



**Relationships of Preparedness of Caregiving and Mutuality to Role Strain in  
Thai Family Caregivers of Patients with Head and Neck Cancer  
Receiving Treatments**

**Duangstuda Wongchuay**

**A Thesis Submitted in Partial Fulfillment of Requirements for the Degree of  
Master of Nursing Science (International Program)**

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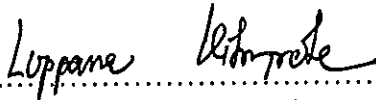
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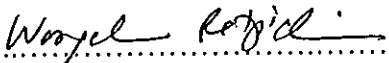
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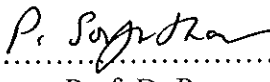
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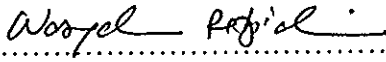
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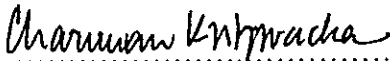
  
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ชื่อวิทยานิพนธ์	ความสัมพันธ์ของความพร้อมในการดูแลและความสัมพันธ์ต่างเกื้อกูล ต่อความเครียดในบทบาทของญาติผู้ดูแลผู้ป่วยโรคมะเร็งศีรษะและลำคอ ในครอบครัวไทยขณะได้รับการการรักษา
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### บทคัดย่อ

ด้วยความรักและผูกพันทำให้ญาติผู้ดูแลยินดีเข้ามาดูแลสมาชิกในครอบครัว  
ที่เจ็บป่วย การทุ่มเทเวลาเพื่อดูแลบุคคลที่รักซึ่งป่วยเป็นมะเร็งอาจส่งผลกระทบต่อญาติผู้ดูแล เมื่อ  
ต้องเผชิญกับหลายบทบาทที่ตนดำรงอยู่เดิมอาจทำให้ไม่สามารถตอบสนองต่อความต้องการของ  
การดูแลซึ่งอาจทำให้ผู้ดูแลเกิดความเครียดในบทบาทได้

การวิจัยครั้งนี้มีวัตถุประสงค์เพื่อศึกษาความสัมพันธ์ของการเตรียมความพร้อมใน  
การดูแลและความสัมพันธ์ต่างเกื้อกูลต่อความเครียดในบทบาทของญาติผู้ดูแลผู้ป่วยโรคมะเร็ง  
ศีรษะและลำคอในครอบครัวไทยขณะได้รับการรักษา กลุ่มตัวอย่างเป็นญาติผู้ดูแลผู้ป่วยมะเร็ง  
ศีรษะลำคอที่ได้รับการรักษาที่โรงพยาบาลมหาวิทยาลัยแห่งหนึ่งในภาคใต้จำนวน 80 ราย เก็บ  
ข้อมูลระหว่างเดือนกุมภาพันธ์ถึงสิงหาคม 2553 เครื่องมือที่ใช้ในการเก็บรวบรวมข้อมูล  
ประกอบด้วย แบบบันทึกข้อมูลส่วนบุคคลของผู้ป่วยและญาติผู้ดูแล แบบวัดความพร้อมในการ  
ดูแล แบบวัดความสัมพันธ์ต่างเกื้อกูล และแบบวัดความเครียดในบทบาทญาติผู้ดูแล ตรวจสอบ  
ความเที่ยงตรงเฉพาะหน้าโดยญาติผู้ดูแลผู้ป่วย 20 ราย และตรวจสอบความเที่ยงของเครื่องมือแบบ

วัดความพร้อมในการดูแล ความสัมพันธ์ต่างเกื้อกูล ความขัดแย้งในบทบาท ความดึงเครียดในบทบาทและความเครียดโดยรวม โดยวิธีครอนบาช แอลฟา ได้ค่าสัมประสิทธิ์แอลฟาเท่ากับ .80, .84, .74, .77, และ .82 ตามลำดับ ส่วนแบบวัดการแสดงบทบาทไม่ตรงกับความคิดหวัง ทดสอบความเที่ยงด้วยการทดสอบซ้ำโดยใช้สถิติสัมประสิทธิ์สหสัมพันธ์เพียร์สันได้ค่าเท่ากับ .79 มีการวิเคราะห์ข้อมูลด้วยค่าสถิติเชิงพรรณนาและค่าสัมประสิทธิ์สหสัมพันธ์เพียร์สัน

ผลการวิจัยพบว่า ญาติผู้ดูแลมีความพร้อมในการดูแล ( $M = 2.77, SD = 0.68$ ) และ ความสัมพันธ์ต่างเกื้อกูลอยู่ในระดับสูง ( $M = 2.73, SD = 0.70$ ) แต่พบว่าญาติผู้ดูแลประเมินผลความพร้อมในการดูแลในเรื่องการจัดการกับภาวะฉุกเฉินอยู่ในระดับต่ำ สำหรับความเครียดในบทบาทอยู่ในระดับต่ำ ( $M = 0.67, SD = 0.23$ ) ความพร้อมในการดูแลไม่มีความสัมพันธ์กับความเครียดในบทบาทของญาติผู้ดูแล ( $r = -.14, p = .10$ ) ความสัมพันธ์ต่างเกื้อกูลมีความสัมพันธ์เชิงลบระดับปานกลางกับความเครียดในบทบาทของญาติผู้ดูแล ( $r = -.47, p < .05$ )

จากผลการวิจัยนี้ เจ้าหน้าที่สุขภาพควรให้ความรู้และทักษะด้านการจัดการกับภาวะฉุกเฉินแก่ญาติผู้ดูแลและให้ความสำคัญในการส่งเสริมความเข้มแข็งของสัมพันธ์ภาพระหว่างญาติผู้ดูแลและผู้ป่วยมะเร็งศีรษะและลำคอเพื่อลดความเครียดในบทบาทผู้ดูแล

**Thesis Title** Relationships of Preparedness of Caregiving and Mutuality to Role Strain in Thai Family Caregivers of Patients with Head and Neck Cancer Receiving Treatments

**Author** Miss Duangsuda Wongchuay

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### **ABSTRACT**

Family caregivers are willing to provide care for ill family member due to love and attachment. Spending time due to a great deal of care for their loved one with cancer may affect their life. They have faced with stress that their existing role is not corresponding to the demands of caregiving role. These may cause strain among family caregivers.

This descriptive correlational study aimed to investigate the relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of patients with head and neck cancer (HNC) receiving treatments. Eighty family caregivers of the HNC patients from a university hospital in southern Thailand were recruited. Data were collected from February to August, 2010. The set of questionnaires used in this study consisted of the Patients' and their Family Caregivers' Demographic Data, Preparedness of Caregiving Assessment Form, Mutuality Assessment Form, and Caregiver Role Strain Assessment Form. Face validity of these tools was tested with 20 family caregivers. The Cronbach's Alpha coefficients of the Preparedness Assessment Form, the Mutuality Assessment Form, the Role Conflict Assessment Form, the Increased Tension Assessment Form, and the

Global Strain Assessment Form, were .80, .84, .74, .77, and .82, respectively indicating adequate internal consistency reliability. The Mismatched Expectation Assessment Form was tested by using test-retest method (Pearson correlation coefficient); its reliability was .79. The data were analyzed by using descriptive statistics and Pearson's Product Moment Correlation.

The results showed that the mean scores of preparedness of caregiving ( $M = 2.77$ ,  $SD = 0.68$ ) and the mean scores of mutuality ( $M = 2.73$ ,  $SD = 0.70$ ) were high. However, one area of preparedness of caregiving regarding responding and handling to patients' emergencies was low. The mean score of caregiver role strain was low ( $M = 0.67$ ,  $SD = 0.23$ ). Additionally, preparedness of caregiving was not significantly related to caregiver role strain ( $r = -.14$ ,  $p = .10$ ) but mutuality was moderately and negatively related to caregiver role strain ( $r = -.47$ ,  $p < .05$ ).

These findings suggest that the health professionals should provide caregiving information and skills for Thai family caregivers to manage with emergencies. Encouraging the strong relationship between family caregivers and HNC patients is also essential to reduce caregiving role strain.

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## CONTENTS

	<b>Page</b>
<b>ABSTRACT</b> .....	<b>iii</b>
<b>ACKNOWLEDGEMENT</b> .....	<b>vii</b>
<b>CONTENTS</b> .....	<b>viii</b>
<b>LIST OF TABLES</b> .....	<b>xi</b>
<b>LIST OF FIGURES</b> .....	<b>xii</b>
<b>CHAPTER I: INTRODUCTION</b> .....	<b>1</b>
Background and Significance of the Problem.....	1
Objectives of the Study .....	6
Research Questions .....	7
Conceptual Framework .....	7
Hypotheses .....	10
Definition of Terms .....	10
Scope of the Study .....	11
Significance of the Study .....	11
<b>CHAPTER II: LITERATURE REVIEW</b> .....	<b>12</b>
Head and Neck Cancer .....	13
Concept of Family Caregiver .....	21



## CONTENTS (continued)

	<b>Page</b>
Preparedness of Caregiving .....	23
Mutuality .....	34
Caregiver Role Strain .....	38
The Relationships of Preparedness, and Mutuality to Role Strain of Thai Family Caregivers of Patients with HNC Receiving Treatments .....	44
<b>CHAPTER III: RESEARCH METHODOLOGY .....</b>	<b>48</b>
Setting .....	48
Population and Sample .....	49
Instrumentation .....	50
Ethical Consideration .....	54
Data Collection .....	55
Data Analysis .....	56
<b>CHAPTER IV: RESULTS AND DISSCUSSION .....</b>	<b>57</b>
Results .....	57
Discussion .....	73

## CONTENTS (continued)

	Page
<b>CHAPTER V: CONCLUSION AND RECOMMENDATIONS .....</b>	<b>87</b>
Summary of the Findings .....	87
Limitations of the Study .....	88
Implications and Recommendations .....	88
<b>REFERENCES .....</b>	<b>90</b>
<b>APPENDICES .....</b>	<b>108</b>
Appendix A : Family Caregivers' Demographic Questionnaire .....	109
Appendix B : Head and Neck Cancer Patients' Demographic Data Form .....	112
Appendix C : The Preparedness of Caregiving Assessment Form .....	114
Appendix D : The Mutuality Assessment Form .....	116
Appendix E : The Caregiver Role Strain Assessment Form .....	118
Appendix F : Consent Form .....	125
Appendix G : Ethical Approval .....	127
Appendix H : Permission of Instrument Use .....	128
Appendix I : Additional Results .....	129
<b>VITAE .....</b>	<b>136</b>

## LIST OF TABLES

Table		Page
1	Frequency and Percentage of Family Caregivers Related to Characteristics .....	58
2	Frequency and Percentage of HNC Patients Related to Characteristics .....	64
3	Mean, Standard Deviation, Level of Preparedness of Caregiving .....	69
4	Mean, Standard Deviation and Level of Mutuality .....	70
5	Range, Mean, and Standard Deviation of Caregiver Role Strain .....	71
6	The Pearson's Product Moment Correlation Coefficient Between Variables .....	72

## LIST OF FIGURE

Figure		Page
1	Research Framework .....	9

# CHAPTER 1

## INTRODUCTION

### *Background and Significance of the Problem*

Head and neck cancer (HNC) is a complex group of cancer, which includes cancer of the lip, oral cavity, salivary glands, paranasal sinuses, nasal cavity, oropharynx, nasopharynx, hypopharynx, larynx, ears and thyroid (Harrison, Sessions, & Hong, 2009). In Thailand, HNC was found and ranked among the ten leading cancer sites in several hospitals in the year of 2008 to 2009 (National Cancer Institute, 2008, 2009; Siriraj Cancer Center, 2008, 2009; Songklanagarind Cancer Center, 2008, 2009). For example, in Bangkok, the capital city of Thailand, data from cancer registries of the National Cancer Institute showed that HNC accounted for approximately 12.81 - 13.20% of the total cancer population (National Cancer Institute). Similar to the percentages of HNC patients in Siriraj Hospital, they were ranged in 11.17 - 13.65% of total cancer (Siriraj Cancer Center). In southern Thailand, the new HNC patients in Songklanagarind Hospital were highly found around 19.43 – 24.22% of all cancers (Songklanagarind Cancer Center).

HNC treatments are well-established. Surgery, radiation, chemotherapy and/or combinations are all currently considered before deciding the optimal therapy for a given patient. In general, the goals of therapy are to cure HNC in early stage, to improve survival for patients with HNC at the locally advanced stage, and to provide palliative care for metastatic cases (Ang & Garden 2006; Bowman, 2007). Although these treatments have several advantages, there are some disadvantages on physical

and psychosocial health of HNC patients, such as oral mucositis, bone marrow suppression, fatigue, weight loss, skin irritation, body image change, depression, uncertainty, social isolation, and loss of work (Argiris, Karamouzis, Raben, & Ferris, 2008; Harrison et al., 2009; Logan, 2009; Lydiatt, Moran, & Burke, 2009; Posner & Vermorken, 2008). To reduce these symptoms, HNC patients need support from health professionals during receiving treatment. However, due to the recent trend towards dehospitalization, the primary providers of these patients, which were once served by health professionals, now increasingly fall into hands of the family members (Glajchen, 2004; Hudson, Aranda, & Kristjason, 2004; Matthews, 2007). The role of family members in caregiving for the patients with HNC during receiving treatments; therefore, becomes more important.

In general, caregivers are the family members or relatives of the patients. They are willing to provide care to the patients due to love and attachment and also the good relationship between the patients and the family members, (Northouse, 2005). The family caregivers would take care of their patients' health; for example, assist them to perform various activities, prevent complications, provide emotional support, and coordinate with the health care team (Christensen & Lin, 2007; Northouse). Such caregiving is the work beyond regular one resulting in a change in daily life and the role of caregivers (Ross, Mosher, Tobin, Hermele, & Ostroff, 2010). Besides, caregivers may face emotional changes in the patients causing increased tension. Family caregivers may found lack of time left for caring of their own health and for their work and social activities (Hawes et al., 2006; Winterling et al., 2004). As a result, the family caregivers face with stress that their existing role is not corresponding to the demands of caregiving role resulting in further role conflict

(Chen et al., 2009; Ross et al., 2010). These events are the common origins of strain and cause global strain among family caregivers.

Role strain is the feeling of difficulty in fulfilling role obligation (Goode, 1960). In caregiving context, role strain was caused from role ambiguity, role conflict, role accumulation, role demands, role overload, patients' illness, and characteristics of caregivers (Komarovskiy as cited in Beitman et al., 2004). Previous findings related to cancer caregivers' role strain were varied. A longitudinal study showed that family caregivers of autologous blood and marrow transplantation (ABMT) patients had low level of overall role strain and the role strain declined steadily from 2 to 12 weeks of patients' recovery (Eldredge et al., 2006). A qualitative research found that spousal caregivers of HNC patients who were being treated with radiation felt strain when they faced with their patients' emotional changes, reduced in their social functioning, and worked harder to earn more money (Kitrungrote, Wonghongkul, Chanprasit, Suthasangsee, & Cohen, 2008). A study of Donnelly et al. (2008) showed that caregivers of cancer patients had high level of strain. In particular, younger and female family caregivers of patients who were receiving cancer treatments faced more global strain than older and male caregivers faced (Schumacher et al., 2008). Moreover, due to lack of preparedness in caregiving and insufficient knowledge about the disease and specific types of care e.g. tracheostomy care, the caregivers had strain (Ferrario, Zotti, Zaccaria, & Donner, 2001). The family caregivers role strain may threaten their well-being and caring for their patients and patients' safety (Christensen et al., 2007). Therefore, it is necessary for family caregivers to learn the role cues, social and cultural norms to reduce their role strain (Hardy & Hardy, 1988).

Preparedness of caregiving is one crucial factor that prevents the family members who occupy the new role of caregivers from strain. Archbold, Stewart, Greenlick, and Harvath (1990) described preparedness of caregiving as perceived readiness for multiple domains of the caregiving role. These domains include giving physical and emotional support, setting up in-home support services, making activities pleasant for both caregiver and patient, dealing with the stress of caregiving, handling the emergency condition, and getting help from health care system. Previously, preparedness of caregiving studies showed different results. A qualitative study showed that spousal caregivers of HNC patients receiving radiation reported that health professionals provided them with information about disease, radiation treatment, and patient's care practice (Kitrungrote et al., 2008). Caregivers of patients with cancer undergoing oncology therapy had preparedness level which ranged from "somewhat" to "pretty well" and were consistent at 24- 48 hour prior to anticipated hospital discharge, 7-10 days postdischarge, and 28-30 day postdischarge (Scherbring, 2002). Moderate preparedness level was reported by family caregivers of ABMT patients at the time of hospital discharge (Eldredge et al., 2006). Study of Schumacher et al. (2008) showed the high level of preparedness in the caregivers of adults who completely received treatment for solid tumors or lymphoma. Moreover, several studies supported that the family caregivers who received high level of preparedness had lower caregiver role strain (Archbold et al., 1990; Schumacher et al., 2008).

Not only is preparedness in which one can contribute to reduce the caregiving role strain, but also the affection of the family caregivers for the care-receiver during providing care is important (Kneeshaw, Considine, & Jennings, 1999). Mutuality is the positive quality of the relationship between caregiver and care-receiver based on



reciprocity, love, shared pleasurable activities, and shared values (Archbold et al., 1990; Archbold et al., 1995). Kitrungrote et al. (2008) found that during a difficult time of caregiving, the spousal caregivers and their HNC patients became closer and learned to comprehend and sympathize with each other more greatly than ever before. High mutuality level was reported by family cancer caregivers from the studies of Eldredge et al. (2006) and Schumacher et al. (2008). Archbold et al. (1990) and Schumacher et al. also found that cancer caregivers who had high mutuality had low level of role strain.

From literature review above, although most investigations were conducted with cancer caregivers in the western countries which may not fully reflect role strain of Thai HNC caregivers due to distinction of culture, social structure, and social expectation (Hardy & Conway, 1988). For instance, western society relies on a nuclear family and appreciates equality in marriage; while Thai society relies on the relationship of the extended family and a high value of subordination of women in marriage (Luckman, 1999; Boonchalaksi, 2000). Moreover, family caregiver role responsibilities of HNC patients while receiving active regimens are unlike to caregiving activities after cancer patients' complete treatments. The nature of caregiving tasks may vary in response to changes in patients' functioning; as patients' physical functioning is limited, and physical functioning influences caregiver role strain (Eldredge et al., 2006; Ross, Mosher, Ronis-Tobin, Hermele, & Ostroff, 2010). Therefore, the results of previous studies may obtain limited description of the role strain of caregivers of HNC patients who have suffered from acute side-effects during receiving treatments.

To date, the scarcity of knowledge revealed the role strain of Thai family caregivers who provide care for HNC patients during receiving treatments. Therefore, it is needed to explore the level of preparedness of caregiving, mutuality, and role strain of Thai family caregivers of HNC patients while receiving treatments. The outcomes of this study would help nurses to prepare family caregivers to develop knowledge and caregiving skill, enhance mutuality, and reduce caregiver role strain during providing care for HNC patients receiving treatments.

### *Objectives*

1. To describe the level of preparedness of caregiving of family caregivers of patients with HNC receiving treatments
2. To describe the level of mutuality of family caregivers of patients with HNC receiving treatments
3. To describe the level of role strain of family caregivers of patients with HNC receiving treatments
4. To investigate the relationship between preparedness of caregiving and role strain of family caregivers of patients with HNC receiving treatments
5. To investigate the relationship between mutuality and role strain of family caregivers of patients with HNC receiving treatments

### *Research Questions*

1. What is the level of preparedness of caregiving of family caregivers of patients with HNC receiving treatments?
2. What is the level of mutuality of family caregivers of patients with HNC receiving treatments?
3. What is the level of role strain of family caregivers of patients with HNC receiving treatments?
4. Is there a relationship between preparedness of caregiving and role strain of family caregivers of patients with HNC receiving treatments?
5. Is there a relationship between mutuality and role strain of family caregivers of patients with HNC receiving treatments?

### *Conceptual Framework*

The role theory proposed by George Hearbert Mead (Hardy & Hardy, 1988) and literature related to caregiving role (Archbold et al., 1990; Burr, Leigh, Day, & Constantine, 1979; Schumacher, 1995) were used to guide the framework of this study.

