

**APPENDICES**

## Appendix A

### Informed Consent Form

My name is Yan Su. I am a master student in nursing science at the Faculty of Nursing, Prince of Songkla University, Thailand. You are being asked to participate in the research project designed to study self-care among Chinese women who have undergone mastectomy and related factors. This study is to know the scope and extent of self-care of postmastectomy women, the level of related factors that are health status, health care system, and information resources after surgery, and the relationship between self-care and related factors. If you agree to participate in this project, you will be interviewed to complete questionnaires, which includes 3 parts: demographic data assessment form, self-care questionnaire, and information resources assessment scale. Please give me your answer as accurately as you can.

There will be no risks to you participating in the project. On the contrary, you may gain some information related to your self-care from the interview and better understand the scope and level of your own self-care in rehabilitation of physical and psychological function. Meanwhile, the information gathered will be useful for development of intervention in order to promote and maintain health of women after surgery.

All gathered information and your responses in connection with this study will remain confidential. Neither your name nor any identifying information will be revealed in the reports of the study.

Your participation in the study is voluntary. Your refusal or failure to comply will not result in any penalty or affect the quality of your health care. You have the right to withdraw from the project any time you want without any problems prior to completion of data collection. If you feel uncomfortable about participation in this study, please do not hesitate to tell me. There is no cost to participate in this study and no financial reward.



**Appendix B****INSTRUMENTS**

Code: -----

Date and Time: -----

Hospital: -----

**Part A: Demographic Data Assessment Form (DDAF)**

Direction: this form covers four parts including personal data, health and illness history, health state covering health state perceived by patient and health state assessed by professional, and health care system. Please select the best answer(s) that can be one or multiple choices corresponding to your situation and fill “√” in the box “” next to the answer you have selected.

**I. Personal Data**

1. Age \_\_\_\_\_ years

2. Race

 1. Han 2. Man 3. Hui 4. Others

3. Religion

 1. None 2. Christian 3. Buddhism 4. Islam 5. Others \_\_\_\_\_

4. Marital status

 1. Single 2. Married 3. Divorced 4. Widowed

5. Educational background

 1. Illiterate 2. Primary school 3. Junior high school 4. Senior high school 5. Vocational training 6. Diploma/Associate

6. Occupation  7. University or above
1. Government staff       2. Health personnel
3. Business       4. Retirement
5. Laid off       6. Housewife
7. Labor       8. Farmer
9. Others \_\_\_\_\_
7. Monthly average income (Yuan/month/person)  1. < ¥ 500.00       2. ¥ 501.00 – 1500.00
3. ¥ 1501.00 – 3000.00       4. ¥ 3001.00 – 5000.00
5. > ¥ 5000.00
8. Medical payment  1. Wholly reimbursed       2. Medical insurance
3. Totally self-paid       4. Others \_\_\_\_\_
9. Home location  1. Urban       2. Suburban       3. Rural
10. Number of family member who stays with the patient \_\_\_\_\_
11. Type of family  1. Nuclear family       2. Extend family

## II. Health and illness history

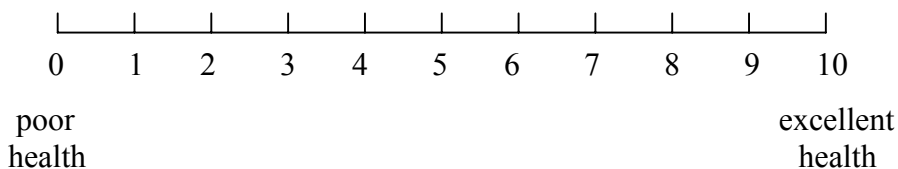
1. Medical diagnosis  1. Left breast cancer       2. Right breast cancer
3. Bilateral breast cancer
2. Stage of breast cancer  1. Stage I       2. Stage II       3. Stage III
3. Time from mastectomy to interview \_\_\_\_\_ days \_\_\_\_\_ month \_\_\_\_\_ year.
4. Medication taken after mastectomy
- 1) Antibiotics  0. No       1. Yes

- 2) Vitamin  0. No  1. Yes
- 3) Analgesic  0. No  1. Yes
- 4) Antiemetic  0. No  1. Yes
- 5) Antipruritic  0. No  1. Yes
- 6) Herb  0. No  1. Yes
- 7) Others \_\_\_\_\_

**III. Health state**

**1. Health state perceived by patient**

1) How would you describe present state of health? Please describe it on the line below.



2) What is the most important thing in your life?

