | -.175 |
| **Symptom distress** | | | | | | | |
| Intercept | 10.388 | .737 | 473.329 | 14.092 | .000 | 8.939 | 11.8363 |
| Time (week) | 2.072 | .262 | 363.985 | 7.894 | .000 | 1.555 | 2.5879 |
| Time$^2$ (week$^2$) | -.167 | .017 | 319.852 | -10.017 | .000 | -.200 | -.1343 |
| **Self- care effectiveness** | | | | | | | |
| Intercept | 2.817 | .067 | 457.630 | 41.971 | .000 | 2.685 | 2.949 |
| Time (week) | -.132 | .025 | 316.477 | -5.345 | .000 | -.180 | -.083 |
| Time$^2$ (week$^2$) | .010 | .002 | 272.668 | 6.429 | .000 | .007 | .013 |

SE = standard error
df = degrees of freedom
Sig = Significance

most frequently identified symptoms requiring initiation of self-care at T1, T2 and T3 are shown in **Table 3**. Difficulty sleeping was one of the five most frequently identified symptoms at T1, T2 and T3, while mood changes, fatigue and vaginal discharge were among the five most frequently reported symptoms only at T1 and T 2.

***Patterns of Changes in Symptom Experience and Self Care Effectiveness:*** As shown in **Table 4**, a linear mixed model was used to analyze the patterns of change, over time, of symptom experience and self-care effectiveness in the repeated measures data. The linear mixed model was used as a statistical technique, since it can be applied with correlated and missing data in prospective studies.[27, 28] The pattern of change among symptom occurrences, intensity and distress was found to be curvilinear, with an increase at T1 and a decline at T3. The effect of time was a significant predictor of change in the symptom experience, including symptom occurrence, intensity and distress ($p$ = 0.00; two-tail test). However, the effect of time on self-care effectiveness was in the opposite direction of symptom experience.

## Discussion

The findings are consistent with those of prior studies in that advanced stages of cervical cancer usually are found in middle-aged women with limited education and finances.[11,12,15] Women from a lower socioeconomic level tend to marry earlier than women from a higher socioeconomic level. Thus, they are prone to being exposed to the human papilloma virus at an early age.[29] Unlike prior studies wherein medical treatment expenses were paid by the subjects, those in this study, due to having low incomes, had their treatments covered by the Thai Universal Coverage of Health Care Policy.[30]

***Symptom experience***: More symptom occurrences were found in this study than in previous studies.[12,15,17] This may have been due to the modified MSAS self-report being used in this study, whereby subjects were able to identify both the symptoms they were experiencing and their responses to the combination of radiotherapy and chemotherapy.

Finding vaginal discharge as one of the five most common symptoms at T1 is consistent with prior findings.[12,31] Vaginal discharge/bleeding is a major symptom of cervical cancer and an indicator of an advanced stage of cancer that often develops when asymptomatic women neglect to have a regular pelvic examination.[32] In addition, worrying is a typical emotional reaction one has when experiencing a stressful situation (i.e. being diagnosed with cervical cancer). Stress can lead to sleep difficulties, constipation and weight loss. However, constipation and weight loss may not result from cervical cancer.[33,34] Although the subjects' symptoms may have been a cluster or set of correlated symptoms, they did not report the same symptoms as the most intense or distressing ones.

Although not reported in other studies,[12,15-17] difficulty swallowing was found to be the most intense and distressful symptom at T1. Although subjects did not experience mechanical difficulty swallowing, they may have had a psychological response to stress (i.e. "I could not swallow any kind of food; I didn't have a tumor at my throat. But, I didn't want to swallow any food after I knew the diagnosis").

Similar to previous studies,[12,15-17] the most common symptom at T2 was fatigue, followed by poor appetite, rectal irritation, diarrhea and weight loss. Fatigue may be precipitated by treatment and/or one's emotional reaction to the disease. Rectal irritation and diarrhea most likely were the result of damage done, by the cancer treatments, to the epithelial cells of the gastrointestinal tract.[36] In addition, weight loss most likely was due to a poor appetite, which is known to commonly decrease during radiotherapy and gradually increase in severity until treatment is completed.[12,17]

Although prior studies have found fatigue to be the most intense symptom and diarrhea to be the fourth most intense symptom,[12,17] diarrhea was reported, in study, as the most intense symptom, while rectal irritation was the most distressing one. It must be kept in mind that diarrhea and rectal irritation often simultaneously occur.