According to the role theory, society is a group of individuals who live together and interact in accordance with their rights, duties, and role relationships. Thus, individuals need to learn their roles so as to appropriately perform such roles based on the culture and expectation of the society. Naturally, an individual can have

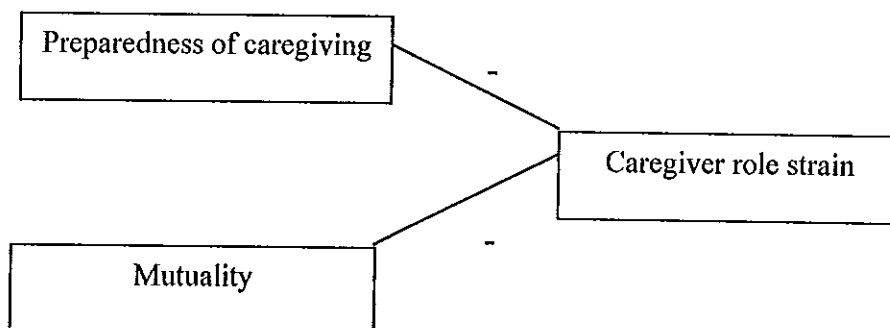
multiple roles such as child, wife, sibling, worker, and others. Therefore, individuals need to learn and understand the roles they have, the person they need to interact with, and the behaviors appropriate for each role. The interaction between the role-occupant and the role-partner is the interactional behaviors that take place with the role-occupant which gives meaning to self, symbolic situation, and the interaction he or she has with the role-partner through "role taking". If the role-occupant does not possess the skills needed to perform the role, and the role-occupant does not understand the expectation of the role-partner, then the difficulty in performing roles can arise and role strain can follow.

In caregiving context, acquisition of the caregiving role is a family role transition that occurs when a family member's self-care ability is decreased caused by illness or aging and there is a concomitant need for the provision of care by others (Schumacher, 1995). Taking on the caregiving role involves changes in established pattern of behaviors and expectations, therefore, anticipatory preparation for new role of caregiver is necessary (Burr et al., 1979). In caregiving process, interactions or closed affective relationships are taken place between role-partner (sick family member) and role-occupant (family caregivers) that enable them to continue caregiving role (Archbold et al., 1990; Tunner, 1962). From caregiving phenomenon, subjective well-being and the well-being of relationship are identified as indicators of healthy transitions (Schumacher).

In this study, the broad concepts as described above were applied to family caregivers of HNC patients receiving treatments. When the family members are taken in the new role of caregivers, they need to learn and understand the caregiving role

and the patients they need to care for as well as to perform appropriate behaviors based on their cultural and social expectation. The concept of anticipatory preparation was conceptualized as preparedness of caregiving that referred to family caregivers' perception about how they well prepared to learn aspects of the caregiving role and evaluated their ability to conduct this role. The concept of interaction between role-partners and role-occupant was referred to mutuality or how family caregivers described the quality of their relationship with HNC patients. Subjective well-being of family caregivers was identified as caregiver role strain that referred to the difficult feeling of family caregivers in performing their role.

In addition, this study used the research constructed by Archbold et al. (1990), who examined mutuality and preparedness as factor of role strain among American caregivers of elder adults, to test the relationships between preparedness of caregiving and mutuality to role strain of Thai family caregivers of HNC patients receiving treatments. Therefore, the relationships of these concepts were examined, and the hypothesized relationships are presented in Figure 1.



*Figure 1* Research Framework

### *Hypotheses*

1. Preparedness of caregiving has a negative relationship with role strain of family caregivers of patients with HNC receiving treatments
2. Mutuality has a negative relationship with role strain of family caregivers of patients with HNC receiving treatments

### *Definition of Terms*

*Preparedness of caregiving.* Preparedness of caregiving refers to the family caregivers' perception of how well prepared they are in taking caregiver role such as providing physical care, providing emotional support, responding and handling emergencies, setting up in-home support services, and dealing with the stress of caregiving. The preparedness for caregiving was measured by using the Preparedness for Caregiving Assessment Form-Thai version (Sritares, 2003). The higher score means the higher level of preparedness for caregiving.

*Mutuality.* Mutuality refers to the family caregivers' perception regarding positive quality of the relationship between themselves and their HNC patients during receiving treatments. This relationship was expressed in terms of love and affection, shared pleasurable activities, shared values, and reciprocity. The mutuality was measured by using the Mutuality Assessment Form-Thai version (Sritares, 2003). The higher score means the higher level of mutuality.

*Caregiver role strain.* Caregiver role strain refers to the family caregivers' perception of difficulty in fulfilling of their caregiving role during their HNC patients

receiving treatments consisting of role conflict, mismatched expectation, increased tension, and global strain. The caregiver role strain was measured by using the Caregiver Role Strain Assessment Form-Thai version (Sritares, 2003). The higher score means the higher level of caregiver role strain.

#### *Scope of the Study*

This study was conducted at a tertiary, university hospital in southern Thailand only. The data were collected through self-report questionnaires from family caregivers of HNC patients during receiving treatments during February–August, 2010.

#### *Significance of the Study*

The findings of this study provide the baseline information according to preparedness of caregiving, mutuality, and role strain of Thai family caregivers of HNC patients receiving treatments. This information will help nurses to improve the nursing practice regarding the preparedness of caregiving, enhancing mutuality, and reducing role strain of family caregivers of HNC patients. In addition, the results of this study will stimulate further family caregiving research.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter presents a review of literature relevant to this study. The review is presented in sequence as follows:

1. Head and neck cancer (HNC)
2. Concept of family caregivers
3. Preparedness of caregiving
  - 3.1 Definition
  - 3.2 Preparedness of caregiving for HNC patients
  - 3.3 Empirical findings of preparedness of caregiving
  - 3.4 Factors related to preparedness of caregiving
  - 3.5 The measure of preparedness of caregiving
4. Mutuality
  - 4.1 Definition
  - 4.2 Empirical findings of mutuality of family caregivers
  - 4.3 Factors related to mutuality of family caregivers
  - 4.4 The measure of mutuality
5. Caregiver role strain
  - 5.1 Definition
  - 5.2 Empirical findings of caregiver role strain
  - 5.3 Factors related to caregiver role strain
  - 5.4 The measure of caregiver role strain



6. The relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of patient with HNC receiving treatments

### *Head and Neck Cancer*

Head and neck cancer is a complex group of cancer, which includes cancer of the lip, oral cavity, salivary glands, paranasal sinuses, nasal cavity, oropharynx, nasopharynx, hypopharynx, larynx, ears, and thyroid (Harrison et al., 2009). The risk factors for HNC are the substance use (i.e., tobacco, alcohol, and tobacco and alcohol together), lack of dietary (i.e., deficiency of vitamin A or iron), viruses (i.e., human papillomavirus, Epstein-Barr virus), and exposure to occupation agents (i.e., exposure to chromium, nickel, radium, mustard gas, and leather tanning) (Argiris et al., 2008; Harrison et al.; Marur & Forastiere, 2008). HNC is more common in men; 66% to 95% of cases occur in men (Ridge, Glisson, Lango, & Feigenberg, 2009).

More than 90% of these HNC malignancies are squamous cell carcinoma (Argiris et al., 2008; Marur & Forastiere, 2008). The most common staging system used in HNC is the standard TNM system: T1-T4 (tumor) N0-N3 (lymph node involvement) M0-M1 (distance metastases). The T staging for HNCs differs according to the primary site; the N staging is common for all subsites except the nasopharynx; and the M staging is common to all sites (Marur & Forastiere). TNM staging can be reduced to clustered stages: I, II, III and IVa, b, c. Patients who present with tumors staged as T1 or T2 with no nodal involvement (stage I-II), called early stage disease. Patients who present with tumors staged as T3 or T4 primary tumors with N2 or N3 lymphadenopathy (stage III-IV), called locally advanced stage

diseases. Stage IV is divided into stage IVa, advanced resectable disease; stage IVb, advanced unresectable disease; and stage IVc, advanced metastatic disease (Haddad, Annino, & Tishler, 2007; Marur & Forastiere; Schroeff & Jong, 2009). Two-thirds of patients with HNC present in advanced stage disease commonly involve to cervical nodes. Only 10% of patients are presented with metastases disease; up to 40% of these stages will be recurrence, also locally at distant site, and often non curable (Argiris et al.; Haddad et al., 2007).

#### *HNC treatments and side effects*

There are several methods used to treat HNC including surgery, radiation, or chemotherapy. Decision to provide single or combination of treatments relies on several factors such as, staging, patients' conditions and preference, and expertise of the clinical team (Argiris et al., 2008). For early-stage cancers, they are best treated with surgery or radiation depending on the subsite and the expertise of the clinical team. Intermediate-stage tumors, i.e., infiltrative tumors, poor-prognosis T2 tumors, or exophytic T3, N0-N1 tumors, may benefit from a combined-treatments approach. The locally advanced tumors are the unfavorable infiltrative T3 or T4 primary tumors with N2 or N3 lymphadenopathy. Patients with locally advanced tumors are best treated with concurrent chemoradiation if the tumor is unresectable, if it is resectable but organ preservation is desired, or if they are receiving postoperative adjuvant radiation with concurrent chemotherapy (Bowman, 2007; Haddad et al., 2007; Marur & Forastiere, 2008; Schroeff & Jong, 2009). Patients with metastatic stage are treated by concurrent chemoradiotherapy. However, chemoradiotherapy in this stage remains palliative, not curative (Bowman; Marur & Forastiere; Schroeff & Jong).

As with cancer treatments, their acute and long term side effects cause HNC patients to have decrease in quality of life (QOL) or suffering in physical and psychosocial problems (Argiris et al., 2008; Posner et al., 2007). The problems commonly found are described as follows.

*Oral complications.* Oral complications caused by the radiation and chemotherapy treatment in HNC patients were resulted from normal tissue damage, which most commonly includes oral mucositis, xerostomia, and ability of tasting either smelling change (Ad & Chalian, 2008; Haddad, et al., 2007; Logan, 2009). Clinical manifestations of oral mucositis include difficulty in eating, drinking, talking, and oral pain (Argiris et al., 2008). Mucositis usually begins approximately two weeks after starting radiation and continues with symptoms for four to five weeks after completion (Harrison et al., 2009). Chemotherapy-induced mucositis is typically less severe and of shorter duration (3-12 days) than that associated with radiation (3-12 weeks) (Rosenthal & Trotti, 2009). Xerostomia was presented resulting from damages of the salivary glands (Haddad et al.; Logan). Patients may notice decreased amounts of saliva, problem with retention of dentures, difficulty of speaking, eating, and swallowing food (Harrison et al.). Taste and smelling change also occurs in HNC patients because the taste and olfactory cells were damaged from radiation (Lu & Kies, 2004).

*Nutrition problems.* The degree of malnutrition is related to the patients' nutritional status before tumor development and to the characteristics of the tumor, and also to the cancer treatment itself (Harrison et al., 2009; Sobol, Conoyer, Zill, Thawley, & Ogura, 2009). Several symptoms related to HNC tumor and its treatments have the potential to seriously compromise the patients' nutritional status by leading

to decreased oral intake and involuntary weight loss (Hayward & Shea, 2009). Common symptoms seen among HNC patients included mucositis, difficult and/or painful swallowing, xerostomia, sticky secretions, alterations in taste and/or smell, nausea and/or vomiting, constipation, decreased appetite, and weight loss. The weight loss has been associated with decreased response to and tolerance of treatment, in addition to decrease in their QOL (Capuano et al., 2010; van den Berg, Rasmussen-Conrad, van Nispen, van Binsbergen, & Merkx, 2008).

*Bone marrow suppression.* When large volumes of active bone marrow are treated with radiation or chemotherapy, the bone marrow function decreases (Harrison et al., 2009). In particular, if chemotherapy is combined with radiation, blood counts can suddenly fall. Red blood cells that carry oxygen, white blood cells that fight with the infection and platelets that control bleeding are usually lowered with chemoradiotherapy use. Therefore, risk for anemia, fatigue, infection, and bleeding are increased with bone marrow suppression (Harrison et al.; Yoshizaki et al., 2009).

*Fatigue.* The causes of fatigue are probably a combination of malnutrition, anemia, pain, sleeplessness, stress, and daily transportation to the outpatient radiation unit (Bansal et al., 2004; Lu & Kies, 2004; Rosenthal & Ang, 2004). A previous study of Storey et al. (2007) found that more than half of patients experienced fatigue during chemotherapy or radiation, and up to 70% of patients with advanced cancer experienced fatigue. Due to fatigue, two-thirds of patients experienced disturbance in their daily life (Biswal, Kumaraswamy, & Mukhtar, 2004).

*Skin change.* The cumulative radiation effects may change skin from erythema through hyperpigmentation to dry desquamation and possibly moist desquamation (Ad & Chalian, 2008; Ang & Garden, 2006; Posner & Vermorken, 2008). Moist

desquamation places skin at risk for infection and causes significant discomfort of patients. Severe moist desquamation can require a break in treatment that may affect the overall effectiveness of radiation (Yoshizaki et al., 2009).

*Speech and respiratory problems.* Surgery for HNC is associated with temporary or permanent speechlessness that limits patients' ability to communicate during the post surgery period. Some patients undergo radical surgeries (i.e., total laryngectomy, glossectomy), resulting in permanent loss of speech, whereas others experience temporary speechlessness because of upper airway edema, extended intubation with an endotracheal tube, or temporary tracheostomy (Rodriguez & Blischak, 2009). Moreover, patients with laryngectomy must breathe through a stoma. The lower respiratory tract is now in direct contact with the atmosphere and air is no longer warmed and moistened leading to the excessive sputum production and coughing in the patients (Haddad et al., 2007; Rodriguez & Blischak; Yoshizaki et al., 2009).

*Fear and anxiety.* Cancer was perceived by several patients as a life-threatening disease, an incurable disease, recurrent disease (Rogers, Scott, Lowe, Ozakin, & Humphris, 2010), or a slow and painful death (Reich, Gaudron, & Penel, 2009). In addition, the patients felt fear and anxious about side effects of cancer treatment outcome based on misconception and a lack of knowledge related to treatment equipment and safety procedure (Posner & Vermorken, 2008).

*Depression.* HNC patients experience the highest rates of major depression of all oncology patients with an incidence of 15-50% (Lydiatt, Moran, & Burke, 2009). Because HNC can be associated with symptoms and side effect on vital functions such as eating, breathing, and speaking, patient can often experience depression

stemming from difficulty in performing those functions (Haisfield-Wolfe, McGuire, Soeken, Geiger-Brown, & De Forge, 2009). In addition, Haisfield-Wolfe et al. (2009) identified that patient's factors and characteristics were correlated with depression in patients with HNC. These factors included being male, being unmarried, being a past or current smoker, being younger than 40, having lower physical functioning, and having larger tumors at diagnosis.

*Alteration of body image.* Face plays an important role in an individual's sense of self and body integrity. Persons who suffer from facial disfigurement as a result of HNC and its treatment experience profound psychological trauma. For instance, amputation of the voice as the result of laryngectomy alters the way patients, their families, and others perceive their bodily changes of function (Kelly, 2003). Liu's study (2008) found that HNC patients after tumor excision and micro-reconstructive surgery were least satisfied with their face figure. Compared with pre-surgery condition, the satisfaction with current appearance was significantly lower.

*Social isolation.* A facial disfigurement, a marked line related to radiation, a skin change to be darken around the face and neck, and alopecia will cause HNC patients in post surgery and/ or receiving radiation or chemotherapy worry with social interaction (Posner & Vermorken, 2008; Rodriguez & Blischak, 2009; Yoshizaki et al., 2009). Moreover, body image concerns including odor, disfigurement, nasogastric tube, or tracheostomy tubes result in patients' difficulties with sexuality issues and going out in public (Smink & Gosselin-Acomb, 2004).

*Barriers to return to work.* The cancer and the side effects of its treatment have an impact on the employment and ability to return to work for HNC patients. Verdonck-de Leeuw, van Bleek, Leemans, de Bree, and Leenmans (2010) found that

the majority of employed HNC survivors returned to work within six month after treatment. Especially, oral dysfunction, loss of appetite, deteriorated social functioning, and high levels of anxiety were barriers for HNC survivors to return to work after treatment.

In addition, after completion of their treatments, QOL of HNC survivors was examined by many researchers. In general, QOL in patients with HNC declines immediately after therapy. This is followed by a slow improvement over time to baseline levels (Murphy, Ridner, Wells, & Dietrich, 2007). Chaukar et al. (2009) surveyed cross-section about the QOL of 212 HNC survivors one year after completion of treatment. The results showed that most survivors poorly included financial difficulties (54%), appetite loss (36%), and fatigue (33%). Survivors with early stage tumors and those treated with surgery alone had significantly better QOL score, when compared with advanced stage tumors and patients receiving either radiation alone or multimodality treatment, respectively. Weymuller et al. (2000) surveyed 210 HNC patients at baseline, 3, 6, 12, 24, and 36 months post-treatment. The majority of patients were treated with primary surgery. Overall QOL decreased 3 months post-treatment for all patients regardless of cancer stage or treatment type. QOL improved towards baseline by 12 month post-treatment. Goldstein, Karnell, Christensen, and Funk (2007) longitudinally collected health-related quality of life (HRQOL) in 479 HNC cancer patients followed for at least three year after diagnosis. The HRQOL for three survivorship groups including short-term (died less than one year), immediate-term (died one to three years), and long-term survivors (alive more than three years) were different at all time points (pretreatment, 3, 6 and 12 months). Differences were greatest between the short-term survivors and long term survivors.

Long-term survivors demonstrated the best HRQOL and an improving HRQOL trajectory at 12 months. The HROQL of short-term survivors declined precipitously throughout all available follow-up. Intermediate-term survivors did show some improvement following treatment but had a declining HRQOL trajectory at 12 months (Goldstein et al., 2007).

In conclusion, HNC is a complex cancer that can be treated with several methods including surgery, radiation, and chemotherapy. Therapy selection depends on site and stage of tumor, patient's status, and physician's expertise. The goals of therapy usually are to cure HNC in early stage, to improve survival for patients with HNC at the locally advanced stage and to provide palliative care for metastatic cases. Acute and long term HNC treatments' side effects cause patients with HNC to behave overwhelmed physically, emotionally and socially. In general, HNC patients undergoing treatments experiences a decrease in QOL after treatments and their QOL returns towards baseline overtime. Thus, this study selected only the HNC patients, who were receiving treatments because they have suffered with several symptoms related to illness and its treatments that require continuous care from health professionals. However, when the trend of short hospital stay is increased; most of HNC patients were treated in outpatient unit or admitted in the hospital for a limited period. Therefore, it is needed for family members to serve as a significant person who can provide direct care for their HNC patients throughout the course of its treatments.



### *Concept of Family Caregivers*

According to the role theory of George Herbert Mead, society is a group of individuals who live together and interact in accordance with their rights, duties, and role relationships. Thus, individuals need to learn their roles so as to appropriately perform such roles based on cultural, familial, and social expectation (Hardy & Conway, 1988).

In the Thai society, families often function within the culture of extended family constructs, even if they are outwardly nuclear families (Obe-om, 2005). Thai people tend to have close family relationships, respect for seniority, and help each other and this trend follows from one generation to the next generation. As a result, hierarchy is significant in the Thai society (Phengjard, 2001). The hierarchical structure defines set of duties and responsibilities and indicates appropriate behavior. Children are taught since in the early age to respect older people and people of higher status, for instance, parents, elders, and teachers (Choowattanapakorn, 1999). The husband tends to be the paramount authority figure; his decisions determine the family's actions and functions in political or the outside domain (Podhisita, 1998). The wife is in charge of the domestic domain and takes care of the children and family members (Podhisita).

The family of Thai people and Buddhism are inseparable. Buddha's teachings emphasize people's behaviors or duties toward people around him/ her to enhance a social harmony among the individuals living with others (Dhammavaro, 2005; Payutto, 1997). For example, a set of important values relating to the family is the values of filial piety, "*Bun-Khun*" (a favor which puts the receiver under an

obligation), "*Katanyu-Katawethi*" (gratitude and obligation to return a favor), and obedience and respect to elders.