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**2. Health state assessed by professional**

This is assessed by physical examination or from medical record on the date of researcher's approach

Item	Yes 0	No 1
1) Have any physical symptom as follows? (1) fatigue (2) pain (3) chest wall stiffness (4) restriction of shoulder movement (5) lymphedema (6) nausea or vomiting (7) diarrhea or constipation (8) hair loss (9) skin infection		

(10) difficulty sleeping		
(11) hot flashes		
(12) weight loss		

(Continued)

Item	Yes 0	No 1
2) Have other GI problem except mentioned above?		
3) Have cardiovascular problem		
4) Have respiratory problem?		
5) Have urinary problem?		
6) Have anemia or blood component problem?		
7) Unable to do daily activity?		
8) Feel restless or agitation?		
9) Feel stress or anxiety about illness and treatment?		
10) Worry about your husband or family burden?		
11) Have any concerns regarding your sexual health?		
12) Have less social activity than usual?		
13) Have any other discomfort or feeling?		

#### IV. Health care system

1. In general, which of the following system or services that you mostly use in your life?

1. Biomedical health care
2. Alternative health care
3. Both or combine

If use, which of the following items are being used ?

Biomedical health care

1. Medication prescribed by physician     2. Chemotherapy
3. Radiotherapy     4. Hormonal therapy

Alternative health care

- 1). Physical alternative practice

1. Physiotherapy     2. Herb medicine     3. Massage  
 4. Qigong     5. Acupuncture     6. Dietary therapy  
 7. Special supplement, vitamins,...

2). Spiritual alternative care

1. Meditation     2. Cosmic therapy

3). Psychological alternative care

1. Visualization therapies

2. After mastectomy, which of the following system or services that mostly use in this period?

1. Biomedical health care  
 2. Both or combine (biomedical and/with alternative health care)

If use, which of the following items are being used ?

Biomedical health care

1. Medication prescribed by physician     2. Chemotherapy  
 3. Radiotherapy     4. Hormonal therapy

Alternative health care

1). Physical alternative practice

1. Physiotherapy     2. Herb medicine     3. Massage  
 4. Qigong     5. Acupuncture     6. Dietary therapy  
 7. Special supplement, vitamins,...

2). Spiritual alternative care

1. Meditation     2. Cosmic therapy

3). Psychological alternative care

1. Visualization therapies

**Part B: Self-Care Questionnaire (SCQ)**

Direction: the following items are in terms of your self-care after mastectomy. These items comprise of 5 sectors: seeking appropriate medical assistance, being aware of



and attending to the effects and results of mastectomy, choosing medically prescribed therapies and management for side effects, modifying self-concept (and self-image) in accepting herself after mastectomy, and learning to live with effects of breast cancer and mastectomy and the related medical measures. Please answer by giving the appropriate number that represents to what extent you perform or do not perform each activity.

0 = not at all, means you have never performed this activity; 1 = sometimes, means you sometimes or occasionally performed this activity; 2 = often, means you often or almost perform this activity; 3 = very much, means you regularly performed this activity very much.

### **Seeking appropriate medical assistance**

1. How often do you ask your physician or nurse or other health care professionals whenever you have any questions about your illness and/or treatment 0 1 2 3
2. How often do you ask question if I do not understand when receiving information about self-care for this illness----- 0 1 2 3
3. How much do you accept that you need help and support from your family members and friends in order to get through this illness and treatment----- 0 1 2 3
4. How much do you accept that you need help and support from your family members and friends in order to get through this illness and treatment----- 0 1 2 3

### **Being aware of and attending to the effects and results of mastectomy**

5. How much are you careful to observe for any changes in your symptoms-----  
----- 0 1 2 3
6. How often do you report any changes or discomfort to your physician or nurse or other professionals----- 0 1 2 3
7. How often do you avoid to carry handbag or heavy object with affected arm-----  
----- 0 1 2 3
8. How often do you do arm exercise----- 0 1 2 3
9. How often do you perform breast self examination----- 0 1 2 3
10. How often do you go to see doctor for follow-up----- 0 1 2 3

**Choosing medically prescribed therapies and management for side effects**

11. How much do you comply to medications prescribed for your illness according to physician's direction----- 0 1 2 3
12. How much are you diligently note any effects of medications and/or any therapy  
----- 0 1 2 3
13. How do you comply your professionals advice on managing side-effect of the medications and/or any therapy----- 0 1 2 3
14. How do you accept your professionals advice on adopting alternative therapy  
----- 0 1 2 3