At T3, changes in skin resulting from radiation therapy were prominent, in addition to difficulty sleeping, sweating, worrying and feeling irritable. All these symptoms are reflective of bodily changes that tend to occur with menopause.[36] It is known that ovarian dysfunction (i.e. menopause) tends to occur after a radiation dosage of approximately 5Gy or 5000cGY;[36] such was the case for subjects in this study. In addition, the emotional changes that were taking place (difficulty sleeping, worrying and feeling irritable) also could have been related to the women's concerns about disease recurrence, although it was not specifically measured in this study.

Although, subjects in prior studies may have focused on their relationships with the health care providers, as well as felt uncertain about the effectiveness of treatments and how long they will survive,[12] those in this study identified problems with sexual interest/activity as the most intense symptom and "feeling nervous" as the most distressful one. These symptoms suggest that the subjects were concerned about their family relationships and returning to a normal life style.

Unlike prior research, the findings of this study support the belief that women's symptoms differ in terms of intensity and distress experienced before, during and after treatment for cervical cancer. In addition, the findings give credence to the need for future investigation regarding whether symptom intensity or distress interfere more than symptom occurrences with the daily life of cervical cancer patients.

***Self care behaviors:*** Difficulty sleeping was reported as the most frequent symptom that led the subjects, at T1, T2 and T3, to initiate self-care behaviors. Although, "rested in bed" was the most frequently used self-care behavior and "took sleeping pills" was the most effective action taken, subjects, during all three measurement periods, reported they also "prayed or meditated" and "read, watched television or listened to music" to promote sleep. Subjects seemed to combine these self-care strategies, as a set of actions, to help relieve sleep difficulties. Such self-care activity is consistent with findings among patients with leukemia.[38]

The subjects reported experiencing emotional changes ("I don't like myself" and feeling nervous) at T1 and T3. Changes reported at T1, potentially, were the subjects' psychological response to being diagnosed with cervical cancer, while those at T3 may have been precipitated by their concern about the effectiveness or outcome of their treatment. At T1, the subjects most frequently used the self-care strategies of "trying to think that whatever will be will be and doing the best that you can" and "relaxed by walking, watching television or listening to music." However, at T3, they most frequently used the self-care strategy, "used Dhamma to calm down," which was reported as being highly effective at T1 and T3.

It is not unusual for cervical cancer patients to experience emotional changes, in that cancer-related anxiety has been recognized as occurring on a continuum that starts prior to one receiving a diagnosis of cancer and then remains throughout life.[33-35] Subjects, in this study, expressed being concerned about many things including: why they had cancer; if it could be cured; what would happen if they received treatment; and, being irritable and/or frustrated to the point of not doing anything because of feeling overwhelmed by anxiety. However, since subjects practiced Buddhism, which teaches how to deal with suffering (since suffering comes from a cause),[37] they tried to free themselves from suffering. In an effort to reduce the cause of their suffering, subjects accepted things as they happened, did the best they could, relaxed, focused on the present and did not think about the past or future. This finding indicates subjects performed self-care activities to deal with stressful life events, in order to maintain their lives and well-being.[37] Although the use of Dhamma appeared to have provided subjects relief at T1 and T3, healthcare providers still need to be sensitive to subjects' beliefs, and provide counseling and information as needed. Fatigue, which may have arisen due to the women being overwhelmed from treatments, having a poor appetite, encountering difficulty sleeping and having diarrhea, it was a symptom that led to the initiation of self-care activities at both T2 and T3. The women reported, consistent with the self-care activities of leukemia patients,[38] they most frequently used the self-care activity, "took naps," which also

was found to have the greatest effectiveness for dealing with fatigue at T2 and T3.

The subjects indicated having to initiate self-care behaviors to deal with vaginal discharge experienced at T1 and T3. Vaginal discharge, a major symptom of cervical cancer,[31] is obvious due to being odiferous. Since subjects may have felt uncomfortable and been concerned the odor may be disturbing to others, it was not surprising they frequently cleaned their external genitalia.

Findings of this study are based upon three measurement periods. Similar to prior findings,[39] subjects identified symptoms with the most frequent occurrence. However, they did not report the same symptoms as being the most intense and distressing at each measurement period. They did, however, identify a set of concurrent symptoms and related self-care strategies used at each of the three time periods.