When a family member is sick or unable to fully recover from illness, he/ she needed help. An important source of assistance is family. A family member who gives care to patient is known as family caregiver. In general, family caregivers refer to individuals that are patients' spouses, children, siblings, friends, or neighbors who provide care to the ill, disable, or dependent patients at home or community with unpaid (Northouse, 2005). The family caregivers are generally considered as informal caregivers (Sirapo-ngam, 1996). There are several reasons of family members to become caregivers which includes altruism (i.e., love, compassion, gratitude or virtue of relationship), responsibility, or no choice (i.e., having time and ability, no one assuming caregiving role) (Kopachon, 2002; Northouse).

According to the type of assistance and care, the family caregivers provided care to the patients as well as the amount of time they spent with the patients each day. Family caregivers are classified into two types: primary and secondary caregiver (Sirapo-ngam, 2000). Primary caregivers refer to individuals who are responsible for providing continuous and constantly direct care to the patients more than the others. Secondary caregivers refer to individuals who are responsible for providing direct care to patients occasionally, when primary caregivers are unable to perform their caregiving duties. In other words, secondary caregivers assist primary caregivers while caring for the patients.

A Study of Sirapo-ngam (2000) showed that most of Thai family caregivers were middle aged women, the relationships between family caregiver and care-receiver were adult child (90%), and 10% were spouses, parents, sibling and others.

Similar to HNC caregiving context, the majority of caregivers were female and were in middle age to elderly. The relationships between family caregivers and patients were spouses (50-70 %), and child, sibling or relatives (30-50%) (Chen et al., 2009; Ross et al., 2010; Tamtup, 2005).

In summary, the family caregivers are the family members who provide care for patients at home or community without receiving any reward in return of their care duties. Most common reasons of family members to become caregivers are altruism, responsibility and capability, or no choice.

#### *Preparedness of Caregiving*

As outpatient treatment for cancer patients have increased, family caregivers needs to assume more responsibilities for determining patient's needs, detecting and dealing with adverse symptoms, and providing physical and emotional support to the patients (Cristine, Crooks, Grunfeld, Stonebridge, & Cristie, 2003). Adequate preparation of caregiving role is viewed as a situational resource that could reduce caregiver role strain and will be vitally important for well-being of family caregivers and patients.

#### *Definition*

The literature revealed limited information on the preparedness for caregiving construct. In a study of elderly spousal caregiver of cancer patients, Rusinak and Murphy (1995) defined caregiving preparedness as the perception of "being well-prepared to tend to care recipient's physical and emotional needs as well as

preparedness to locate and initiate services, and to handle the stress of caregiving” (p.35). Caregiver preparedness, as defined by Archbold et al. (1990), refers to the caregiver’s perception of how ready he or she is to do need caregiving activities. The preparedness is based on gaining knowledge and skills of an anticipated role prior to experiencing the reality of life in that role. It is believed that by learning what will be needed in this new role first, the transition into it will be less problematic (Burr et al., 1979). Adequate preparedness is a state of readiness and a skill level and knowledge base congruent with the demands of the situation (Uten, 2006).

Archbold et al. (1990) suggested that preparedness can reduce the crisis nature and stress of assuming caregiving. A lack of preparedness in managing a patient’s day-to-day care may result in the caregiver experiencing undue stress and interfering with the ability to provide necessary care to the care-recipient.

#### *Preparedness of caregiving for HNC patients*

Due to the disease and the complexity of HNC treatments, the patients often require multidimensional needs. Thus, the family caregivers should learn caregiving role and adjust themselves to ensure that their patients will receive effective care (Blake & Lincoln, 2002; Blake, Lincoln, & Clarke, 2003). The preparations related to knowledge and skills of the HNC caregiving are included as follow.

*1. Providing physical care.* Physical care is a personal care that directly helps with daily activities and specific care for HNC patients to maintain their health and decrease their physical symptoms. The physical care for HNC patients included nutritional provision and physical symptom management (Kitrungrote et al., 2008). Nutritional provisions were related to the caregivers’ involvement in their patients’

food choice and diet preparation and encouragement for eating or providing enteral feeding. Providing water or liquid will keep the HNC patients' mouth moist over time to lessen their trouble in chewing and swallowing (Hayward & Shea, 2009). Moreover, the caregivers should deal with their HNC patients' physical symptoms by relieving oral mucositis and throat soreness (i.e., avoiding spicy and acid diets, caring oral hygiene, or relieving oral ulceration), managing weakness (i.e., nourishing nutrient food, giving time for rest) (Kurtin, 2009). Keeping the HNC patients' radiated-skin intact and reducing its irritation are important such as gentle skin washing with water alone, preventing friction of affected skin with clothing, and maintaining a moisture on skin (Mallick & Waldron, 2009). Reducing pain and preventing contraction of throat muscles of HNC patients are also continuously performed by family caregivers throughout the treatment phase (Harris, 2000; Kitrungrrote et al., 2008).

*2. Providing emotional support.* The HNC patients faced many challenges that leads to increased risk of psychological problems (Vickery et al., 2003; Weymuller, Deleylannis, & Yueh, 2003). Psychological support is important for example, providing encouragement and supporting emotions to inspire the patients to have inner strength and fight the severe disease (Juarez, 2003). The studies of Badr and Taylor (2006) and Kitrungrrote et al. (2008) showed that spousal caregivers of cancer patients perceived their role as those who are the providers of motivation, hope, and a positive attitude for their patients to act and fight the disease. They gave various methods to their patients such as inspiring their hope, being with, and fostering self worth.

3. *Finding out about and setting up service of patients.* Family caregivers have to interact with health professionals and fill out legal forms and other documents. They go to medical appointments with their patients to access input from the health professionals and deal with the medication regimen (Cristine et al., 2003). Moreover, the caregivers seek treatment options and serve as patient advocates when interacting with the health care system (Badr & Taylor, 2006).

4. *Managing the stress of caregiving.* Family caregivers were experienced emotional and psychological distress as they undertook new and demanding responsibilities associated with the caregiving role (Penner, 2009). A correlational study by Verdonck-de Leeuw et al. (2007) reported that 20% of spousal caregivers of HNC patients who received treatment demonstrated clinically significant level of emotional distress. Emotional distress in spousal caregivers was related to the presence of a tube feeding in patients, a passive coping style characterized by being worried, turning inward on oneself, not being capable of taking action to improve difficult situations, and a disruption in their daily schedule as a result of caregiving (Verdonck-deLeeuw et al.). Therefore, it is necessary for the family caregivers taking care of themselves by coping with the stress of caregiving and seeking psychological support from other people.

A qualitative study of Kitrungrrote et al. (2008) found that while spousal caregivers of HNC patients were encountering stressful situations, they readjusted themselves by rearranging a way of their life. For example, they managed stress (i.e., distraction, imagination, positive thinking, and releasing tension), reorganized their daily activities, and integrated Buddha's teachings into their life. Moreover, they hold onto hope for their ill love one's life and received various supports from several social

resources. Similarly, spousal caregivers of patients with cancer in western countries reported that they used positive attitude, avoidance, physical activities, and writing a diary to reduce their stress (Lethborg, Krissane, & Burns, 2003; Persson, Severinsson, & Hellström, 2004).

In addition, evidence suggests that family caregivers of patients with cancer require psychological support from health care professionals to cope with multiple ongoing stressors that accompany the demands of caregiving responsibilities. Receiving a good training (i.e., coaching, psycho-education, problem solving) would not only reduce the stress experienced by caregivers, but would also help to ensure that appropriate care is being provided safely (Given, Given, & Kozachik, 2001). Support groups also allow family caregivers to share information about resources and coping strategies, and may reduce feelings of isolation (Northouse, 2005).

*5. Making activities pleasant for both family caregivers and their patients.*

The patients feel decreased fear of being separated from their spouses when they have enjoyable intimate relationship and companionship with their spousal caregiver (Arskey, Hepworth, & Qureshi, 2000). Similarly, spousal caregivers of HNC patients reported that they feel pleased by serving their loved ones with love and intimacy including emotional and behavioral closeness to make them feel satisfied (Kitrungrote et al., 2008). For instance, they talked and made fun with each other. Both of them became closer to each other and sympathize with each other more greatly than ever before. In 2004, Hudson found that 60% of the 47 Australian spousal caregivers reported a positive caregiving experience during caring for a dying relative at home, such as giving a massage, seeing a spouse smile, and being able to laugh together.

6. *Responding to and handling emergencies.* Family caregivers need to know basic management in simply emergency conditions of HNC patients. For example, tracheostomy can be blocked acutely by bleeding from tracheostomal recurrence or severe crusting of secretions (Haddad et al., 2007; Harrison et al., 2009; Scarpa, 2009). If blockage occurs, the inner tube of tracheostomy should be removed, followed by suctioning through the outer tube. Re-suctioning can be related with instillation of normal saline into the tube if necessary. If obstruction still persisted, one can remove and clean or replace the outer tube (Haddad et al.; Harrison et al.). If the patients' conditions are not improved, family caregivers need to take the patients to hospital.

In addition, cancer patients are particularly vulnerable to sepsis and septic shock because their immune systems are badly weakened by chemotherapy (Harrison et al. 2009; Yoshizaki et al., 2009). Perhaps the most important way to reduce the chance for sepsis is to first prevent any infections (Regazzoni, Irrazabal, Luna, & Poderoso, 2004). Caregivers need to prevent infection by washing hand before dressing, preparing food, other hygiene care, and observing their patients' fever. Faster the patient with sepsis is diagnosed and treated, the better the prognosis and fewer complications (Martin, Mannino, Eaton, & Moss, 2003).

In the terminal phase of cancer, many patients showed the reduced oral intake due to causes related to their cancer or its treatments. This symptom has the potential to seriously compromise the patients' nutritional status by leading to decreased oral intake, involuntary weight loss (Hayward & Shea, 2009), and dehydration (Dalal & Bruera, 2004). If patients who undergoing radiation therapy had severe weight loss, they were more likely to have visited the emergency department



during their treatment for dehydration (Beaver, Matheny, Roberts, & Myers, 2001). The caregivers should encourage patients to have adequate nutritional and water during treatment to avoid dehydration.

*7. Getting the help and information from health care system.* As cancer care increasingly shifts from inpatient settings to outpatient settings, patients often receive complex treatments at home and community. Therefore, family caregivers had become more involved in taking care of cancer patients, both physically and emotionally. They may play a significant role in decision-making and facilitate informed choice for the patients' benefit, thereby, their information needs must be necessary. A previous study of Richardson and Birchall (2002) found that the spousal caregivers of patients with HNC needed information sheets and provision of information on local support groups and on telephone help lines to enable them to cope with stressful situations.

Health professionals are the primary resource persons for caregivers. In 2008, Kitrungrrote et al. reported that all spousal caregivers received informational support from health care professional. The radiation oncologists and oncology nurses educated them about the disease and its proposed treatment and gave them a leaflet about patient's care practice. In addition, health care volunteers regularly visited the patients in the temporary patient's residence. They gave the caregivers more informational care. Although all caregivers perceived the numerous support from health professionals, some of them needed other support from health professionals for examples specific symptom managements.

Adams, Bouton, and Watson (2009) conducted a systematic review related to information needs of partner and family members of cancer patients from

32 papers published between 1998 and 2008. The information needs of family caregivers included treatment, diagnosis/prognosis, coping, self care/ home care, cancer, impact on the family, support information, impact on relationship with partner, practical issue, hospital care, and follow-up/ rehabilitation. However, the most frequently unmet needs were diagnosis/ prognosis, the impact on the family, the impact on the relationship with the partner, practical issues, coping, and treatment. Similarly, the study of Persson et al. (2004) showed that spousal caregivers of cancer patients had or no informational support from health professional, and the health professional had not invited them to participated or involve in information session of patient's care. Thus, the findings of studies related to information support from health professionals to cancer caregivers were inclusive.

#### *Empirical findings of preparedness of caregiving*

Preparedness for caregiving has received the least attention in research of cancer caregivers, despite the clinical imperative of preparing family caregiver for their role (Houts, Nezu, Nezu, & Bucher, 1996). Previous studies have shown that the family caregivers of patients with cancers perceived different levels of caregiving preparedness. Schumacher et al. (2008) studied in 87 family caregivers of adults with solid tumors or lymphoma who were being treated with chemotherapy, radiation, or surgery. The caregivers ranged in age from 23-82 years were female (78%), and spouses of the patients (77%). Approximately half (49%) were employed at the time of the study, 28 % full-time. The finding showed that the caregivers had high level of preparedness. Fifty-two family caregivers of ABMT patients were recruited from Pacific Northwest (Eldredge et al., 2006). Of these, 22 (67%) stopped working during

the transplant and recovery, Twenty-five percent were responsible for rearing on a daily basis. Fifty-six percent temporarily relocated to be near the transplant center. At the time of hospital discharge, the caregivers reported that they felt moderately well prepared about discharge planning (Eldredge et al.). Scherbring (2002) conducted longitudinal study with 59 lay caregivers of patients with various cancers. Most of caregivers were spouses (86%), then children (9%), and others (5%). The duration of the caregiving relationship, as reported by caregivers most frequently was less than six months (44%), more than three years (25%), 6-12 months (17%), and 1-3 years (14%). This study found that overall, the preparedness of caregiving's score ranked on the scale between "somewhat well prepared" to "pretty well prepared". Its scores were consistent over time period including before or at discharge, 7-10 day after discharge, and one month after discharge. Rušinak and Murphy (1995) examined 30 elderly caregivers for their spouses, who had been recently diagnosed with cancer, the caregivers reported a moderate level of perceived preparedness to care. However, 691 Swedish men who lost a wife to breast, ovarian, or colon cancer reported that they had low preparedness at the time of the wife death (Hauksdóttir, Steineck, Fürst, & Valdimarsdóttir, 2010). Adam (2000) interviewed caregivers about how well hospital staff prepared them to take care of a relative with illness at home, the result showed that they needed more preparation and knowledge to care for family members who are ill at home.

#### *Factors related to preparedness of caregiving*

Several factors have influence on the preparedness of caregiving including characteristics of patients and caregivers and the relationships between caregivers and

patients. Kopachon (2002) reported that the middle-aged caregivers had the high preparedness and responsibility in life. They had enough experiences to solve their problems, which were needed to face the stressful situations in each day with their patients. Female caregivers tended to learn all caregiving tasks quickly because they usually had experiences of being carer as they are responsible for taking care of the family members and house chores so they tended to learn rapidly all tasks such as physical hygiene, cooking and feeding (Mui, 1995; Walker, 1995). Family caregiving role generally comes from love and a sense of care repayment which are an altruistic motivation tended to induce caregivers to seek out information and learn new caregiving role that is beneficial for the patients (Kitrungle et al., 2008; Kopachon). In addition, receiving caregiving assistance and having caregiving experiences (i.e., knowledge, skills, coping strategies) effected on caregivers that they had high preparedness (Scherbring, 2002). However, the anxiety related to symptoms and mood of caregiving (i.e., fatigue, vigor, confusion and total mood disturbances) were negatively related to preparedness of caregiving (Hauksdóttir et al., 2010; Schumacher et al., 2008). Cancer patients who had more complex needs for emotional support and uncertainty about a future may lead the caregivers felt low preparedness (Eldredge et al., 2006; Scherbring).

#### *The measure of preparedness of caregiving*

The conceptualizations of caregiving preparedness were operationalized in a different manners, the measure of this concept was varied. Hauksdóttir et al. (2010) measured the carers' preparedness with a direct one question: "How prepared were you for your wife's death?". Its answer was given on a 7-point digital-visual scale

(DVS) anchored by “not at all prepared” to “very well prepared”. The reliability of this measurement was not reported. Eldredge et al. (2006) developed the Preparedness for Caregiving Tool to measure specific activities of caregivers of patients with cancer at hospital discharge. This tool contained 22 items that were content validated by experts. Its internal consistency estimate was .94.

Rusinak and Murphy (1995) used the Preparedness Measure of Archbold and Stewart (1986) to evaluate the preparedness of caregiving. It is composed of items related to the care recipient’s physical and emotional needs, preparedness to locate and initiate the services, and to handle the stress of caregiving. Its internal consistency reliability was reported as a Cronbach’s alpha of .72. Scherbring (2002) and Schumacher et al. (2008) used the Preparedness Scale developed by Archbold et al. (1990). It consists of eight items that ask caregivers to evaluate how well prepared they think for multiple domains of caregiving. This tool was tested for both construct validity and reliability in a longitudinal study of 78 older caregiving dyads. Support for construct validity was obtained by testing the hypothesized relationship between preparedness and caregiver role strain. As predicted, higher scores on preparedness were associated with the lower strain from direct care, increased tension, feelings of being manipulated, mismatched expectations and global strain. Preparedness was not associated with strain from economic burden and role conflict. Cronbach’s alpha for the Preparedness Scale was .72, and the stability was found over an 8-month period and it was evident by a correlation coefficient of .57 (Archbold et al., 1990). In other studies, this tool was continually used with family caregivers of various patient groups such as cerebrovascular disease (Ostwald et al., 2009), Parkinson’s disease

(Lyons et al., 2009), and coronary bypass graft (Kneeshaw et al., 1999). Those studies have shown that the values of Cronbach's alpha were in the range of .91-.96.

In Thailand, the Preparedness Scale (Archbold et al., 1990) was translated into the Thai language by Wirojratana (2002) and back translated by bilingual translators. It was used in family caregivers of patients with cerebrovascular disease (Kopachon, 2002; Saengratsamee, 2004; Sritares, 2003), dementia (Somboon, 2005), and post traumatic brain injury (TBI) (Samartkit, 2008) with Cronbach's alphas of .84 - .98. In this study, the preparedness in caregiving was measured by using the Preparedness Assessment Form of Archbold et al. because its psychometric properties were well-accepted values and its relevance can be used with Thai family caregivers as indicated by the above research evidence.

### *Mutuality*

Many researchers have found that mutuality or the quality of the relationship between the family caregivers and their care-receivers is an important aspect of family caregiving (Archbold et al., 1990; England & Evan, 1992; Henson, 1997). They believed that high mutuality allows the family caregivers to persist in difficult circumstances.

### *Definition*

The mutuality derived from the notion of "mutual empathy", which indicated the ability to experience the feelings and thoughts of another person, while still maintaining a sense of one's own different feelings and thoughts (Miller as cited in

Sanftner et al., 2006). Mutuality can be defined as a connection with or understanding of another that facilitates a dynamic process of joint exchange between people. The process of being mutual characterized by a sense of unfolding action that is shared in common, a sense of moving toward common goal, and a sense of satisfaction for all involved (Henson, 1997). Curley (1997) described mutuality as a synchronous, co-constituting relationship that stimulates the process of personal becoming. Similarly, Tanji et al. (2008) defined mutuality as the quality of interaction or reciprocity of sentiment in a relationship.

Mutuality occurs when each person is receptive and responsive to the other, and there is the possibility of fluidity and change in such a way that each person is influenced by the other (Miller as cited in Sanftner et al., 2006). The consequences of mutuality will be increased sense of control over one's situation, self-confidence, empowerment, self-direction, and pleasure in clients and health care relationships. Mutuality has been found to be closely linked to intimacy, emotional residency, self-disclosure and satisfaction and cohesion (Sormanti & Kayser, 2004). Then, it will result in a decreased threat of lawsuits and work stress (Archbold et al, 1990; England & Evan, 1992; Henson, 1997).

In caregiving context, Archbold et al. (1995) defined mutuality of caregiving is the positive quality of relationship between the caregiver and care-receiver based on reciprocity, love, shared pleasurable activities, and shared values. Hirschfeld (as cited in Archbold et al., 1990) defined mutuality in caregivers, who provide help to persons as "the caregiver's ability to find gratification in the relationship with the impaired person and meaning in the caregiving situation" (p.5). The important components of mutuality included (a) "the caregiver's ability to find gratification in the relationship

with the impaired person and meaning from the caregiving situation” and (b) “the caregiver’s ability to perceive the impaired person as reciprocating by virtue of his/her existence”. High level of mutuality enables caregivers to continue caregiving despite in objectively difficult situations (Hirschfeld as cited in Archbold et al.).