**Modify self-concept (and self-image) in accepting yourself after mastectomy**

15. How does your illness increases your understanding on life meaning and personal strength----- 0 1 2 3
16. How often do you take care of yourself----- 0 1 2 3
17. How well do you accept changing on your body due to your illness and treatment  
----- 0 1 2 3
18. How well do you wear prosthesis when attending social activities 0 1 2 3
19. How well could you change your roles at home----- 0 1 2 3
20. How well could you change your roles at work----- 0 1 2 3

**Learning to live with effects of breast cancer and mastectomy and the related medical measures**

21. How well could you adjust your life style because of your illness- 0 1 2 3
22. How well do you learn new things for taking care of yourself----- 0 1 2 3
23. Have you ever tried to contact the women with similar surgery to relieve your pain  
----- 0 1 2 3
24. Are there any group or club where you can go to meet people with mastectomy  
----- 0 1 2 3
25. Do you think the group like this helps you to cope with your case 0 1 2 3

### Part C: Information Resource Questionnaire (IRQ)

Direction: this questionnaire is to learn level of adequacy and types of information you received. Please rate the following items and indicate your answer with “√” beneath the number you have selected.

0 = never received, means you have never received this information;

1 = received but inadequacy, means you have received this information but not enough to correspond to your needs;

2 = received and adequate, means you have received this information and enough to correspond to your needs.

Received Information	Level of Adequacy of Received Information		
	0	1	2
1. The extent of the disease			
2. The chances of cure and the prognosis			
3. The process and duration of cure			
4. Type and all the possible side-effects of conventional treatment			
5. Type and effect of alternative therapy			
6. Psychological effect of treatment			
7. Ways to prevent the recurrence of cancer			
8. Ways to maintain adequate nutrition			
9. Examples of cases who had experience about the illness			
10. Effect of treatment on family/friend			

Other information that you want to receive \_\_\_\_\_

In addition, the researcher also wants to learn the sources and significance of information you received in your self-care after mastectomy. Please rank in order of sources of information you received (you can refer to the following items) and fill the number you have ranked from 1 to 10 in the box.

1 = very important; 10 = the least important.

Physicians

Nurses

- |  |   |
|--|---|
| <input type="checkbox"/> Friends or relatives          | <input type="checkbox"/> Brochures        |
| <input type="checkbox"/> Medical journals or textbooks | <input type="checkbox"/> Videotapes       |
| <input type="checkbox"/> Television or radio programs  | <input type="checkbox"/> Women's journals |
| <input type="checkbox"/> Newspapers                    | <input type="checkbox"/> Internet         |

### Appendix C Reliabilities of SCQ and IRQ

Questionnaire	Correlation coefficient	P value
Self-care	.76	< .01
Dimension 1	.68	< .01
Dimension 2	.58	< .01
Dimension 3	.28	< .01
Dimension 4	.60	< .01
Dimension 5	.55	< .01
Information resources	.75	< .01

### Appendix D Frequency and percentage regarding characteristics of health state assessed by professional (N = 95).

Characteristics	Yes N (%)	No N (%)
1. Physical symptoms		
1) Fatigue	50 (52.6)	45 (47.4)
2) Pain	20 (21.1)	75 (79.0)
3) Chest wall stiffness	25 (26.3)	70 (73.7)
4) Restriction of shoulder movement	29 (30.5)	66 (69.5)
5) Lymphedema	22 (23.2)	73 (76.8)
6) Nausea or vomiting	17 (17.9)	78 (82.1)
7) Diarrhea or constipation	26 (27.4)	69 (72.6)
8) Hair loss	23 (24.2)	72 (75.8)
9) Skin infection	2 (2.1)	93 (97.9)
10) Difficulty sleeping	34 (35.8)	61 (64.2)
11) Hot flashes	46 (48.4)	49 (51.6)
12) Weight loss	7 (7.4)	88 (92.6)
2. Other GI problem except for being mentioned in physical symptoms	16 (16.8)	79 (83.2)
3. Cardiovascular problem	19 (20.0)	76 (80.0)
4. Respiratory problem	6 (6.3)	89 (93.7)
5. Urinary problem	4 (4.2)	91 (95.8)
6. Anemia or blood component problem	9 (9.5)	86 (90.5)
7. Unable to do daily activity	10 (10.5)	85 (89.5)
8. Restless or agitation	51 (53.7)	44 (46.3)
9. Stress or anxiety about illness and treatment	39 (41.1)	56 (59.0)
10. Worry about your husband or family	32 (33.7)	63 (66.3)

burden		
11. Concerns regarding your sexual health	24 (25.3)	71 (74.7)
12. Less social activity than usual	25 (26.3)	70 (26.3)
13. Other discomfort or feeling	8 (8.4)	87 (91.6)