***Patterns of Changes in Symptom Experience and Self Care Effectiveness:*** The patterns of the three components of the SMM symptom experience domain (symptom occurrences, intensity and distress) were similar. Changes in each of these variables were curvilinear, with one peak at T2 that probably was due to the fact that symptoms usually occur after treatment is started, gradually increase to a peak during treatment and decrease after completion of treatment.[12,17] In addition, these findings support the SMM symptom management strategy domain and the fact that symptom experience may change over time.[14]

The pattern of self-care effectiveness contained in the symptom management strategies domain formed a U shaped curve, with one lower peak at T2 that may have been due to symptom occurrence, intensity and distress being high secondary to the side effects of treatment. The effectiveness of self-care decreased when symptom experience, across all dimensions, decreased and then increased again when subjects experienced fewer symptoms at T3. These findings support the SMM symptom management strategy domain.

## Limitations

This study was conducted among a convenience sample receiving treatment for cervical cancer at one of four hospitals in Thailand. Therefore, the findings are generalizable only to those similar to the subjects in this study. In addition, since data obtained were self-report, one has to assume subjects were truthful in their responses.

## Conclusions and Recommendations

Symptoms related to cervical cancer treatment are a major problem women experience prior to, during and after treatment. However, appropriate self-care behaviors can help to alleviate some of the symptoms experienced. The results of this study may be helpful in guiding health care providers, working with women with cervical cancer, regarding: (a) symptoms that tend to occur most often; (b) symptoms that tend to be of the greatest intensity and cause the greatest amount of distress; and, (c) self-care behaviors that have been found to be effective in relieving symptoms. Symptoms in need of special attention were found to include: mood changes, sleep difficulties, fatigue and vaginal discharge. Thus, health care providers need to provide women, experiencing these symptoms, instructions regarding effective self-care activities to use pre-treatment, during treatment and post-treatment. Future research needs to examine, in greater depth, the combination of self-care activities used by women, with cervical cancer, pre-treatment, during treatment and post- treatment. Such examination could provide additional information on the effectiveness of the combined self-care activities used, as women contend with each symptom encountered.

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# ประสบการณ์ของอาการและการดูแลตนเองในสตรีไทยที่เป็นมะเร็งปากมดลูก

*บัวหลวง สำแดงฤทธิ์, สมจิต หนุเจริญกุล, Marylin J. Dodd, สฤกพรรณ วิไลลักษณ์, ธวัชชัย วรพงศธร, คนึงนิจ พงษ์ถาวรกมล*

**บทคัดย่อ :** การศึกษานี้มีวัตถุประสงค์เพื่อสำรวจ (1) อาการที่เกิด ความรุนแรงและการรบกวนของอาการในสตรีไทยที่เป็นมะเร็งปากมดลูกรายใหม่ ตั้งแต่ก่อน ระหว่างและภายหลังการรักษา 1 เดือน (2) วิธีและประสิทธิภาพของการดูแลตนเองที่สตรีใช้ในการลดอาการที่เกิดบ่อย มีความรุนแรงและมีการรบกวนการดำเนินชีวิตที่สตรีเลือกจำนวน 5 อาการ และ (3) รูปแบบการเปลี่ยนแปลงของอาการและประสิทธิภาพในการดูแลตนเองตั้งแต่ก่อนจนถึงภายหลังการรักษาในสตรีจำนวน 190 คนที่มีคุณสมบัติตามเกณฑ์ที่กำหนดและเข้ารับการรักษาในโรงพยาบาลสังกัดมหาวิทยาลัย 1 แห่ง กระทรวงกลาโหม 2 แห่งและสถาบันมะเร็งแห่งชาติ 1 แห่ง เครื่องมือที่ใช้ในการวิจัยมี 3 ชนิดได้แก่ แบบบันทึกข้อมูลส่วนบุคคล โรคและการรักษา แบบประเมินอาการจากโรคและการรักษาและแบบสอบถามพฤติกรรมการดูแลตนเอง เก็บข้อมูล 3 ครั้ง ตั้งแต่ก่อน ระหว่างและภายหลังรับการรักษาครบ 1 เดือน