#### *Empirical findings of mutuality of family caregivers*

The mutuality of the caregiver and care-receiver was examined in few studies of family caregivers of patients with cancer (Schumacher et al., 2008). At the time of discharge from hospital, family caregivers of ABMT patients had high mutuality level (Eldredge et al., 2006). Schumacher et al. (2008) also found the high level of mutuality in the 87 caregivers of adults who were being treated for solid tumors or lymphoma, 77% of them were spouses. Regarding gaining a close marital relationship, the spousal caregivers reported that they and their cancer patients became closer and learned to comprehend and sympathize with each other more greatly than ever before. Their marital relationship with their ill spouses was strengthened (Hilton, Crawford, & Tarko, 2000; Kitrungrrote et al., 2008).

#### *Factors related to the mutuality of family caregivers*

Mutuality will happen when both the participants must first respect the worth and dignity of the other person and truly want to seek understanding of, and in, the other. The individuals must care enough about the situation and enter into meaningful dialogue to understand the other’s potential. Empathy, on both sides of the relationship, is a prerequisite for the mutual understanding that must occur within the relationship (Olsen as cited in Curley, 1997).



Previous researchers examined the factors related to mutuality. Schumacher et al. (2008) reported that higher mutuality is found in being female caregiver and being a spouse rather than a non-spouse. Physical health and depression of caregivers and patients were both significantly associated with mutuality (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007). This finding is supported by Pearlin, Mullan, Semple, and Skaff's work (1990) which reported that the reciprocity in relationship can be greatly reduced, especially in the case of dementia. Family relationships can become complicated by patient's illness experience and thus can altered the way the older adult and family caregiver share the information and communicate regarding well-being and the care situation (Druley, Stephens, Martire, & Ennis, 2003). Similarly, Sritares' study (2003) showed that the wife caregivers felt lost good relationship after their husbands had cerebrovascular disease because their patients had limitations in expressing behaviors and emotions, and they may have unusual speaking.

#### *The measure of mutuality of family caregivers*

The mutuality was measured by several approaches. Mui (1995) used a single item question for asking the caregiver to rate the quality of his or her current relationship with the patient. This question was used for assessing the quality of the relationship between the parent and child. It was rated on a 3-point scale ranging from 1 = very well, to 3 = not too well. The reliability of this tool was not presented.

Another tool commonly used to assess mutuality is the Mutuality Assessment Form that was developed by Stewart and Archbold (1990). This form had four dimensions that measured the positive aspects of relationship quality: reciprocity, love, shared pleasurable activities and shared values. Evidence of both construct

validity and reliability was obtained in a longitudinal study of 78 older caregiving dyads. Support for construct validity was obtained by testing the hypothesized relationships between mutuality and caregiver role strain. As predicted, higher scores on mutuality were associated with lower strain from direct care, increased tension, feelings of being manipulated, mismatched expectations, role conflict and global strain. However, mutuality was not associated with strain from worry, lack of resources or economic burden. Cronbach's alpha for the mutuality scale was .91, and the stability over an eight months was evidenced by a correlation of .79 (Archbold et al., 1990). The Mutuality Assessment Form was continually used with family caregivers of people with different illnesses such as cancer (Schumacher et al., 2008), cerebrovascular disease (Ostwald et al., 2009), parkinson's disease (Lyons et al., 2009), and coronary bypass graft (Kneeshaw et al., 1999). Their Cronbach's alpha values were in range of .91-.96.

In Thailand, the Mutuality Assessment Form of Archbold et al. (1990) was translated in to the Thai language by Wirojratana (2002) and back translated by bilingual translators. It was used in family caregivers of patients with cerebrovascular disease (Saengratsamee, 2004; Songwattanayut, 2002; Sritares, 2003) and post TBI (Samartkit, 2008). These Cronbach's alphas were ranged from .85 -.89. In this study, the mutuality was measured by using the Mutuality Assessment Form of Archbold et al.

### *The Caregiver Role Strain*

Role theory assumes that people fulfill roles based upon cultural, familial, and social expectations. These expectations may be conscious or unconscious; however,

these expectations influence the person's feelings about their performance and their ability. In this way, the expectations that are embedded within the family role can influence the degree of stress that the individual may feel (Hardy & Conway, 1988).

### *Definition*

Goode (1960) defined role strain as the difficulty one experience in fulfilling one's perceived role obligation. Ward (1986) stated that role strain is an undesirable state perceived by the individual within a role arising from the stress associated with the role.

Sources of role strain are composed of role conflict (individuals face conflicting role obligations), role accumulation (individuals take part in many different obligations), role demands (the rigidities of time and spaces), role ambiguity (individuals faces lack of clarity associated with their certain role), and role overload (individuals are understood as being unable to meet the totality of role responsibilities) (Komarovsky as cited in Beitman et al., 2004). Biddle and Thomas (as cited in Ward, 1986) have summarized the sources of role strain as "pressure may derive from conflicts demands and norms, opposing evaluations of the actor by others, differences between the actor's conceptions of himself and the statements about him by others, interdependencies excessive in hindrance or cost, a problematic complement of positions, a discontinuous transition between positions-and many others" (p. 40).

Consequences of role strain were addressed by Ward (1986). These includes restriction of roles, resigning from the role, decreasing the level of involvement and keeping the role distance, concealing stressors to social prestige, converting with the

stressors; coping with stressors, negotiating the meaning of the problems, and role bargaining.

In the role of caregiver, Archbold et al. (1990) and Yang and Kirschling (1992) defined caregiver role strain as caregivers' perceived difficulty in fulfilling the caregiving role. Archbold and Stewart (1990) divides caregivers' role strain into four categories as follows:

1. *Role conflict*. Role conflict refers to the caregivers' perception of difficulty in performing the role caregivers as it may clash with other roles they have always performed.

2. *Role mismatched expectation*. Role mismatched expectation refers to the caregivers' perception of the difficulty in performing the caregiving duty as it clashes with the expectations of the patients, other people such as families and friends, or the caregivers themselves.

3. *Increased tension*. Increased tension refers to the caregivers' perception of the difficulty in performing the caregiving duty because of the tension, stress, and anxiety that have arisen during providing care to the patients. They may feel that they are not able to continue the role of caregivers.

4. *Global strain*. Global strain refers to the caregivers' perception of the overall difficulty in providing care to patients. Global strain includes the following, losing personal freedom, sad feeling, depression in taking the caring role etc. It can cause some strain and the effect strain may lead to a reduction of quality of care, as caregivers feel stressful, become impatient, and lose their confidence in caring for the patients. Especially, when the caregiver does not see an increase in the patient's health, this can affect in the caregiver's confidence.

### *Empirical findings of caregiver role strain*

Previous studies have examined the role strain of family caregivers of patients with cancer, and their findings were varied. A qualitative study of Kitrungrote et al. (2008) reported that during taking care HNC patients, who were receiving radiation, 15 spousal caregivers felt strain resulting from physical health deterioration, emotional distress over their ill spouses' behaviors, restrictions of family and social life, and family's financial hardship. Among 30 family caregivers who cared for patients with chronic pain, 28 of them had role strain and other 2 had risk of role strain (da Cruz, Pimenta, Kurita, & de Oliveira, 2004). Moreover, a risk of role strain was found in female caregivers, spousal caregivers, or caregivers who had complex roles; no experience of caring; or had health problems (da Cruz et al., 2004). Schumacher et al., (2008) found that 87 family caregivers of adults who were received treatment for solid tumors or lymphoma had moderate level of role strain. A great amount strain was found in 75 spouses of patients with laryngectomy during the first year of patients' diagnosis. In particular, wife caregivers experienced more strain than did the husband caregivers. After the initial difficulty, these caregivers showed a steady decrease in strain during the first year after diagnosis (Blood, Simpson, Dineen, Kauffman, & Raimondi, 1994). A longitudinal study showed that family caregivers of ABMT patients had low level of overall role strain, and the role strain declined steadily from 2 to 12 weeks of patients' recovery (Eldredge et al., 2006).

### *Factors related to caregiver role strain*

Eldredge et al. (2006) reviewed and summarized the factors related to role strain in family caregivers including demographic factors, patients' illness

characteristic, and caregiving relationship characteristics. Demographic factors of higher caregiver role strain such as younger age of the caregiver, inexperience with caregiving, being a female caregiver, being a spouse (Blood et al., 1994; Schumacher et al., 2008), depression (Williams, Dilworth, Goodwin, 2003), low economic status and lack of resource (da Cruz, et al., 2004; Kopachon, 2002; Séoud et al., 2007; Songwattanyut, 2002). However, role strain was negatively associated with preparedness of caregiving, predictability, and self-transcendence (Kopachon, 2002; Matayamool, 2003; Saengratsamee, 2004). Patients' illness characteristics which are related to caregiver role strain include caregivers of person with new disease, recurrence, or metastatic cancer. The strain in family caregivers is higher when their patients had low level of physical functioning or high demands of caregiving (Eldredge et al, 2006). Several researchers believed that high mutuality or good relationship between caregivers and patients allows the caregivers to persist in difficult care circumstances (Archbold et al., 1990; Songwattanyut, 2002). On the other hand, research suggested that low mutuality may be the real risk factor for high role strain, especially as amount of care increase (Schumacher et al., 2007).

#### *The measure of caregiver role strain*

Several approaches were used to measure the concept of caregiver role strain. da Cruz et al. (2004) developed a 10-item questionnaire based on indicators of caregiver role strain and risk for caregiver role strain related to Carpenito and NANDA tool to measure the role strain of caregivers of patients who had chronic pain. Five nurses experienced in dealing with patients with chronic pain judged the face validity of the questionnaire and made suggestions to improve it. The

questionnaire was tested on four nonparticipant caregivers, resulting in a few small changes to improve some items (da Cruz et al.).

In cancer caregiving context, several tools were used to measure the caregiver role strain. The caregiver role strain in the study of Eldredge et al. (2006) was measured in tandem with Caregiving Activities Scale (82 caregiving activities) by asking the caregivers of ABMT patients to indicate how difficult it was to complete different caregiving activities (1 = easy to 4 = very hard). The reliability of this tool was not computed.

Blood et al. (1994) measured the cancer caregivers' strain by using 13 items of Caregiver Strain Index (CSI) of Robinson (1983). Construct validity of this tool was supported by correlations with the physical and emotional health of the caregiver and the subjective views of the caregiving situation. Its internal consistency for the CSI was established at .86. Although the CSI is brief, easily administered instrument, this tool is limited by lack of a corresponding subjective rating of caregiving impact.

In 1990, Archbold et al. developed the Caregiver Role Strain Assessment Form from qualitative research of caregivers of elderly people with chronic illness to measure caregiver role strain. It consists of four parts: (1) A Role Conflict Assessment Form, (2) A Mismatched Expectation Assessment Form, (3) An Increased Tension Assessment Form, and (4) A Global Strain Assessment Form. This form was continually improved and used as a standard instrument at the present time. It was used with family caregivers of peoples suffering from different illnesses, for example, neurological problems (Seoud et al., 2007), elderly (William et al., 2003). Their Cronbach's alphas were in range of .67-.96. Recently, Schumacher et al. (2008) applied a three-item version of the Global Strain Scale (Archbold et al. 1990) to

measure caregiver strain of cancer caregivers. The Global Strain Scale asked about the overall sense of confinement, difficulty, and stress experienced during caregiving. This scale represented caregivers' perceptions of the situation as a whole, as differed from their perceptions of individual caregiving tasks. A five-point response format is used, ranging from 0 (none) to 4 (a great deal). Cronbach's Alpha of this tool was .75.

In Thailand, the Caregiver Role Strain Assessment Form of Archbold et al. (1990) was translated in to the Thai language by Wirojratana (2002) and used the same process as mentioned earlier. It was used in caregivers of patients with cerebrovascular disease (Kopachon, 2002; Prawtaku, 2006; Saengratsamee, 2004; Songwattanayut, 2002; Sritares, 2003) and post TBI (Samartkit, 2008) demonstrating the Cronbach's alphas of .70 -.92. In this study, the caregiver role strain was measured by using the Caregiver Role Strain Assessment Form of Archbold et al.

*The Relationships of Preparedness of Caregiving and Mutuality to Role Strain of Thai Family Caregivers of Patients with HNC Receiving Treatments*

The relationships of preparedness of caregiving and mutuality to role strain of family caregivers were investigated and their results were inconsistent. Archbold et al. (1990) initially studied in 78 dyads of elderly, some of patients had cancer. The findings demonstrated that mutuality was negative related to caregiver role strain, and preparedness were inversely related to some aspects of caregiver role strain, most notably strain from direct care mismatched expectation, and increased tension. Subsequent studies have mutuality and preparedness in other clinical populations which includes family caregivers of individual with chronic illness. Their results were



controversial. In cancer caregiving context, Schumacher et al. (2008) reported that the preparedness and mutuality were low negatively related to role strain in cancer caregivers ( $r = -.25, p < .05$ ;  $r = -.36, p < .05$ ). However, preparedness and mutuality were not correlated with the role strain of family caregivers of ABMT patients ( $r = -.14, p > .05$ ;  $r = -.18, p > .05$ ), respectively because they felt more prepared to meet patients' physical needs soon after discharge; and at the same time, caregivers faced more trouble when their patients were emotional distressed (Eldredge et al., 2006). For Thai family caregivers of patients with cerebrovascular disease, some studies found that preparedness was negatively related to caregiver role strain ( $r = -.36, p < .001$ ) (Kopachon, 2002); ( $r = -.30, p < .01$ ) (Saengratsamee, 2004) whereas Sritares's study (2003) showed not correlated ( $r = -.10, p > .05$ ). Mutuality was correlated negatively to caregiver role strain ( $r = -.32, p < .05$ ) (Songwattanyut, 2002); ( $r = -.18, p < .05$ ) (Sritares). However, mutuality was not found to be related in the finding of Saengratsamee's study ( $r = -.07, p > .05$ ) because the caregivers were daughter of patients and the relationship with the patients had been good before they became a caregiver. It may also be due to the homogeneity of caregivers' characteristics leading no variation of perception on mutuality.

### *Conclusion*

Head and neck cancer (HNC) is a complex group of cancer that includes cancer of the lip, oral cavity, salivary glands, paranasal sinuses, nasal cavity, oropharynx, nasopharynx, hypopharynx, larynx, ears and thyroid. HNC is treated by surgery, radiation, chemotherapy or combinations based on the stage of the disease,

patients' conditions and physician's expertise. The goals of therapy are to cure, keep survival or control symptoms. Although these treatments have several advantages, there are disadvantages concerning the physical and psychosocial health of HNC patients in acute phase and in a long run. These patients also required supportive care from health care professionals. However, the trend of shortening hospital stay is high, family members have to engage in caring for HNC patients at home. To provide the physical and emotional support to their patients effectively, the family caregivers need to be well prepared for their caregiving role. The preparations of HNC caregiving knowledge and skills includes providing physical care and emotional support, responding and handling emergencies, setting up in-home support services, dealing with the stress of caregiving, making activities pleasant for both family caregiver and their patients, and getting helps from the health care system. In addition, the good relationships between family caregivers and HNC patients are important to help them to provide continuous care and protect them from role strain.

Based on the literature review, the findings of previous caregiving studies from western countries may not be readily relate to the role strain of Thai family caregivers of patients with HNC. The differences of family structure, social expectation, and cultural value between western countries and Thailand may contribute to family caregivers' perception regarding their role behaviors. In addition, the studies were conducted with various types of family caregivers who take care of cancer patients at different phases of treatments including pre-treatment, during treatments, and post-treatments. The patients' physical functions which varied at different phases of treatments may have influence on the time of caregiving task and caregiver role strain.

To date, the number of Thai HNC patients is increasing and ranked the tenth leading cancer sites in Songklanagarind Hospital (Songklanagarind Cancer Center, 2008, 2009). Most of them were treated at outpatients and needed supportive care from their family members. The existing studies on Thai HNC caregivers of HNC patients receiving treatments had conducted limited methods of inquiry. Although the previous qualitative research examined the experiences of Thai spousal caregivers of HNC patients undergoing radiation therapy and the data reflected only the perspective of specific group of caregivers that may perceive differently from that of multiple groups. Since the family caregivers are essential members of the health care team for helping their HNC patients' adaptation to the HNC and its treatments. Thus, there was a need for health professionals to examine the preparedness of caregiving, mutuality, and role strain of Thai family caregivers of HNC patients during receiving treatments. Such knowledge can be helpful for health professional in preparing of caregiving skill, promoting mutuality, and reducing caregiving role strain.

## CHAPTER 3

### RESEARCH METHODOLOGY

A descriptive correlational study was employed to investigate the relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of patients with HNC receiving treatments. The setting, population and sample, instrumentation, ethical consideration, data collection methods, and data analysis are presented as follows.

#### *Setting*

This study was conducted at a well-established university hospital in southern Thailand. It is a tertiary care center with 836 beds for serving general and cancer patients, who live in Songkhla province and nearby provinces. From statistical report (Songklanagarind Cancer Center, 2008, 2009), it was revealed that in the year 2008 to 2009, a number of new HNC patients increased from 984 to 1,017. They were treated with surgery, radiation, chemotherapy, or a combination of these treatments.

This hospital has one radiation department that provides services to the cancer populations as outpatient and inpatient service from Monday to Friday at 9 a.m. to 4 p.m. The general radiation fractionation for treatment in HNC is 1.8-2 Gy/ fraction, up to total dose of 70 Gy, five days a week over six to seven weeks.

The Ear-Nose-Throat (ENT) ward is served for HNC patients who are treated by chemotherapy and/or surgery. Chemotherapy regimen consists of 5-fluorouracil and Cisplatin which are administered every three to four weeks over six cycles (Ang

& Garden, 2006; Haddad et al., 2008). The HNC patients are admitted for few days during receiving chemotherapy. During hospitalization, the family caregivers are allowed to stay with their patients during daytime.

### *Population and Sample*

The target population in this study was family caregivers (primary caregivers) of patients with HNC receiving treatments in Songklanagarind Hospital.

### *Sample and sample size*

In this study, the estimated sample size was determined by using power analysis. The effect size could be estimated based on previous related studies, which had the same or similar problem (Polit & Beck, 2004). The previous study that examined the relationship between preparedness of caregiving and role strain, and mutuality and role strain of 87 family caregivers of American cancer patients revealed the correlation coefficient  $r$  of -.25, and -.36,  $p < .05$ , respectively (Schumacher et al., 2008). Using an average effect size of this study ( $r = .30$ ), a power of the test ( $1-\beta$ ) = .80, and a significant level ( $\alpha$ ) = .05, 88 subjects were needed (Polit & Beck: p. 500). However, during the study period only 80 subjects were enrolled. This number was considered adequate based on a post-hoc power analysis with an average effect side of .33, and  $\alpha = .05$ , and  $n = 80$ , a power was calculated yielding a value of .80.

### *Sampling*

Subjects in this study were recruited using convenience sampling. The inclusion criteria for family caregivers were as follow:

1. Age over 18 years,
2. Be identified by the HNC patient, who was receiving cancer treatments that he/she (i.e., spouse, adult child, parent, friend, or neighbor) has primarily provided care for the patient for a long time at least four weeks , and
3. Be able to speak Thai language

### *Instrumentation*

The instruments used in this study were divided into four parts as follows:

*1. Demographic Data Collection Form.* The demographic data collection form composed of two parts; (1) The Family Caregivers' Demographic Questionnaire and (2) The HNC patients' Demographic Data Form

*1.1 The Family Caregivers' Demographic Questionnaire.* The Caregivers' Demographic Questionnaire included general information (age, gender, marital status, religion, level of education, occupation, average family income, sufficiency income, medical expense), caregiving information (relation with their patient, reason to become caregiver, duration of caring, time spent per day for taking care HNC patients, experience of caregiving, caregiver assistant of caring for HNC patients, and taking care for other persons), and personal health data (history and present of illness, common medicine use, frequency of medicine use), information about caregiving, and training caregiving skills. This questionnaire was completed by the family caregivers (Appendix A).