**Appendix E** Frequency and percentage of the levels of health states perceived  
by patient and assessed by professional (N = 95)

Variable	High ( $> \bar{X} + SD$ ) N (%)	Moderate ( $\bar{X} \pm SD$ ) N (%)	Low ( $< \bar{X} - SD$ ) N (%)
Health state perceived by patient	8.61 15 (15.8%)	8.61-5.53 69 (72.6%)	5.53 11 (11.6%)
Health state assessed by professional	21.85 17 (17.9%)	21.85-14.69 63 (66.3%)	14.69 15 (15.8%)

**Appendix F** Mean and standard deviation regarding self-care of postmastectomy  
women

Self-care activity	Mean	SD
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**Seeking appropriate medical assistance**

1. How often do you ask your physician or nurse or other health care professionals whenever you have any questions about your illness and/or treatment	2.14	.78
2. How often do you ask question if you do not understand when receiving information about self-care for this illness	2.00	.84
3. How much do you accept that you need help and support from your physician, nurse, and other professionals when you get worse	2.39	.72
4. How much do you accept that you need help and support from family members and friends in order to get through this illness and treatment	2.62	.64

**Being aware of and attending to the effects and results of mastectomy**

5. How much are you carefully to observe for any changes in your symptoms	2.18	.83
6. How often do you report any changes or discomfort to your physician or nurse or other professionals	1.96	.85
7. How often do you avoid to carry handbag or heavy object with affected arm	1.88	.99
8. How often do you do arm exercise	2.08	.84
9. How often do you perform breast self examination	1.64	.98
10. How often do you go to see doctor for follow-up	2.97	.23

**Choosing medically prescribed therapies and management for side effects**

11. How much do you comply to medications prescribed for your illness according to physician's direction	2.60	.53
12. How much are you carefully note any effects of medications and/or any therapy happened to you	2.18	.76
13. How do you comply your professionals advice on managing side-effect of the medications and/or any therapy	2.57	.65
14. How do you accept your professionals advice on adopting alternative therapy	1.29	1.14

**Modify self-concept (and self-image) in accepting herself after mastectomy**

15. How does your illness increases your understanding on life meaning and personal strength	1.88	1.07
16. How often do you take care of yourself	2.60	.51
17. How well do you accept changing on your body due to your illness and treatment	2.54	.76
18. How often do you wear prosthesis when attending social activities	2.33	1.10

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19. How well could you change your roles at home	2.84	.37
20. How well could you change your roles at work	2.62	.69
<b>Learning to live with effects of breast cancer and mastectomy and the related medical measures</b>		
21. How well could you adjust your life style because of your illness	2.63	.57
22. How well do you learn new things for taking care of yourself	2.32	.79
23. Have you ever tried to contact the women with similar surgery to relieve your pain	1.62	.99
24. Are there any group or club where you can go to meet people with mastectomy	.76	1.08
25. Do you think the group like this helps you to cope with your case	1.18	1.10

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**Appendix G** Frequency, percentage, mean and standard deviation regarding levels of self-care of postmastectomy women (N = 95)

Self-care activity	High	Moderate	Low
	( $>\bar{X} + SD$ ) N (%)	( $\bar{X} \pm SD$ ) N (%)	( $<\bar{X} - SD$ ) N (%)
1. Seeking appropriate medical assistance	>11.48 25 (26.3%)	11.48-6.82 54 (56.8%)	<6.82 16 (16.8%)
2. Being aware of and attending to the effects and results of mastectomy	>15.67 16 (16.8%)	15.67-9.77 64 (67.4%)	<9.77 15 (15.8%)
3. Choosing medically prescribed therapies and management for side effects	>10.56 19 (20.0%)	10.56-6.72 61 (64.2%)	<6.72 15 (15.8%)
4. Modify self-concept (and self-image) in accepting herself after mastectomy	>17.88 18 (19.0%)	17.88-11.74 64 (67.4%)	<11.74 13 (13.7%)
5. Learning to live with effects of breast cancer and mastectomy and related medical measures	>11.66 18 (19.0%)	11.66-5.36 63 (66.3%)	<5.36 14 (14.7%)
<b>Total</b>	<b>&gt;62.92 18 (19.0%)</b>	<b>62.92-44.72 64 (67.4%)</b>	<b>&lt;44.72 13 (13.7%)</b>