ผลการศึกษาพบว่า การเกิดอาการและวิธีการดูแลตนเองมีความแตกต่างกันในแต่ละช่วงของการรักษา การมีสารคัดหลั่งจากช่องคลอดเป็นอาการที่พบมากที่สุดในระยะก่อนการรักษา แต่อาการกลืนไม่ลงเป็นอาการที่มีความรุนแรงและรบกวนการดำเนินชีวิตมากที่สุด การมีอารมณ์เปลี่ยนแปลงเป็นอาการที่ผู้ป่วยต้องจัดการมากที่สุดทั้งระยะก่อนและหลังการรักษา การคิดว่าไม่ว่าเหตุการณ์อะไรจะเกิดก็ต้องเกิด และการผ่อนคลาย เป็นการดูแลที่ผู้ป่วยใช้มากที่สุด ในขณะที่การใช้ธรรมะเพื่อจัดการการเปลี่ยนแปลงทางอารมณ์เป็นวิธีที่มีประสิทธิภาพมากที่สุดทั้งในระยะก่อนและหลังการรักษา นอกจากนี้การทำความสะอาดบริเวณอวัยวะสืบพันธุ์ภายนอก เป็นวิธีที่ผู้ป่วยใช้มากที่สุดเมื่อมีสิ่งคัดหลั่งทางช่องคลอด อ่อนเพลียเป็นอาการที่พบมากที่สุดขณะรักษา ส่วนอาการท้องเสียและการติดเชื้อบริเวณทวารหนักเป็นอาการที่มีความรุนแรงและรบกวนการดำเนินชีวิตมากที่สุด การงีบหลับเป็นวิธีการดูแลตนเองที่ใช้มากและมีประสิทธิภาพมากที่สุดในการลดอาการอ่อนเพลียทั้งในระหว่างและหลังการรักษา การเปลี่ยนแปลงของผิวหนังเป็นอาการที่พบมากที่สุด ในระยะ 1 เดือนภายหลังการรักษา ความลำบากในการมีเพศสัมพันธ์เป็นอาการที่มีความรุนแรงมากที่สุด ในขณะที่ความวิตกกังวลเป็นอาการที่รบกวนการดำเนินชีวิตมากที่สุด อย่างไรก็ตาม การนอนหลับยากเป็นอาการที่ต้องจัดการทั้งสามระยะของการรักษา การนอนพักบนเตียงเป็นวิธีการดูแลตนเองที่ใช้มาก และวิธีที่มีประสิทธิภาพมากที่สุด ได้แก่ การรับประทานยานอนหลับ การเปลี่ยนแปลงของอาการเพิ่มขึ้นในระหว่างการรักษาและลดลงภายหลังการรักษา ส่วนประสิทธิภาพของการดูแลตนเองมีการเปลี่ยนแปลงลดลงระหว่างการรักษาและเพิ่มขึ้นภายหลังการรักษาอย่างมีนัยสำคัญทางสถิติ ผลการศึกษาครั้งนี้จะช่วยให้บุคลากรในทีมสุขภาพสามารถช่วยเหลือและส่งเสริมให้ผู้ป่วยได้รับการดูแลให้เหมาะสมกับอาการที่เกิดขึ้นในแต่ละช่วงเวลาของการรักษา

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***ติดต่อที่ : บัวหลวง สำแดงฤทธิ์*** *RN, PhD (Candidate), มหาวิทยาลัยมหิดล ประเทศไทย* ***E-mail:*** *rabualuang@staff2.mahidol.ac.th or bualuangs@hotmail.com*
***สมจิต หนุเจริญกุล*** *RN, PhD, ศาสตราจารย์เกียรติคุณ ภาควิชาพยาบาลศาสตร์ คณะแพทยศาสตร์โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล ประเทศไทย*
***Marylin J. Dodd,*** *RN, PhD, FAAN, Professor, Department of Physiological Nursing, School of Nursing, University of California at San Francisco, U.S.A.*
***สฤกพรรณ วิไลลักษณ์*** *MD, ศาสตราจารย์ คณะแพทยศาสตร์ โรงพยาบาลรามาธิบดี มหาวิทยาลัยมหิดล ประเทศไทย*
***ธวัชชัย วรพงศธร*** *PhD, รองศาสตราจารย์ คณะสาธารณสุขศาสตร์ มหาวิทยาลัยมหิดล ประเทศไทย*
***คนึงนิจ พงษ์ถาวรกมล*** *RN, PhD, รองศาสตราจารย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล ประเทศไทย*