*1.2 The HNC Patients' Demographic Data Form.* The HNC Patients' Demographic Data Form included general information (age, gender, marital status,

religion, level of education, and occupation) and personal health data (medical diagnosis, stage, level of the patient's dependency, treatments, and symptoms) (Appendix B). The patients' data were collected by interviewing their caregiver and their health data were obtained from the medical record.

2. *The Preparedness of Caregiving Assessment Form.* The Preparedness for Caregiving Assessment Form, Thai version (Sritares, 2003) was used to measure the preparedness of caregiving in this study. It had eight positive items including providing physical care, giving emotional care, finding out services, managing stress of caregiving, performing pleasant activities, dealing with emergency situation, seeking support and health, and overall well prepared. Each item was rated on a five-point response format ranging from 0 (not at all), 1 (not too well), 2 (somewhat well), 3 (pretty well), to 4 (very well). Each item score was summed and averaged to provide a total, composite score. The higher score means the higher level of preparedness for caregiving (Appendix C).

The total scores were interpreted as follows:

0.01 - 1.33	= Low
1.34 - 2.66	= Moderate
2.67- 4.00	= High

3. *The Mutuality Assessment Form.* The Mutuality Assessment Form, Thai version (Sritares, 2003) was used to assess the mutuality in this study. The interactive nature of mutuality was reflected in four dimensions; reciprocity, love, shared pleasurable activities, and shared values. This tool had 15 items, each item was rated on a five-point response format ranging from 0 (not at all), 1 (a little), 2 (some), 3 (quite a bit), to 4 (a great deal). Each item score was summed and averaged to provide

a total, composite score. The higher score means the higher level of mutuality (Appendix D).

The total scores were interpreted as follows:

0.01 - 1.33	= Low
1.34 - 2.66	= Moderate
2.67 - 4.00	= High

4. *The Caregiver Role Strain Assessment Form.* The Caregiver Role Strain Assessment Form, Thai version (Sritares, 2003) was used to measure caregiver role strain. It is composed of four parts (Appendix E):

4.1 *A Role Conflict Assessment Form.* A Role Conflict Assessment Form consisting of 14 negative items which were asked to family caregivers about what were the barriers were to be responsible for their other roles. If they did not have that role, it was rated "not apply". If they had that role, it was rated from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), to 4 (very much). The higher scores mean that caregiver has high role conflict.

4.2 *A Mismatched Expectation Assessment Form.* A Mismatched Expectation Assessment Form consisting of seven negative items which were asked to family caregivers about the expectations of the patients, other people such as families and friends, or the caregivers themselves. Each item had multiple choices (YES/NO/NOT SURE). If the caregivers choose "NOT SURE", that item was rated missing value. If the caregivers choose "NO", that item was rated 0. If the caregivers selected "YES", it was rated from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (a quite bit), to 4 (very much). The higher scores mean that caregiver has high mismatched expectation.



*4.3 An Increased Tension Assessment Form.* An Increased Tension Assessment Form consists of 14 negative items which were asked to family caregivers about how giving care to a patient has affected their daily lives. Each item was rated from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), to 4 (very much). The higher scores mean that caregiver has high increased tension.

*4.4 A Global Strain Assessment Form.* A Global Strain Assessment Form consisting of seven items which were asked to family caregivers about their level of confidence in caregiving and different experiences while giving care to the patient. Six items were rated for negative experiences. Each of them was rated from 0 (not at all), 1 (a little), 2 (somewhat), 3 (a quite bit), to 4 (very much). Except, one item (7th) was positive. The higher scores mean that caregiver has high global strain.

A composite score of role conflict, mismatched expectation, increased tension, and global strain was computed by combining altogether each subscale score and then averaging it with the total items that were applying to each subject only. This composite score represent the level of caregiver role strain that were interpreted as follows:

0.01 - 1.33	= Low
1.34 - 2.66	= Moderate
2.67- 4.00	= High

#### *Validity and Reliability*

The validity and reliability of the Preparedness of Caregiving Assessment Form, the Mutuality Assessment Form, and the Caregiver Role Strain Assessment

Form were evaluated by 20 family caregivers of HNC patients who had the same criteria with the actual sample. The face validity was tested by those caregivers who read through the questions, and decided whether each tool/ item was easy to understand or not. The caregivers reported that these tools were appropriate and clear. Then, the researcher used the tools for interview the actual sample.

The reliability of the Preparedness Assessment Form, the Mutuality Assessment Form, and the Role Conflict Assessment Form, the Increased Tension Assessment Form, and the Global Strain Assessment Form were examined for internal consistency which yields Cronbach's Alpha coefficients of .80, .84, .74, .77, and .82, respectively. The Mismatched Expectation Assessment Form was examined by using test-retest reliability (Pearson correlation coefficient) yielding a value of .79.

### *Ethical Considerations*

This study was approved by the Institutional Review Board (IRB) of Faculty of Nursing, Prince of Songkla University, Thailand, and also was granted permission by the target hospital. The objectives and procedures of the study were explained to each subject. The human rights of the subjects were given due respected. The subjects were assured for anonymity and confidentiality. Potential subjects were informed about the purposes of the study and how they would be involved. They were also informed that they had the right to stop or withdraw from the study based on their own reason without fear of any negative consequence to the care provided to the patients. The written informed consent form was obtained from each subject (Appendix F).

### *Data Collection*

The researcher collected data the following these steps:

1. Obtained the ethics approval from the Research Ethics Committee of the Faculty of Nursing, Prince of Songkla University and Faculty of Medicine.
2. Obtained the permission for data collection from the Director of Songklanagarind hospital to recruit family caregivers of HNC patients receiving treatments in Radiation unit and ENT ward (Appendix G).
3. Asked the permission for conducting the study from the head nurse of ENT ward and the head of Radiation department.
4. Identified the HNC patients who were accompanied by family caregivers by asking the staff nurses to seek their interest in participating in the study. If they did, then the staff nurses introduced the researcher to potential subjects.
5. Give broad explanation about this study and, obtained informed consent from subjects after explanation of the purposes of the study and its procedure.
6. Collect the data during daytime.

ENT ward	Everyday	2-5 p.m.
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Radiation unit	Monday to Friday	8 a.m.-2 p.m.
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The researcher distributed the questionnaires to each subject. They were asked to respond to the questionnaires individually. For those who were unable to read, the researcher read each question word by word to them and helped mark then rating on each questionnaire. The researcher checked the completions of each questionnaire.

### *Data Analysis*

The data were analyzed by using descriptive and inferential statistics.

1. The demographic data of HNC patients and family caregivers were analyzed in frequency, percentage, mean, and standard deviation.

2. The level of preparedness of caregiving, mutuality, and role strain of Thai family caregivers of HNC patients was analyzed in frequency, percentage, mean, and standard deviation.

3. The relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of HNC patients were analyzed by Pearson product-moment correlation after checking the assumptions. All data met the assumptions of normality and linearity. The significant level was set at .05.

## CHAPTER 4

### RESULTS AND DISSCUSSION

This chapter presents the results of this study according to the research questions and hypotheses. The major findings were discussed accordingly: demographic data of family caregivers and HNC patients, preparedness of caregiving, mutuality, caregiver role strain, the relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of HNC patients receiving treatments.

#### *Results*

##### *Demographic data of family caregivers*

Eighty family caregivers participated in this study. Nearly half of them (48.8%) aged between 41 and 60 years with a mean of 46 years old ( $SD = 12.51$ ). The majority of family caregivers were female (88.8%), married (70.0%), and Buddhist (85.0%). The relationships between family caregivers of HNC patients were spouses (48.8%) and child (32.5%). The major reason of becoming family caregivers was love and attachment (71.2%), and duty and responsibility (28.8%). More than half of them (58.7%) had no education to primary school. Most of caregivers had family income ranged from 1,000 to 10,000 baht per month (77.5%). While providing care for their patients, two-thirds of family caregivers (67.5%) were temporarily stopped working, and 19.1% of them were part-time. Nearly half of caregivers (43.8%) had enough money without saving, and 38.8% of them did not have enough money and loans.

More than half of them (56.2%) had the duration of caregiving ranged from one month to three months. The time spent in caregiving varied from one to eight hours per day (43.7%). Most of them (80.0%) had no experienced in caregiving. Around sixty percent of them received information and were trained in caregiving skill. The places for caring their HNC patients were their own house/relative's house (60.0%), and rent house/ dormitory/ hotel/ temporarily patients' residence (40.0%).

During caring for the patient, a half of caregivers (48.8 %) had a caregiving assistant. The majority of caregivers (75.0%) had not other persons with caring responsibility. Forty percent of caregivers had previous illness such as hypertension (n = 24) diabetes mellitus (n= 8), and breast cancer (n =1). During taking caregiving role, one-fourth (26.2%) of family caregivers had health problems i.e. sleep disturbance and headache. A summary of the characteristics of family caregivers is presented in Table 1.

Table 1

*Frequency and Percentage of Family Caregivers Related to Characteristics (N= 80)*

Characteristics	n	%
Age (years) Range = 20 – 70 years $M = 46.28$ $SD = 12.51$		
20-40	25	31.2
41-60	39	48.8
> 60	16	20.0

Table 1 (Continued)

Characteristics	n	%
<b>Gender</b>		
Female	71	88.8
Male	9	11.2
<b>Marital status</b>		
Single	16	20.0
Married	56	70.0
Widowed	6	7.5
Separated	2	2.5
<b>Religion</b>		
Buddhist	68	85.0
Christian	6	7.5
Muslim	6	7.5
<b>Relation to patient</b>		
Spouse	39	48.7
Child	16	32.5
Sibling	9	11.2
Parent	3	3.8
Others (friend and neighbors)	3	3.8

Table 1 (Continued)

Characteristics	n	%
<b>The reason to becoming caregiver</b>		
Duty/responsibility	23	28.8
Love and attachment	57	71.2
<b>Education level</b>		
No education	13	16.2
Primary school	34	42.5
Secondary school/ Diploma	22	27.5
Bachelor's degree	11	13.8
<b>Occupation</b>		
No job	14	17.5
Labor	23	28.7
Farmer	29	36.2
Government officer	3	3.8
Merchant	11	13.8
<b>Working during caring for patient</b>		
Stop working	54	67.5
Part time	14	17.5
Full time	12	15.0



Table 1 (Continued)

Characteristics	n	%
Family income (baht/month) Range = 1,000 - 45,000 baht		
1,000 – 5,000	30	37.5
5,001 – 10,000	32	40.0
10,001 – 15,000	4	5.0
> 15,000	14	17.5
Sufficiency of income		
Not enough and loans	31	38.7
Enough money without saving	35	43.8
Enough money with saving	14	17.5
Duration of taking care patients (month) Range = 1-60 $M = 5.36$ $SD = 9.12$		
1 – 3	45	56.2
4 – 6	21	26.2
7 – 12	5	6.3
13-60	9	11.3
Time spent of caring (hour/day) Range = 1-24 $M = 13.58$ $SD = 8.90$		
1 - 8	35	43.7
9 - 16	13	16.3
17 -24	32	40.0

Table 1 (Continued)

Characteristics	n	%
Getting information about caregiving		
No	33	41.2
Yes (i.e, disease, treatments and their complications, hygiene care)	47	58.8
Getting training on caregiving skills		
No	36	45.0
Yes	44	55.0
Caregiver assistant		
No	41	51.2
Yes	39	48.8
Place for caring		
Own house or relative's house	48	60.0
Rent house/ dormitory/ hotel or temporarily patients' residence	32	40.0
Caring for other persons		
No	60	75.0
Yes	20	25.0

Table 1 (Continued)

Characteristics	n	%
Health problems before caring		
No	48	60.0
Yes *	32	40.0
diabetes mellitus	8	25.0
hypertension	24	75.0
breast cancer	1	3.13
Health problem during caring		
No	59	73.8
Yes	21	26.2
Sleep disturbance*	17	80.9
Headache*	14	66.7

\* Each patient had more than one symptoms

#### *Demographic data of HNC patients*

Most of HNC patients' ages were between 41 and 60 years old with a mean of 57 years old ( $SD = 11.68$ ). The majority of them were males (76.2%), married (82.5%) and Buddhist (95.0%). Three-fourths (74.7%) had no education to primary school. Most of HNC patients (75%) used universal health insurance for medical expense. Thirty percent of patients were diagnosed as cancer at base of tongue, 25 % were oral cancer. Nearly three-fourths (72.5%) were newly diagnosed as cancer stage II-III. The majority of them (37.5%) were received radiation alone, and one-third (32.5%) were received radiochemotherapy. The most three common symptoms of

HNC patients were sore throat (81.2%), dry mouth (75.0%), and fatigue (73.8%).

Sixty percent of them could independently help themselves (see Table 2).

Table 2

*Frequency and Percentage of HNC Patients Related to Characteristic (N = 80)*

Characteristics	n	%
Age (years)    Range = 35 – 80 $M = 56.80$ $SD = 11.68$		
35-40	8	10.0
41-60	39	48.8
61-80	33	41.2
Gender		
Female	19	23.8
Male	61	76.2
Marital status		
Single	5	6.2
Married	66	82.5
Separated	9	11.2
Religion		
Buddhist	76	95.0
Muslim	4	5.0

Table 2 (Continued)

Characteristics	n	%
Education level		
No education	9	12.2
Primary school	50	62.5
Secondary school/ Diploma	19	23.8
Bachelor's degree	2	2.5
Occupation		
No job	13	16.2
Labor	16	20.0
Farmer	35	43.8
Government officer	1	1.3
Merchant	10	12.5
Own business	5	6.2
Medical expense		
Government support	8	10.0
Social security	12	15.0
Universal health insurance	60	75.0
(30 baht health care scheme)		

Table 2 (Continued)

Characteristics	n	%
Types of HNC		
Base of tongue	24	30.0
Oral cavity	20	25.0
Larynx	13	16.2
Nasopharynx	9	11.3
Hypopharynx	8	10.0
Ears	4	5.0
Tonsil	2	2.5
Stage of HNC		
Stage I	12	15.0
Stage II	28	35.0
Stage III	30	37.5
Stage IV	10	12.5
Recurrent HNC		
No	75	93.8
Yes	5	6.2

Table 2 (Continued)

Characteristics	n	%
Types of treatment		
Chemotherapy alone	11	13.8
Radiation alone	30	37.5
Surgery (tumor removal, tracheostomy) and radiation	13	16.2
Radiation and chemotherapy	26	32.5
Dose of radiation during collecting data (Gy)*		
30 – 50	45	65.2
51 – 70	24	34.8
Cycle of chemotherapy (time)**		
2 – 3	30	81.1
4 – 5	7	18.9
Level of patients' dependency		
Partial dependence	32	40.0
Independence	48	60.0
Symptoms***		
Sore throat	65	81.2
Dry mouth	60	75.0
Fatigue	59	73.8

Table 2 (Continued)

Characteristics	n	%
Oral mucocitis	53	66.2
Difficulty swallowing	52	65.0
Lot of secretion airway	50	62.5
Loss of taste/smell	41	51.2
Nausea/ vomiting	36	45.0
Weight loss	36	45.0
Pain	31	38.8
Stress	18	22.5
Loss of speech	17	21.2
Anxiety	12	15.0
Bleeding from tracheostomy/wound	11	13.8
Skin infection	4	5.0
Sleep disturbance	4	5.0
Septic shock	2	2.5
Electrolyte imbalance	1	1.3
Trachea swelling	1	1.3

\* Total number of patients who received radiation is 69

\*\* Total number of patients who received chemotherapy is 37

\*\*\* Each patient had more than one symptoms



*Preparedness of caregiving*

Table 3 presents the mean and standard deviation of the family caregivers according to the level of caregiving preparedness. Overall, the caregivers reported that they had preparedness of caregiving at a high level ( $M = 2.77$ ,  $SD = 0.68$ ). The items with highest and lowest average scores were “take care of patient’s physical need” ( $M = 3.16$ ,  $SD = 0.91$ ) and respond to emergencies ( $M = 2.14$ ,  $SD = 1.22$ ), respectively.

Table 3

*Mean, Standard Deviation, Level of Preparedness of Caregiving (N= 80)*

Preparedness of Caregiving	<i>M</i>	<i>SD</i>	Level
1. Take care of patient’s physical needs	3.16	0.91	High
2. Take care of patient’s emotional needs	2.84	0.99	High
3. Find out about and set up services of patient	2.66	0.91	Moderate
4. Manage with the stress of caregiving	2.49	0.87	Moderate
5. Make caregiving activities pleasant for both caregivers and their patient	2.80	0.80	High
6. Respond to and handle emergencies	2.14	1.22	Moderate
7. Get the help and information from the health care system	2.74	1.02	High
8. Overall, care for patients	2.99	0.86	High
Total	2.77	0.68	High

### *Mutuality*

Overall, the average scores of mutuality were at a high level ( $M = 2.73$ ,  $SD = 0.70$ ). The item with highest average scores was “feel love for patient” ( $M = 3.52$ ,  $SD = 0.76$ ). The item with lowest average scores was “confide in patient” ( $M = 2.11$ ,  $SD = 1.20$ ) (Table 4).

Table 4

*Mean, Standard Deviation and Level of Mutuality (N = 80)*

Statements	<i>M</i>	<i>SD</i>	Level
1. See eye to eye (agree on things)	2.63	1.18	Moderate
2. Feel close to patient	3.36	0.78	High
3. Enjoy sharing past experiences with patient	2.33	1.21	Moderate
4. Perceive to patient's appreciating	2.74	1.12	High
5. Attach to patient	3.46	0.83	High
6. Receive help from patient	2.79	1.06	High
7. Like to sit and talk with patient	2.89	0.97	High
8. Feel love for patient	3.52	0.76	High
9. Share the same values	2.69	0.85	Moderate
10. Get comfort from patient	2.28	1.14	Moderate
11. Laugh together	2.26	0.99	Moderate
12. Confide in patient	2.11	1.20	Moderate
13. Receive emotional support from patient	2.52	0.94	Moderate
14. Enjoy the time spend together	3.10	0.92	High

Table 4 (Continued)

Statements	<i>M</i>	<i>SD</i>	Level
15. Perceived the patient's expression regarding feeling of warmth toward caregivers	2.91	1.02	High
Total	2.73	0.70	High

*Role strain of family caregivers*

The results indicated that the average scores of caregiver role strain were at low level ( $M = 0.67$ ,  $SD = 0.23$ ). When each aspect were considered, it was found that the mean scores of global strain were at the highest level ( $M = 1.12$ ,  $SD = 0.38$ ), while the mismatched expectation had lowest mean score ( $M = 0.35$ ,  $SD = 0.31$ ), as seen in Table 5.

Table 5

*Range, Mean, and Standard Deviation of Caregiver Role Strain (N= 80)*

Variables	<i>M</i>	<i>SD</i>	Level
Caregiver Role Strain	0.67	0.23	Low
Role conflict	0.67	0.43	Low
Mismatched expectation	0.35	0.31	Low
Increased tension	0.56	0.37	Low
Global strain	1.12	0.38	Low

*Relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of patients with HNC receiving treatments*

After normal distribution of data was met, the Pearson's product moment correlation coefficient was used to test the relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers. The result showed that preparedness of caregiving was not related to caregiver role strain ( $r = -.14, p = .10$ ). There was a moderate negative relationship between mutuality and role strain ( $r = -.47, p < .05$ ) (Table 6).

Table 6

*The Pearson's Product Moment Correlation Coefficient Between Variables (N= 80)*

Variables	Caregiver Role strain
Preparedness of Caregiving	-.14
Mutuality	-.47*

\* $p < .05$

## *Discussion*

The findings of this study are discussed and presented as follows: characteristics of family caregivers, the characteristics of HNC patients, preparedness of caregiving, mutuality, caregiver role strain, and the relationships of preparedness of caregiving and mutuality to role strain of Thai family caregivers of patients with HNC receiving treatments.