**Appendix H** Frequency and percentage regarding each activity of self-care of postmastectomy women (N = 95).

Self-care activity	Frequency / Percentage			
	0	1	2	3
<b>Seeking appropriate medical assistance</b>				
1. How often do you ask your physician or nurse or other health care professionals whenever you have any questions about your illness and/or treatment		23 (24.2%)	36 (38.0%)	36 (38.0%)
2. How often do you ask question if you do not understand when receiving information about self-care for this illness		33 (34.7%)	29 (30.5%)	33 (34.7%)
3. How much do you accept that you need help and support from your physician, nurse, and other professionals when you get worse		13 (13.7%)	32 (33.7%)	50 (52.6%)
4. How much do you accept that you need help and support from family members and friends in order to get through this illness and treatment		8 (8.4%)	20 (21.1%)	67 (70.5%)

**Appendix H (Continued)**

Self-care activity	Frequency / Percentage			
	0	1	2	3



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**Being aware of and attending to the effects and results of mastectomy**

5. How much are you carefully to observe for any changes in your symptoms	2 (2.1%)	19 (20.0%)	34 (35.8%)	40 (42.1%)
6. How often do you report any changes or discomfort to your physician or nurse or other professionals	2 (2.1%)	30 (31.6%)	33 (34.7%)	30 (31.6%)
7. How often do you avoid to carry handbag or heavy object with affected arm	9 (9.5%)	25 (26.3%)	29 (30.5%)	32 (33.7%)
8. How often do you do arm exercise	4(4.2%)	21(22.1%)	33(34.7%)	37(39.0%)
9. How often do you perform breast self examination	14 (14.7%)	26 (27.4%)	35 (36.8%)	20 (21.1%)
10. How often do you go to see doctor for follow-up		1 (1.1%)	1 (1.1%)	93 (98.0%)

**Choosing medically prescribed therapies and management for side effects**

11. How much do you comply to medications prescribed for your illness according to physician's direction		2 (2.1%)	34 (35.8%)	59 (62.1%)
12. How much are you carefully note any effects of medications and/or any therapy happened to you	2 (2.1%)	14 (14.7%)	44 (46.3%)	35 (36.8%)
13. How do you comply your professionals advice on managing side-effect of the medications and/or any therapy	2 (2.1%)	2 (2.1%)	31 (32.6%)	60 (63.2%)
14. How do you accept your professionals advice on adopting alternative therapy	33 (34.7%)	19 (20.0%)	25 (26.3%)	18 (19.0%)

**Modify self-concept (and self-image) in accepting herself after mastectomy**

15. How does your illness increases your understanding on life meaning and personal strength	17 (17.9%)	9 (9.5%)	37 (39.0%)	32 (33.7%)
16. How often do you take care of yourself		1 (1.1%)	36 (37.9%)	58 (61.1%)
17. How well do you accept changing on your body due to your illness and treatment	2 (2.1%)	9 (9.5%)	20 (21.1%)	64 (67.4%)

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**Appendix H (Continued)**

Self-care activity	Frequency / Percentage			
	0	1	2	3

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18. How often do you wear prosthesis when attending social activities	14 (14.7%)	4 (4.2%)	14 (14.7%)	63 (66.3%)
19. How well could you change your roles at home			15 (15.8%)	80 (84.2%)
20. How well could you change your roles at work	2 (2.1%)	5 (5.3%)	20 (21.1%)	68 (71.6%)
<b>Learning to live with effects of breast cancer and mastectomy and the related medical measures</b>				
21. How well could you adjust your life style because of your illness		4 (4.2%)	27 (28.4%)	64 (67.4%)
22. How well do you learn new things for taking care of yourself	3 (3.2%)	10 (10.5%)	36 (37.9%)	46 (48.4%)
23. Have you ever tried to contact the women with similar surgery to relieve your pain	17 (17.9%)	20 (21.1%)	40 (42.1%)	18 (19.0%)
24. Are there any group or club where you can go to meet people with mastectomy	59 (62.1%)	10 (10.5%)	16 (16.8%)	10 (10.5%)
25. Do you think the group like this helps you to cope with your case	38 (40.0%)	14 (14.7%)	31 (32.6%)	12 (12.6%)

**Appendix I** Pearson's product moment correlation coefficient (statistical significance) between health state perceived by patient and health state assessed by professional

	Health state perceived by patient
Health state assessed	.40
by professional	(.00)