### *Characteristics of family caregivers*

The majority of caregivers were female (88.8%) and middle-aged (41 to 60 years old) with the average of 46 years old. They were spouses (48.8%) and adult children (32.5%). This is consistent with the finding of the previous studies, which supported that the role of family caregivers of cancer patients usually falls on females who have a direct relationship with the patients, particularly wife or daughters (Chen et al. 2009; Deeprasert, 2000; Kitrungrrote et al., 2008; Tamtup, 2005). Three-fourths of them gave the reason of being family caregivers as their love and attachment to the patients. This behavior of the caregiver seems to be derived from Thai society and cultural values, which expect females to be responsible for housework and take care of the family members both in normal and ill times (Hoffman & Mitchell, 1998; Suwanno, 1997). Referring to the daughters, if the parents are sick, they usually are the first choice of being the caregiver. This responsibility has been taught to them from their parents and perpetuated from generation to generation (Saengratsamee, 2004). Similarly, the wife is advised to be in charge of the domestic domain and takes care of the children and family members (Podhisita, 1998). Moreover, from literature

review, it was found that most of HNC patients were males who were married. This may be one reason that in this study the majority of caregivers found were the wife caregivers who want to closely care for their ill husbands, and their ill husbands always expects that their wives to be the first person to take the caregiver role (Kitrungrote et al.; Srithares, 2003)

The findings demonstrated that most caregivers (77.5 %) had low to rather low family income level that was similar to what was reported in Tamtup's study. Most of subjects temporarily quitted their jobs (67.5 %), and 60% of subjects resided in another place nearby the hospital to take care of their patients closely. These results were congruent with the previous studies (Kitrungrote et al., 2008; Tamtup, 2005) which reported that in order to give their patients the best care, the caregivers needed to sacrifice by quitting their jobs. The caregivers reported no saving (44%); and 40.0% had to loan money to maintain their normal living expenses such as housing, foods, transportation, etc. Caregiver also reported that additional cost is also involved transporting the patient back and forth to the hospital and other unsubsidized expenses such as wound dressing materials, feeding food, etc, particularly when the leader of the family had to quit the job. Although the Thai government has offered the universal coverage to ensure that all Thais receive basic health care needs, patient and family still need to be responsible for other tangible and intangible expenses.

This study revealed that nearly half of caregivers (41.2%) did not get information about caregiving, and 45% of them reported that they were not trained in caregiving skill. It is possible that in general, when Thai family caregivers saw that the health professionals were busy, they were highly concerned and thought that a radiation oncologist and nurse may not have enough time for them to asking them

what they would like to know regarding their patients issues. Moreover, some family caregivers have caregiving assistants such as their sons/ daughters who could take their patients for daily trip for the radiation therapy instead of them. These may make they felt less received information and were not trained caregiving skill from health professionals.

More than half of them (56.2%) had the duration of being a family caregiver ranged from one month to three months. The caregivers (43.7%) spent time 1-8 hours per day. It may be explained that 60 % of caregivers perceived that their HNC patients had low dependency, and some had caregiving assistants. Therefore, they spent less time in caregiving tasks with the patient. These findings were similar to the studies of Schumacher et al. (2008) and Tamtup (2005).

This study found that 40% of caregivers had health problems before performing the caregiving tasks. This may be due to the physical deterioration caused by middle to old ages (Prawtaku, 2006). In addition, 26.2% of family caregivers developed health problems during taking on caregiving role such as headache and sleep disturbance. It may be explained that some caregivers had previous health problems. In addition, due to the concern about their patients' health, these caregivers continuously perform caregiving tasks. Such heavy tasks can cause the caregivers to have less time to adequately respond to their own health needs and loss the follow-up with their physician. Also, some of them felt difficulty in sleeping and taking a rest when living with the new living arrangement. As a result, some caregivers in this study had headache and sleep disturbance. These findings were supported by the studies of Hawes et al.'s (2006) and Kitrungrrote et al. (2008). They found that

caregivers had experienced physical health deterioration because of lack of time for sleep and rest.

#### *Characteristics of HNC patients*

The majority of the patients were male (76.2%). They were adults whose mean age was 57 years old ( $SD = 11.68$ ). These results were congruent with the findings of previous studies which reported that the incidence of HNC was usually found in men, with the high increased rate in adult (Chen et al. 2009; Rodrigues, McMillan, & Yarandi, 2004). The cancer at the base of the tongue and oral cavity were highest found in this study. Based on the Tumor Registry's Report (Songklanagarind cancer center, 2009), the oral cancer was in the forth rank of all cancers in Songklagarind Hospital. Most patients were diagnosed with stage II-III HNC (72.5%). They were treated with radiation alone (37.5%) or chemoradiation (32.5%). Head and neck cancers are best treated with surgery or radiation alone at an early stage of the disease and with a combined-treatment approach such as surgery and radiation or chemoradiation for locally advanced tumor (Marur & Forastiere, 2008; Schroeff & Jong, 2009). In this study, the most common symptoms reported by HNC patients were, in order, sore throat (81.2%), dry mouth (75.0%), and fatigue (73.8%). These complications were observed due to the acute toxicities of HNC radiation and or chemotherapy that occur during a course of treatment. The acute toxicities resulted primarily from the damage caused by the ionizing radiation to the mucosal lining of the upper aerodigestive tract (Mallick & Waldron, 2009). In addition, the combination of oral mucocitis (53%), difficulty swallowing, nausea/vomiting (36%), weight loss (36%), and daily transportation to and from the Radiation Unit may result in fatigue



among HNC patients in this study. These findings were consistent with those of Tamtup (2005) and Storey et al. (2007).

#### *Preparedness of caregiving*

The findings showed that the family caregivers perceived a high level in preparedness of caregiving ( $M = 2.77$ ,  $SD = 0.68$ ). Overall, it means that the caregivers of HNC patients had a high perception of how readily prepared they were for the caregiving tasks. The reason may be that the most caregivers in this study were spouses and children, thus, their caring role generally stemmed from love and a sense of care and repayment which are an altruistic motivation for the caregivers (Deeprasert, 2000; Sirapo-ngam, 1996). Consequently, they tended to seek out information and learned new things of caregiving role that proved beneficial for their patients. Consistently, Mead (as cited in Hardy & Hardy, 1988) stated that individuals need to learn and understand the roles that they have, the person they need to interact with, and the behaviors appropriate for each role. Moreover, the caregivers in this study recognized that the health professionals provided knowledge and caregiving skills at the beginning of their patients' treatments including diet preparation and tube feeding, hygiene care, wound dressing, and emotional supports. With this preparation, the caregivers learned to take care of patients and were able to respond to their patients' needs. Similarly, Schumacher et al. (2008) found that family caregivers of lymphoma and solid cancer patients who were receiving treatments had high level of preparedness. Hudson et al. (2009) also reported that family caregivers of patients with advanced cancer who attended the education program had shown significant improvement in levels of preparedness.

In addition, items of preparedness of caregiving were analyzed. An item that showed the highest mean score was “take care for patients’ physical needs” ( $M = 3.16$ ,  $SD = 0.91$ ). Physical needs are easily observed and cared, for examples, diet preparation, hygiene care, radiated-skin care, wound care etc. Moreover, the majority of samples in this study were female including wife or mother who had experiences in taking care of family members and performing the home duties. Therefore, when taking caregiving role, these caregivers tended to learn all caregiving tasks quickly (Suwanno, 1997; Walker et al., 1995).

The item with lowest average score was “respond to handle emergencies” ( $M = 2.14$ ,  $SD = 1.22$ ). Obviously, 30% of caregivers rated this item as “not at all prepared” to “not too well prepared” (Appendix I, Table I1). Some family caregivers may not have sufficient specific knowledge and understanding about how to manage the emergency situations at home/ community settings, for examples, airway management, wound breakdown management, infection control, or adequate hydration. As a result, they would not be able to recognize serious complications that would happen to the patient and how to deal with these complications. As reported from caregivers in this study, some HNC patients had severe complications including bleeding from tracheostomy/ wounds ( $n = 11$ ), septic shock ( $n = 2$ ), electrolyte imbalance ( $n = 1$ ), and tracheal swelling ( $n = 1$ ). This finding was similar to Kitrungrrote et al.’s study (2008). It showed that some of the spousal caregivers who took care of laryngectomy patients felt difficult with airway obstruction because they did not know how to remove blood strain from the patients’ tracheostomy tube. Most caregivers of HNC patients (67 to 88 %) reported that the information regarding the patients’ medical symptoms was the most frequently unmet need (Ross et al., 2010).

The family caregivers' anxiety related to patients' symptoms was negatively related to preparedness of caregiving (Hauksdóttir et al., 2010; Schumacher et al., 2008). This may be one reason that the caregivers rated the item "responding and handling to emergencies" at the lowest level. This finding reflects the fact that preparation for caregiving in emergency situations is needed in order to fulfill the caregiving role effectively.

### *Mutuality*

In this study, the family caregivers perceived mutuality at a high level ( $M = 2.73$ ,  $SD = 0.70$ ). It could be implied that the sample group had a good relationship with the patients during providing care. This may be because family has a strong family bond in Thai culture. Most caregivers in this study are spouses or adult children who have relation through kinship and blood ties and have affective states of closeness and a more positive quality of relationship to care-receiver (Limanonda, 1995). Consequently, they become caregivers with willingness, love, and bonding with their patients. They considered that they should express gratitude to their patients by taking care of them when they were ill or old. Therefore, they were glad to take care of their ill spouse or parent and had positive attitude towards caregiving. This result was supported by Horowitz and Shindelman who reported that close affective relations are the norm in caregiving situations (Archbold et al., 1990). The affective relationship as involving past and current closeness and shared activities can influence caregiver behavior in care. As showed in this study, several caregivers (67.5%) temporarily quitted their job so as to spent more time of sharing and being with their patients throughout HNC treatments course. Similarly, the previous studies (Eldredge

et al., 2006; Schumacher et al., 2008) found that family caregivers had a positive impact from caregiving on their relationship. Hilton et al. (2000) and Kitrungrrote et al. (2008) also reported that caregivers gain closeness from their sick spouses, which created a good relationship during caregiving.

In addition, each items were analyzed and their results showed that the item with the highest scores was “feel love for patients” ( $M = 3.52$ ,  $SD = 0.76$ ). This possibly explained that most of Thai caregivers in this study were spouses and children. In general, caregivers and their ill spouses have spent their live both happiness and suffering for a long time. Once, cancer was diagnosed in their loved one, the spousal caregivers had empathy and wanted to care for them with love and closeness (Badr & Taylor, 2006; Kitrungrrote, 2008). Children caregivers have gratitude for their parents who have nurtured them in the past. As a result, they were grateful to their sick parents and compassionate with them. Moreover, the sibling caregivers also have attachments with the patients who have grown up with them and shared a strong family tie (Prawtaku, 2006; Suwanno, 1997). These factors contribute to the feeling of love in caregivers for their patients (Hirani, 2003; Juarez, 2003). These finding is consistent with the qualitative studies of Kitrungrrote et al. and Limpanichkul and Magilvy (2004). They revealed that being a caregiver helped him/her develop feeling of love and attachment toward the patients.

On the other hand, the caregivers gave the average scores of item “confide in patient” at the lowest level ( $M = 2.11$ ,  $SD = 1.20$ ). It means that the caregivers did not release the stressful information to their patient. This may be because the caregivers believed that it is harmful for their patient to discuss any negative aspects of the situation with them (Porter, Keefe, Hurwitz, & Faber, 2005). Moreover, their HNC

patients had stress and anxiety. Since their patients' mind was fragile, it would worsen and deteriorate their health if they received the ill-omened or inauspicious news. Therefore, several caregivers of this study attempted to keep negative things to themselves (37.6%) and not to disclose it to their patients (Appendix I, Table I2). This finding was supported by Kitrungrrote et al.'s study (2008), which found that for example, spousal caregivers of HNC patients said "*He [the patient] is already stressed enough, so he shouldn't hear anything bad.... He is sick... stress would make him worsen...*".

#### *Caregiver role strain*

The finding revealed that the caregivers had a low level of means of role strain ( $M = 0.67, SD = 0.23$ ). It means that the caregivers have less role strain when taking the family caregiver role which is consistent with the previous study about family caregivers of ABMT patients (Eldredge et al., 2006). This may be due to the several factors including caregiver's and patient's aspects.

About caregivers' aspect, one plausible explanation is that the family caregivers in this study were mostly female (88.8%), so they accepted the Thai society's expectation that female is the caregiver role given to persons in the family whether parents, husbands, daughters or sons, or siblings both in healthy or in illness status (Saengratsamee, 2004). As a consequence, they perceive low level of role strain. In addition to this, the caregivers stated that they became caregivers because of love and the long-term family relationship or marital relationship that helped them to develop a deeply mutual understanding or knowing each other. Assuming the role of best expert in knowing their patients' mind, the caregivers were able to please

everything in order to meet their patients' needs although these patients sometime had excessive expectations from the caregivers. These are important indicators to reduce them feel about role mismatched expectations ( $M = 0.35$ ,  $SD = 0.31$ ) (Appendix I, Table I4). This finding is consistent with previous research of Kitrungrote et al. (2008) and Natechang (2002).

In addition, 65.7 % of caregivers have to quit their job temporarily. At the same time, most of them (75%) did not have to take care of any other persons. Also, they can completely take care of the patients without worrying about their other role duties. Besides, within an extended family in Thai society, there are several generations living in on one household or several houses within the same area (Boonchalaksi, 2000). Therefore, a half of caregivers (48.5%) who lived in their own house had caring assistants (i.e., family members) to help them release from the caregiving strain, then, they may have some time for rest and relaxing activities. They felt that caregiving did not have effects on time for meeting friends ( $M = 0.89$ ,  $SD = 0.76$ ), did not increase stress in their lives ( $M = 0.79$ ,  $SD = 0.94$ ), and decreased conflict among family members ( $M = 0.26$ ,  $SD = 0.50$ ). These results are congruent with Goode's work (1960), which showed that each person has many roles and each role within role set, and each role has given expectations from self, others, and society. To reduce role strain, the person should delete roles from their role set and need to have mutual social support. Matching with the prior study of Limpanichkul and Magilvy (2004), revealed that getting some support from the family was related to reduce role strain.

Regarding the ability of patient's self-care, 60% of caregivers highly perceived that their patient's level independency. Therefore, the patients can do

routine activities by themselves. This may also one factor influencing caregivers feel low role strain of caregiving. Similar to previous studies showed that the caregivers who perceive low patients' dependency, experienced low level of burden or role strain (Schumacher et al., 2008; Sritares, 2003). According to above mentioned information, most of the subjects in this study reported that they had low role strain of caregiving.

However, when considering the global strain dimension of caregiver role strain, it presented the highest average score ( $M = 1.12$ ,  $SD = 0.38$ ) (Table 5). Then, its two items were analyzed. One item i.e., "feel confidence in caregiving more than now" was rated by 53.7 % of caregivers at "not at all" to "a little bit", and another item i.e., " feel difficult when patients had symptom changes" was rated by 62.3 % caregivers at "somewhat" to "a quite bit" (Appendix I, Table I7). This means that the caregivers felt lack self confidence and difficult in taking care of patients when they faced with their patients' symptom changes during receiving treatments. It may be because when the family members took on the caregiving role, they were needed to have predictability as a caregiver qualification which helped to guide how they can respond to patient needs for effective caregiving. Apart from that, daily caregiving both physical and psychological need, and caregivers learning can helps them in predicting or guessing what will happen and how to take care of patients, including being able to control various situations. The above mentioned qualifications help to decrease over anxiety and reduce pressure from serious situations (Stewart & Archbold, 1992). However, the caregivers in this study perceived that they have not well-prepared in the management with patients' emergency conditions. This is a reason that they gave the scores of global strain dimension at the highest level. This

finding is supported by the previous studies of Ferrario et al. (2001), Kitrungrote et al. (2008), and Ross et al. (2010).

*Relationship between preparedness and caregiving role strain of Thai family caregivers of patients with head and neck cancer receiving treatments*

Preparedness had no relationship with caregiver role strain ( $r = -.14, p > .05$ ). In other words, the level of preparedness of the caregivers caused no difference in caregiving role strain, or no matter how much the preparedness of caregiving that caregivers have, role strain does not vary. It could be due to the fact that the caregivers felt well-experienced to respond patients' physical and emotional needs, which included all matters in the house. These caregiving activities usually are one part of female caregivers' responsibilities which are quite similar to their traditionally care for the family members both in normal and ill times (Irvin & Acton, 1996; Krach & Books, 1995). Apart from that, the samples were in middle-aged (48.8%) so they could adapt themselves to caregiving situations easily (Cheunjairung, 1993; Wongchantra, 1996). As a result, they did not think the caregiving duty affects the role of parent, spouses, children, and social interactions ( $M = 0.73, SD = 0.79$ ;  $M = 0.56, SD = 0.73$ ;  $M = 0.53, SD = 0.73$ ;  $M = 0.79, SD = 0.76$ ), respectively (Appendix I, Table I3). Moreover, the 60% caregivers highly perceived that their patients were able to perform their self-care activities, and, they did not spent much time to take care of the patient. At the same time, they had no responsibility for taking care others. Therefore, these may lead them felt not have difficulty in caregiving. The finding of this study was similar to the study of Eldredge et al., (2006) that showed no relationship between preparedness and caregiver role strain. But it differs from the



study of Schumacher et al., (2008) which found that caregivers who felt well-prepared had a low level of role strain. It is possible that in the previous study, preparedness was measured globally (with the overall sense of confinement, difficulty, and stress experienced during caregiving), and not in relation to specific caregiving task.

*Relationship between mutuality and caregiver role strain of Thai family caregivers of patients with head and neck cancer receiving treatments*

Mutuality was found to have a moderate negative correlation with the caregiver role strain ( $r = -.47, p < .05$ ). This finding suggested that the more the mutuality between the caregivers and the patients, the less the caregiver role strain. The result supported the research hypothesis. This may be due to the fact that the samples are spouses and adult children of the patients, and their relationships with the patients had been good even before they became a caregiver. As a result, taking care of their patient is a way to convey their care and love through caring all the time. The patients and caregivers could learn, understand and appreciate each other more than before (Walker et al. 1990). It can also be postulated that good relationship can reduce the feeling of obligation, thus the caregivers realized that the caregiving role is not difficult ( $M = 0.67, SD = 0.23$ ). This finding was supported by works of Archbold et al., (1990) and Tunner (1962 as cited in Glajchen, 2004), which indicated that in caregiving process, interactions or closed affective relationships between sick family member are taken place that enable family caregivers to continue caregiving role. Therefore, mutuality is an important motivation for the caregivers to have no feeling of caregiving role strain. This finding is consistent with previous studies which found

that mutuality has negative relationship with caregiver role strain (Archbold et al., 1990; Schumacher et al., 2008; Songwattayanut, 2002; Sritares, 2003).

In conclusion, this study was aimed to examine the relationships of preparedness of caregiving and mutuality to caregiving role strain of Thai family caregivers of HNC patients while receiving treatments. The findings of this study indicate that the family caregivers perceived preparedness of caregiving and mutuality at high level and felt low strain in caregiving role. The mutuality had a moderately negative correlation with caregiver role strain, but the preparedness of caregiving was not related. Therefore, the results of this study partially supported the caregiving role research constructed by Archbold et al. (1990). This caregiving role research appears to be a useful model to explain clinical phenomena, and direct subsequent research. However, the Caregiver Role Strain Form in this study was adequately reliable; the lengthy of this questionnaire may be potential burden for the subjects. Therefore, its psychometric testing should be considered for future study.

## CHAPTER 5

### CONCLUSION AND RECOMMENDATIONS

This descriptive correlational study was designed to examine the relationships between preparedness of caregiving and mutuality to role strain of Thai family caregivers of patients with HNC receiving treatments. Data were collected from February to August 2010 at Songklanagarind hospital. The set of questionnaires consisted of the HNC Patients and Their Family Caregivers' Demographic Data Form, Preparedness of Caregiving Assessment Form, Mutuality Assessment Form, and Caregiver Role Strain Assessment Form. These forms were tested for the face validity. The Cronbach's alpha reliability of the Preparedness of Caregiving Assessment Form, Mutuality Assessment Form, Role Conflict Assessment Form, Increased Tension Assessment Form, and the Global Strain Assessment Form were .80, .84, .74, .77, and .82 respectively. The Mismatched Expectation Assessment Form was examined by test-retest method (Pearson correlation coefficient); its reliability was .79. The data were analyzed by using descriptive statistics and Pearson's Product Moment Correlation.

#### *Summary of the Study Findings*

Subjects involved in this study were 80 family caregivers of patients with HNC. Most of them were female and were in middle-aged. They reported their preparedness of caregiving and mutuality at high level ( $M = 2.77$ ,  $SD = 0.68$ ;  $M = 2.73$ ,  $SD = 0.70$ ), respectively. However, the subject rated one area of

preparedness regarding responding and handling to emergencies at the lowest level. They perceived their caregiving role strain at low level ( $M = 0.67$ ,  $SD = 0.23$ ). Moreover, the findings showed that mutuality was moderately negative related to caregiver role strain ( $r = -.47$ ,  $p < .05$ ), while preparedness of caregiving was not related to caregiver role strain ( $r = -.14$ ,  $p = .10$ ).

### *Limitations of the Study*

For this study, the following limitations were recognized:

1. This study utilized a convenience sample of family caregivers of HNC patients at one tertiary hospital. Therefore, the findings from this study may not be representative of all HNC caregivers in other hospitals.
2. Cross-sectional data were collected; therefore, changes in the preparedness of caregiving, mutuality and caregiver role strain over time were not examined.
3. The data collection procedure potentially created burden to the subjects due to the lengthiness of questionnaires.

### *Implications and Recommendation*

The findings of this study provide several important implications for the nursing profession including nursing practice and nursing research as follow:

#### *Implications for nursing practice*

1. Based on the results of this study, it is indicated that caregivers are worried about the management with HNC patients' emergency conditions. This may indicates

that a lack of preparedness regarding responding and handling to emergencies among family caregivers is alarming. Therefore, it should be create a program of preparedness for caregiving which aims to give instruction and training in necessary skills for patients' HNC emergencies managements to reduce caregiver role strain.

2. The results of the study indicated that mutuality had a negative correlation with caregiver role strain. It is, therefore, advised to encourage the caregiver involvement, so as to enhance a good relationship during providing care to reduce their role strain.

3. Since the findings of this study revealed that the caregivers had health problems before and during caregiving, thus the nurses should have an awareness of their health conditions, provide health information, and plan with them to protect or reduce them from more illness.

#### *Implications for nursing research*

Based on the limitations and the findings of this study, several recommendations for future research are presented.

1. Extending the study setting to other hospital would be needed to ensure external validity.

2. A longitudinal study should be conducted to examine preparedness of caregiving, mutuality, and caregiver role strain over time.

3. Although the Caregiver Role Strain Form was adequately reliable, its modification and psychometric testing is necessary for future research.

## References

- Ad, V. B., & Chalian, A. (2008). Management of clinically negative neck for the patients with head and neck squamous cell carcinomas in the modern era. *Oral Oncology, 44*, 817-822.
- Adam, J. (2000). Discharge planning of terminally ill patients home from an acute hospital. *International Journal of Palliative Nursing, 6*, 338-345.
- Adams, E., Boulton, M., Watson, E., (2010). The information needs of partners and family members of cancer patients: A systematic literature review. *Patient Education and Counseling, 77*, 179-186.
- Ang, K. K., & Garden, A. S. (2006). *Radiotherapy for head and neck cancers* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.
- Archbold, P. G., Stewart, B. J. Greenlick, M. R., & Harvath, T. A. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 13*, 375-384.
- Archbold, P. G., Stewart, B. J., Miller, L. L., Harvath, T. A. Greenlick, M. R., Buren, L. V., et al. (1995). The PREP system of nursing intervention: A pilot test with families caring for older member. *Research in Nursing & Health, 18*, 3-16.
- Argiris, A., Karamouzis, M., Raben, D., & Ferris, R. L. (2008). Head and neck cancer. *Lancet, 371*, 1695-1709.
- Arskey, H., Hepworth, D., & Qureshi, H. (2000). *Carers' needs and the carer act: An evaluation of the process and outcomes of assessment*. Working Paper DH1743. Paper presented at the York, Social Policy Research Unit, University of York.

- Badr, H., & Taylor, C. L. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology*, *15*, 673-683.
- Bansal, M., Mohanti, B. K., Shah, N., Chauahy, R., Bahadur, S., & Shukla, N. K. (2004). Radiation related morbidities and their impact on quality of life in head and neck cancer patients receiving radical radiotherapy. *Quality of Life Research*, *2*, 481-488.
- Beaver, M. E., Matheny, K. E., Roberts, D. B., & Myers, J. N. (2001). Predictors of weight loss during radiation therapy. *Otolaryngology-Head and Neck Surgery*, *125*, 645-648.
- Beitman, C. L., Johnson, J. L., Clark, A. L., Highsmith, S. R., Burgess, A. L., Minor, M. C., et al. (2004). Caregiving role strain of older workers. *Work*, *22*, 99-106.
- Biswal, B. M., Kumaraswamy, N., & Mukhtar, F. (2004). Prevalence of fatigue among cancer patients undergoing external radiotherapy. *The Southeast Asian Journal of Tropical Medicine and Public Health*, *35*, 463-467.
- Blake, H., & Lincoln, N. B. (2002). Cognitive impairments following a stroke: The strain on caregivers. *British Journal of Therapy and Rehabilitation*, *9*, 334 – 337.
- Blake, H., Lincoln, N. B., & Clarke, D. D. (2003). Caregiver strain in spouses of stroke patients. *Clinical Rehabilitation*, *17*, 312-317.
- Blood, W. G., Simpson, K. C., Dineen, M. Kauffman, S. M., & Raimondi, S. C. (1994). Spouses of individuals with laryngeal cancer: Caregiver strain and Burden. *Journal of Communication Disorder*, *27*, 19-35.
- Boonchalaksi, W. (2000). *Family size and elderly care*. Unpublished doctoral dissertation, Mahidol University, Bangkok, Thailand.

- Bowman, V.B. (2007). Head and Neck Cancer. In M. E. Langhorne, J. S. Fulton, & S. E. Otto (Eds.), *Oncology Nursing* (5th ed.) (pp. 213-231). St.Louis, MO, Mosby Elsevier.
- Burr, W. R., Leigh, G. K., Day, R. D., & Constantine, J. (1979). Symbolic Interaction and the Family. In W. R. Burr, R. Hill, F. I. Nye, & I. L. Reiss (Eds.), *Contemporary Theories About the Family: Vol. II* (pp. 42-111). New York, NY: Free Press.
- Capuano, G., Gentile, P. C., Bianciardi, F., Tosti, M., Palladino, A., & Di Palma, M. (2010). Prevalence and influence of malnutrition on quality of life and performance status in patients with locally advanced head and neck cancer before treatment. *Support Care Cancer*, 18, 433-437.
- Chauker, D. A., Walvekar, R. R., Das, A. K., Deshpande, M. S., Chaturvedi, P., Chaturvedi, P. et al. (2009). Quality of life in head and neck cancer survivors: A cross-sectional survey. *American Journal of Otolaryngology*, 3, 176-180.
- Chen, S., Tsai, M., Liu, C., Yu, W., Liao, C., & Chang, J. T. (2009). Support needs of patients with oral cancer and burden to their family caregivers. *Cancer Nursing*, 32,473-481.
- Cheunjaireung, C. (1993). *The relationship between health perception spouse support and adaptation of the post cardiac valvular replacement patients*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Choowattanapakorn, T. (1999). The social situation in Thailand: The impact on Elderly people. *International of Health Research*, 5, 99-106.
- Christensen, D., & Lin, P. (2007). Practical treatment strategies for patients with



- Alzheimer's disease. *Journal of Family Practice*, 56, 17-23.
- Coristine, M., Crooks, D., Grunfeld, E., Stonebridge, C., & Cristie, A. (2003).  
Caregiving for women with advanced breast cancer. *Psycho-Oncology*, 12,  
709-719.
- Curley, M. (1997). Mutuality-an expression of nursing presence. *Journal of Pediatric  
Nursing*, 12, 208-213.
- da Cruz, D. A., Pimenta, C. A., Kurita, G. P., & de Oliveria, A. C. (2004). Caregivers  
of patients with chronic pain: Response to care. *International Journal of  
Nursing Terminologies and Classifications*, 15 (1), 5-13
- Dafal, S., & Bruera, E. (2004). Dehydration in cancer patients: To treat or not to treat.  
*Journal of Supportive Oncology*, 2, 467-487.
- Deeprasert, A. (2000). *Mental health and caring behaviors of caregivers of children  
with mental retardation*. Unpublished master's thesis, Mahidol University,  
Bangkok, Thailand.
- Dhammavaro S. (2005). *Buddhism: Ethics and the path to peace* (3rd ed.).  
Chiang Mai: Anupong Printing,
- Donnelly, M. Anderson, L. A., Johnston, B. T., Watson, R. G. P., Murphy, S. J.,  
Comber, H., et al. (2008). Oesophageal cancer: Caregiver mental health and  
strain. *Psycho-Oncology*, 17, 1196-1201.
- Druley, J. A., Stephens, M. A. P., Martire, L. M., & Ennis, N. (2003). Emotional  
congruence in older couples coping with wives' osteoarthritis: Exacerbating  
effects of pain behavior. *Psychology & Aging*, 18, 406-414.
- Eldredge, D. H., Nail, L. M., Maziarz, R. T., Hansen, L. K., Ewing, D., & Archbold,  
P. G. (2006). Explaining family caregiver role strain following autologous

- blood and marrow transplantation. *Journal of Psychosocial Oncology*, 24, 53-74.
- England, S.L., & Evans, J. (1992). Patients' choices and perceptions after an invitation to participate in treatment decisions. *Social Science Medicine*, 34, 1217-1225.
- Ferario, S. R., Zotti, A. M., Zaccaria, S., & Donner, C. F. (2001). Caregiver strain associated with tracheostomy in chronic respiratory failure. *Chest*, 119, 1498-1502.
- Given, B. A., & Given, C. W., & Kozachik, S. (2001). Family support in advanced cancer. *Cancer Journal Clinics*, 51, 213-231.
- Glajchen, M. (2004). The emerging role and needs of family care. *The Journal of Supportive Oncology*, 2, 145 -155.
- Goldstein, D.P., Hynds, K.L., Christensen, A.J., Funk, G.F. (2007). Health-related quality of life profiles based on survivorship status for head and neck cancer patients. *Head & Neck*, 29, 221-229.
- Goode, W. J. (1960). A theory of role strain. *American Sociological Review*, 25, 483-496.
- Haddad, R., Annino, D., & Tishler, R. B. (2007). Multidisciplinary approach to cancer treatment focus on head and neck cancer. *Dental Clinical North America*, 5, 1-17.
- Haisfield-Wolfe, M. E., McGuire, D. B., Soeken, K., Geiger-Brown, J., & DeForge, B. R. (2009). Prevalence and correlates of depression among patients with head and neck cancer: A systematic review of implications for research. *Oncology Nursing Forum*, 36, 1-19.

- Hardy, M. E., & Conway, M. E. (1988). *Role theory: Perspectives for health Professional* (2nd ed.). Norwalk, Connecticut: Appleton & Lange.
- Hardy, M., & Hardy, W. (1988). Role stress and role strain. In M. E. Hardy & M. E. Conway (Eds.), *Role Theory: Perspectives for Health Professionals* (2nd ed.) (pp. 159-240). Norwalk, Connecticut: Appleton & Lange.
- Harrison, L. B., Sessions, R. B., & Hong, W. K. (2009). *Head and neck cancer: A multidisciplinary approach* (3rd ed.). Philadelphia: Lippincott Williams & Wilkins.
- Hauksdóttir, A., Steineck, G., Fürst, C. J., & Valdimarsdóttir, U. V. (2010). Long-term harm of low preparedness for a wife's death from cancer: A population-based study of widowers 4-5 years after the loss. *American Journal of Epidemiology*, 172, 389-396.
- Hawes, S. M., Malcarne, V. L., Ko, C. M., Sadler, G. R., Banthia, R., Sherman, S. A., et al. (2006). Identifying problems faced by spouses and partners of patients with prostate cancer. *Oncology Nursing Forum*, 33, 807-814.
- Hayward, M. C., & Shea, A. M. (2009). Nutritional needs of patients with malignancies of head and neck. *Seminars in Oncology Nursing*, 25, 203-211.
- Hegney, D., Pearce, S., Rogers-Clark, C., Martin-McDonald, K., & Buikstra, E. (2005). Close, but still too far: The experience of Australian people with cancer commuting from a regional to a capital city for radiotherapy treatment. *European Journal of Cancer Care*, 14, 75-82.
- Henson, R. H. (1997). Analysis of the concept of mutuality. *Journal of Nursing Scholarship*, 29, 77-81.
- Hilton, B. A., Crawford, J. A., & Tarko, M. A. (2000). Men's perspectives on

individual and family coping with their wives' breast cancer and chemotherapy. *Western Journal of Nursing Research*, 22, 438-459.

- Hirani, T. (2003). *Informal caregiving experience and meaning home-based palliative cancer care*. Unpublished Master of Nursing, University of Alberta, Edmonton, Alberta.
- Hoffman, R. L., & Mitchell, A. M. (1998). Caregiver burden: Historical development. *Nursing Forum*, 33(4), 5-11.
- Houts, P. S., Nezu, A. M., Nezu, C. M., & Bucher, J. A. (1996). The prepared family caregiver: A problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27, 63-73.
- Hudson, P. L., Aranda, S., & Kristjason, L. J. (2004). Meeting the supportive needs of family caregivers in palliative care: Challenges for health professionals. *Journal of Palliative Medicine*, 7, 19-25.
- Hudson, P., Thomas, T., Quinn, K., Cockayne, M., & Braithwaite, M. (2009). Teaching family carers about home-based palliative care: Final results from a group education program. *Journal of Pain and Symptom Management*, 38, 299-308.
- Irvin, B. L. & Acton, G. J. (1996). Stress mediation in caregivers of cognitively impaired adult: Theoretical model testing. *Nursing Research*, 45, 160-166.
- Juarez, G. (2003). *Perception of caregiving experience and quality of life: Mexican/Mexican-American caregivers providing care to adults with advanced cancer*. Unpublished Doctor of Philosophy in Nursing, University of California, LA.
- Kelly, D. H. (2003). Some thoughts on what is a "master clinician". *Otolaryngology:*

*Head & Neck Surgery, 11*, 143.

- Kitrungrote, L., Wonghongkul, T., Chanprasit, C., Suttharangsee, W., & Cohen, M. Z. (2008). Experiences of spousal caregivers of patients with head and neck cancer undergoing radiation therapy. *The Journal of Nursing Research, 12*, 207-218.
- Kneeshaw, M. E., Considine, R. M., & Jennings, J. (1999). Mutuality and preparedness of family caregivers for elderly women after bypass surgery. *Applied Nursing Research, 12*, 128-135.
- Kopachon, C. (2002). *Influences on preparedness, rewards of caregiving, and factors in role strain of caregivers of patients with cerebrovascular disease*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Krach, P. & Books, J. A. (1995). Identifying the responsibilities & need of working adult who are primary caregivers. *Journal of Gerontological Nursing, 21*(10), 41-50.
- Kurtin, S. E. (2009). Systemic therapies for squamous cell carcinoma of the head and neck. *Seminars in Oncology Nursing, 25*, 183-192.
- Lethborg, C. E., Krissane, D., & Burns, W. I. (2003). "It's Not the Easy Part": The experience of significant others for women with early stage breast cancer at treatment completion. *Social Work in Health, 37*(1), 63-85.
- Limanonda, B. (1995). Families in Thailand: Beliefs and realities. *Journal of Comparative Family Studies, 26*(1), 67-82.
- Limpanichkul, Y., & Magilvy, K. (2004). Managing caregiving at home: Thai caregivers living in the United States. *Journal of Cultural Diversity, 11*(1), 18-24.

- Logan, R. M. (2009). Advances in understanding of toxicities of treatment for head and neck cancer. *Oral Oncology*. Retrieved June 20, 2009, from <http://www.sciencedirect.com/science>
- Lu, C., & Kies, M. S. (2004). Systemic therapy for recurrent and metastases diseases. In L. B. Harrison, R. B. Sessions & W. K. Hong (Eds.), *Head and neck cancer: A multidisciplinary approach* (pp. 919-923). Philadelphia: Lippincott Williams & Wilkins.
- Luckman J. (1999). *Transcultural Communication in Nursing*. San Francisco: Delmar.
- Liu, H. E. (2008). Changes of satisfaction with appearance and working status for head and neck tumor patients. *Journal of Clinical Nursing*, 17, 1930-1938.
- Lydiatt, W. M., Moran, J., & Burke, W. J. (2009). A review of depression in the head and neck cancer patient. *Clinical Advances in Hematology and Oncology*, 7, 397-403.
- Lyons, K. S., Sayer, A. G., Archbold, P. G., Hornbrook, M. C., & Stewart, B. J. (2007). The enduring and contextual effects of physical health and depression on care-dyad mutuality. *Research in Nursing & Health*, 30, 84-98.
- Lyons, K. S., Stewart, B. J., Archbold, P. G., & Carter, J. H. (2009). Optimism, pessimism, mutuality, and gender: Predicting 10-year role strain in Parkinson's disease spouses. *Gerontologist*, 49, 378-387.
- Mallick, I., & Waldron, J. N. (2009). Radiation therapy for head and neck cancers. *Seminars in Oncology Nursing*, 25, 193-202.
- Marur, S., & Forastiere, A. A. (2008). Head and neck cancer: Changing epidemiology, diagnosis, and treatment. *Mayo Clinic Proceedings*, 83,

489-501.

- Martin, G. S., Mannino, D. M., Eaton, S., & Moss, M. (2003). The epidemiology of sepsis in the united states from 1979 through 2000. *The New England Journal of Medicine*, *348*, 1546-1554.
- Matayamool, C. (2003). *Factors affecting to role strain of caregivers in stroke patients*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Matthews, E. (2007). Family caregiving. In M. E. Langhorne, J. S. Fulton, & S. E. Otto (Eds.), *Oncology Nursing* (5th ed.) (pp. 620-648). St.Louis, MO, Mosby Elsevier.
- Mui, A. C. (1995). Caring for the frail elderly parents: Comparison of adult sons and daughters. *The Gerontologist*, *35*(1), 86-93.
- Murphy, B. A., Ridner, S., Wells, N., Dietrich, M. (2007). Quality of life research in head and neck cancer: A review of the current state of the science. *Critical Reviews in Oncology/Hematology*, *62*, 251-267
- Natechang, S. (2002). *Influencing of caregiver role strain, worry from caring, and caregivers' factors on health status of caregivers of stroke patients*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- National Cancer Institute. (2008). *Hospital based cancer registry*. Retrieved October 4, 2010, from [http://www.nci.go.th/cancer\\_record/cancer\\_rec1.html](http://www.nci.go.th/cancer_record/cancer_rec1.html)
- \_\_\_\_\_. (2009). *Hospital based cancer registry*. Retrieved October 4, 2010, from [http://www.nci.go.th/cancer\\_record/cancer\\_rec1.html](http://www.nci.go.th/cancer_record/cancer_rec1.html)
- Northouse, L. L. (2005). Helping families of patients with cancer. *Oncology Nursing Forum*, *32*, 743-750.

- Obe-om, T. (2005). *The experiences of families with stroke survivors in Chiang Mai province*. Unpublished Doctor of Philosophy in Nursing, Chiang Mai University, Thailand.
- Ostwald, S. K., Godwin, K. M., & Cron, S. G. (2009). Predictors of life satisfaction in stroke survivors and spousal caregivers after inpatient rehabilitation. *Rehabilitation Nursing, 34*, 160-167.
- Payutto, P. A. (1997). *Thammanoon chewit (A constitution for living)* (6th ed.). Bangkok, Thailand: Private publisher.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*, 583- 594.
- Penner, J. L. (2009). Psychosocial care of patient with head and neck cancer. *Seminars in Oncology Nursing, 25*, 231-241.
- Persson, E., Severinsson, E., & Hellström, A. L. (2004). Spouses' perceptions of and reactions to living with a partner who has undergone surgery for rectal cancer resulting in a stoma. *Cancer Nursing, 27*(1), 85-90.
- Phengjard, J. (2001). *Family caregiving of persons living with HIV/AIDS in urban Thailand*. Unpublished doctoral dissertation, University of Washington.
- Podhisita, C. (1998). Buddhism and Thai world view. In A. Pongsapich (Ed.), *Traditional and changing Thai world view* (pp. 31-62). Bangkok, Thailand: Chulalongkorn University Press.
- Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods*. Philadelphia: Lippincott Williams & Wilkins.
- Posner, M. R., Hershock, D. M., Blajman, C. R., Mickiewicz, E., Winqvist, E.,



- Gorbounava, V., et al. (2007). Cisplatin and fluorouracil alone or with docetaxel in head and neck cancer. *The New England Journal of Medicine*, 357, 1705-1715.
- Posner, M. R., & Vermorken, J. B. (2008). Induction therapy in the modern era of combined-modality therapy for locally advanced head and neck cancer. *Seminars in Oncology*, 35, 221-228.
- Porter, L. S., Keefe, F. J., Herbert, K. H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-Oncology*, 24, 1030-1042.
- Prawtaku, S. (2006). *A comparison of needs for helps and caregiver role strain among spouse, children and sibling's caregivers of patients with stroke*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Regazzoni, C. J., Irrazabal, C., Luna, C. M., & Poderoso, J. J. (2004). Cancer patients with septic shock: Mortality predictors and neutropenia. *Support Care Cancer*, 12, 833-839.
- Reich, M., Gaudron, C., & Penel, N. (2009). When cancerophobia and denial lead to death. *Palliative and Support Care*, 7, 253-255.
- Richardson A. & Birchall M.J. (2002) Learning from patients with cancer and their spouse: A focus group study. *Journal of Laryngology and Otology*, 116, 1028-1035.
- Ridge, J. A., Glisson, B. S., Lango, M. N., & Feigenberg, S. (2009). Head and neck tumors. In: R. Pazdur, L. D. Wagman, K. A. Camphausen, & W. J. Hoskin. (Eds.). *Cancer management: A multidisciplinary approach* (pp. 1-6). New York, NY: United Business Media.

- Rodriguez, C. S., & Blischak, D. M. (2009). Communication needs of nonspeaking hospitalized postoperative patients with head and neck cancer. *Applied Nursing Research (online available)*. Retrieved June 20, 2009, from <http://www.sciencedirect.com/science>
- Rodriguez, C. S., McMillan, S., & Yarandi, H. (2004). Pain measurement in older adults with head and neck cancer and communication impairments. *Cancer Nursing, 27*, 425-433.
- Rogers, S. N., Scott, B., Lowe, D., Ozakinci, G., & Humphris, G. M. (2010). Fear of recurrence following head and neck cancer in the outpatient clinic. *European Archives of Oto-rhino-laryngology, 267*, 1943-1949.
- Rosenthal, D. I., & Ang, K. K. (2004). Radiation oncology. *Seminars in Radiation Oncology, 14*, 101-102.
- Ross, S., Mosher, C. E., Tobin, V. R., Hermele, S., & Ostroff, J. S. (2010). Psychosocial adjustment of family caregivers of head and neck cancer survivors. *Support Care Cancer, 18*, 171-178.
- Ruangjiratain, S. (2003). *Experiences of Thai women caring for their husbands living with HIV/AIDS*. Unpublished dissertation, Oregon Health & Science University, OR.
- Rusinak, R. L., & Murphy, J. F. (1995). Elderly spousal caregivers: Knowledge of cancer care, perceptions of preparedness, and coping strategies. *Journal of Gerontological Nursing, 21*(3), 33-41.
- Saengratsamee, A. (2004). *Role strain of caregiver daughters of patients with cerebrovascular disease*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.

- Sanftner, J. L., Cameron, R. P., Tantillo, M., Heigel, C. P., Martin, D. M., Sippel-Silowash, J. A. et al. (2006). Mutuality as an aspect of family functioning in predicting eating disorder symptoms in college women. *Journal of College Student Psychotherapy, 21*(2), 41-66.
- Samartkit, N. (2008). *Caregiver role strain and rewards or caregiving: A study of caring for traumatic brain injured patients in eastern Thailand*. Unpublished doctoral dissertation, Mahidol University, Bangkok, Thailand.
- Scarpa, R., (2009). Surgical management of head and neck carcinoma. *Seminars in Oncology Nursing, 25*, 172-182.
- Scherbring, M. (2002). Effect of caregiver perception of preparedness on burden in an Oncology population. *Oncology Nursing Forum, 29*(6), 70-76.
- Schroeff, M., & Jong, R. (2009). Staging and prognosis in head and neck cancer. *Oral Oncology, 45*, 356-360.
- Schumacher, K. L. (1995). Family caregiver role acquisition: Role-making through situated interactions. *Scholarly Inquiry for Nursing Practices: An International Journal, 9*, 211-226.
- Schumacher, K. L., Beidler, S. M., Beeber, A. S., & Gambino, P. (2006). A transactional model of cancer family caregiving skill. *Advances in Nursing Science, 29*, 271-286.
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effect of caregiving demand, mutuality, and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum, 35*, 49-56.
- Séoud, J., Nehmé, C., Atallah, R., Zablit, C., Yérétzian, J., Lévesque, L., et al. (2007).

- Caring context of family caregivers of impaired elderly persons in Lebanon: Relationship with caregiver health. *International Journal of Nursing Studies*, 44, 259-272.
- Sirapo-ngam, Y. (1996). Family Caregiver: Concept and research issues. *Ramathibodi Nursing Journal*, 2, 84-94.
- Sirapo-ngam, Y. (2000). Family caregiving research in Thailand. *Nursing and Health Sciences*, 2, A1-A8.
- Siriraj cancer center. (2008). *Tumour registry*. Retrieved September 9, 2010, from <http://www.si.mahidol.ac.th/th/department/cancer>.
- \_\_\_\_\_. (2009). *Tumour registry*. Retrieved September 9, 2010, from <http://www.si.mahidol.ac.th/th/department/cancer>.
- Smink, K. A., & Gosselin-Acomb, T. K. (2004). Evaluation of an educational tool to enhance outcomes for patients with head and neck cancer. *Clinical Journal of Oncology Nursing*, 8, 490-494.
- Sobol, S. M., Conoyer, M., Zill, R., Thawley, S. E., & Ogura, J. H. (2009). Nutritional concepts in the management of the head and neck cancer patient. *The Laryngoscope*, 89, 794-803.
- Somboon, S. (2005). *Caregiving preparedness among caregivers of persons with dementia attending at Suan Prung psychiatric hospital*. Unpublished independent study, Chiang Mai University, Thailand.
- Sormanti, M., & Kayser, K. (2000). Partner support and changes in relationships during life-threatening illness: Women's perspectives. *Journal of Psychosocial Oncology*, 18(3), 45-66.
- Songklanakarind Cancer Center. (2008). *Hospital based cancer registry*.

Retrieved August 13, 2010, from <http://medinfo2.psu.ac.th/cancer>

\_\_\_\_\_. (2009). *Hospital based cancer registry*.

Retrieved December 2, 2010, from <http://medinfo2.psu.ac.th/cancer>.

Songwattayanut, W. (2002). *The study on the influences of mutuality, predictability of caregiving and personal factors relating to strain from direct care of patients with cerebrovascular disease on family caregivers*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.

Sritares, W. (2004). *The factors influencing caregiver role strain of cerebrovascular disease patients' wives*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.

Stewart, B. J., & Archbold, P. G. (1992). Focus on psychometrics nursing intervention studies require outcome measures that are sensitive to change: Part two. *Research in Nursing & Health*, 16, 77-81.

Storey, D. J., Waters, R. A., Hibberd, C. J., Rush, R. W., Cargill, A. T., Wall, L. R., et al. (2007). Clinically relevant fatigue in cancer outpatients: The Edinburgh Cancer Centre symptom study. *Annals of Oncology*, 18, 1861-1869.

Suwanno, J. (1997). *Family caregivers' capabilities in caring for hospitalized stroke patients before discharge*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.

Tamtup, S. (2005). *Influences of perceived family hardiness and duration of caregiving, and physical health and depression of patients, on subjective burden of caregivers of head and neck cancer patients receiving radiotherapy*. Unpublished master's thesis, Prince of Songkla University, Thailand.

Tanji, H., Anderson, K. E., Gruber-Baldini, A. L., Fishman, P. S., Reich, S. G.,

- Weiner, W. J. et al., (2008). Mutuality of the marital relationship in Parkinson's disease. *Movement Disorder*, 13, 1843-1849.
- Turner, R. H. (1962). Role-taking: Process versus conformity. In A. M. Rose (Ed.), *Human behavior and social processes: An interactionist approach* (pp. 20-40). Boston: Houghton Mifflin.
- Uten, D. (2006). *Caregiving preparedness among caregivers of persons with alcohol induced psychotic disorders at Suan Prung Psychiatric hospital, Chiang Mai province*. Unpublished independent study, Chiang Mai University, Thailand.
- van den Berg, M. G., Rasmussen-Conrad, E. L., van Nispen, L., van Binsbergen, J. J. & Merks, M. A. (2008). A prospective study on malnutrition and quality of life in patients with head and neck cancer. *Oral Oncology*, 44, 830-837.
- Verdock-de Leeuw, I. M., Eerenstein, S. E., Van der Linden, M. H., de Bree, K.R., & Leemans, R. (2007). Distress in spouses and patients after treatment for head and neck cancer. *Laryngoscope*, 117, 238-241.
- Vickery, L. K., Latchford, G., Hewison, J. Bellew, M., & Feber, T. (2003). The impact of head and neck cancer and facial disfigurement on the quality of life of patients and their partners. *Head & Neck*, 25, 289-296.
- Walker, A. J., Pratt, C. C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations*, 44, 402-411.
- Ward, C. R. (1986). The meaning of role strain. *Advance Nursing Science*, 8 (2), 39-49.
- Weymuller, E. A., Deleylannis, F. F. W. B., & Yuch, B. (2003). Quality of life in patients with head and neck cancer. In E. N. Myers, J. Y. Suen, J. N. Myers, & E. N. Hanna (Eds.), *Cancer of head and neck* (pp. 809-825). Philadelphia:

Saunders.

- Weymuller, E. A., Yueh, B., Deleyiannis, F. W. B., Kuntz, A. L., Alsarraf, R., & Coltrera, M. D. (2000). Quality of life in patients with head and neck cancer. *Archives of Otolaryngology Head & Neck Surgery*, *126*, 329-365.
- Williams, S. W., Dilworth-Anderson, P., & Goodwin, P. Y. (2003). Caregiver role strain: The contribution of multiple roles and available resources in African-American women. *Aging & Mental Health*, *7*, 103-112.
- Winterling, J., Wasteson, E., Glimelius, B., Sjöden, P. O., & Nordin, K. (2004). Substantial changes in life: perceptions in patients with newly diagnosed advanced cancer and their spouses. *Cancer Nursing*, *27*, 381-388.
- Wirojratana, V. (2002). *Development of Thai family care inventory*. Unpublished dissertation, Oregon Health & Science University, OR.
- Wongchantra, C. (1996). *The relationship between demographic data, social support and dependent care agency in care-takers of children with cerebral palsy*. Unpublished master's thesis, Mahidol University, Bangkok, Thailand.
- Yang, C., & Kirchling, J. M. (1992). Exploration of actors related to direct care and outcomes of caregiving. *Cancer Nursing*, *15*, 173-181.
- Yoshizaki, T., Kondo, S., Wakisaka, N., Muro, S., Kitagawa, N., Tsuji, A., et al. (2009). Concurrent intra-arterial chemotherapy and radiotherapy for advanced laryngeal cancer. *Annals of Otolaryngology, Rhinology & Laryngology*, *118*, 172-178.

**APPENDICES**



## Appendix A

No .....

Date .....

### Family Caregivers' Demographic Questionnaire

Please answer all of the following questions and do not leave any question blank. Please check  $\checkmark$  in  that corresponds to your answer, or write your answer in the blank where appropriate.

1. Age ..... Year

2. Gender

1. Female

2. Male

3. Marital status

1. Single

2. Married

3. Widowed

4. Divorced

4. Religion

1. Buddhist

2. Christian

3. Muslim

4. Others (please specified) .....

5. Education level

1. No education

2. Primary school

3. Secondary school/ Diploma

4. Bachelor's degree

5. Master's degree or higher



## 16. Other persons with caring responsibility

1. No  2. Yes (please specified) .....

## 17. Health problem before caring

1. No  2. Yes (please specified) .....

## 18. Health problem during caring

1. No  2. Yes (please specified) .....

## 19. Common medicine use

1. No  
 2. Yes (please specified: drug name, dose, frequency) .....

## 20. Getting information about caregiving

1. No  2. Yes (please specified) .....

## 21. Getting training on caregiving skills

1. No  2. Yes (please specified) .....

## 22. Place for caring

1. Own house  
 2. Relative's house  
 3. Rent house/ dormitory/hotel  
 4. Temporarily patients' residence  
 5. Others (please specified) .....

## Appendix B

### Head and Neck Cancer Patients' Demographic Data Form

Please answer all of the following questions and do not leave any question blank. Please check  $\checkmark$  in  that corresponds to your answer, or write your answer in the blank where appropriate (item 1-9 for family caregivers).

1. Age ..... Year
2. Gender
  - 1. Female
  - 2. Male
3. Marital status
  - 1. Single
  - 2. Married
  - 3. Widowed
  - 4. Divorced
4. Religion
  - 1. Buddhist
  - 2. Christian
  - 3. Muslim
  - 4. Others (please specified) ...
5. Education Level
  - 1. No education
  - 2. Primary school
  - 3. Secondary/ Diploma
  - 4. Bachelor's degree
  - 5. Master's degree or higher
6. Occupation
  - 1. No job
  - 2. Labor
  - 3. Farmer
  - 4. Government officer
  - 5. Merchant
  - 6. Retired
  - 7. Other (please specified) .....

## 7. Medical expense

- |   |  |
|---|--|
| <input type="checkbox"/> 1. Own money       | <input type="checkbox"/> 2. Government support         |
| <input type="checkbox"/> 3. Social security | <input type="checkbox"/> 4. Universal health insurance |

## 8. Level of patients' dependency

- |  |  |
|--|--|
| <input type="checkbox"/> 1. Dependence   | <input type="checkbox"/> 2. Partial dependence |
| <input type="checkbox"/> 3. Independence |  |

## 9. Symptoms

- |  |   |
|--|---|
| <input type="checkbox"/> 1. Oral mucocitis           | <input type="checkbox"/> 2. Sore throat                   |
| <input type="checkbox"/> 3. Loss of taste/smell      | <input type="checkbox"/> 4. Dry mouth                     |
| <input type="checkbox"/> 5. Difficult swallowing     | <input type="checkbox"/> 6. Nausea/vomiting               |
| <input type="checkbox"/> 7. Pain                     | <input type="checkbox"/> 8. Loss of speech                |
| <input type="checkbox"/> 9. Lot of airway secretions | <input type="checkbox"/> 10. Skin infection               |
| <input type="checkbox"/> 11. Bleeding                | <input type="checkbox"/> 12. Weight loss                  |
| <input type="checkbox"/> 13. Fatigue                 | <input type="checkbox"/> 14. Anxiety                      |
| <input type="checkbox"/> 15. Stress                  | <input type="checkbox"/> 16. Other (please specified) ... |

-----

**For researcher' record**

10. Diagnosis .....

11. Stage of cancer .....

## 12. Types of treatments

- |   |
|---|
| <input type="checkbox"/> 1. Surgery (please specified ..... |
| <input type="checkbox"/> 2. Radiation .....Gy               |
| <input type="checkbox"/> 3. Chemotherapy .....Cycle         |
| <input type="checkbox"/> 4. Others (please specified) ..... |

## Appendix C

## Preparedness of Caregiving Assessment Form

Please check  $\checkmark$  in , that corresponds to how prepared you feel.

Not at all = you feel not at all prepared

Not too well = you feel not too well prepared

Somewhat well = you feel somewhat well prepared

Pretty well = you feel pretty well prepared

Very well = you feel very well prepared

Preparedness	Not at all	Not too well	Some what well	Pretty well	Very well
1. How well prepared do you think you are to take care of your patient's physical needs?					
2. How well prepared do you think you are to take care of your patient's emotional needs?					
3. How well prepared do you think you are to find out about and set up services for your patient?					
4. How well prepared do you think you are to manage for the stress of caregiving?					
5. How well prepared do you think you are to make caregiving activities pleasant for both you and your patient?					

Preparedness	Not at all	Not too well	Some what well	Pretty well	Very well
6. How well prepared do you think you are to respond to and handle emergencies that involve your patient?					
7. How well prepared do you think you are to get the help and information you need from the health care system?					
8. Overall, how well prepared do you think you are to care for your patient?					

## Appendix D

### Mutuality Assessment Form

Please check  $\surd$  in  $\square$ , that corresponds to how much mutuality do you feel.

- Not at all                    = you feel not at all
- A little                      = you feel a little
- Somewhat                  = you feel somewhat
- Quite a bit                 = you feel quite a bit
- A great deal                = you feel a great deal

Statements	Not at all	A little	Some what	Quite a bit	A great deal
1. To what extent do the two of you see eye to eye (agree on things)?					
2. How close do you feel close to him or her?					
3. How much do you enjoy sharing past experiences with him or her?					
4. How much does he or she express feeling of appreciation for you and the things you do?					
5. How much attached are you to him or her?					
6. How much does he or she helps you?					
7. How much do you like to sit and talk with him or her?					
8. How much love do you feel love for him or her?					
9. To what extent do the two of you share the same values?					



Statements	Not at all	A little	Some what	Quite a bit	A great deal
10. When you really need it, how much does he or she comfort you?					
11. How much do the two of you laugh together?					
12. How much do you confide in him or her?					
13. How much emotional support does he or she gives emotional support to you?					
14. To what extent do you enjoy the time the two of you spend together?					
15. How often does he or she express feelings of warmth toward you?					

## Appendix E

### Caregiver Role Strain Assessment Form

Caregiver role strain refers to the family caregivers' perception of difficulty in fulfilling of their caregiving role during their HNC patients receiving treatments composing of role conflict, mismatched expectation, increased tension, and global strain.

#### Part 1: Role conflict Assessment Form

Please indicate whether or not you have each by check  in  "No Role" or "Yes".

If you choose "Yes", then please  in , which corresponds to the amount of role conflict that you feel.

- Not at all                    = you feel not at all
- A little                     = you feel a little
- Some                        = you feel somewhat
- Quite a bit                = you feel quite a bit
- Very much                 = you feel very much

To what extent does caring for your patient interfere with your ability to involved in .....	No Role	Yes				
		Not at all	A little bit	Some what	Quite a bit	Very much
1. Spouse activities in the way that you think you should be?						
2. Parent activities in the way that you think you should be?						
3. Child activities in the way that you think you should be?						
4. Sister/brother activities in the way that you think you should be?						

## Part 1 (Continued)

To what extent does caring for your patient interfere with your ability to involved in .....	No Role	Yes				
		Not at all	A little bit	Some what	Quite a bit	Very much
5. Grandfather/grandmother activities in the way that you think you should be?						
6. Aunt/ uncle activities in the way that you think you should be?						
7. Friend activities in the way that you think you should be?						
8. Work activities in the way that you think you should be?						
9. Housework activities in the way that you think you should be?						
10. Student activities in the way that you think you should be?						
11. Religion activities in the way that you think you should be?						
12. Social activities in the way that you think you should be?						
13. Self care activities in the way that you think you should be?						
14. Other responsibility in the way that you think you should be?						

## Part 2: Mismatched Expectation Assessment Form

Please indicate whether or not you have each mismatched expectation by check  $\checkmark$  in  "YES / NO / NOT SURE". If you choose "YES", then please  $\checkmark$  in , which corresponds to the amount mismatch that you feel.

- Not at all                    = you feel not at all
- A little                      = you feel a little
- Somewhat                   = you feel somewhat
- Quite a bit                 = you feel quite a bit
- Very much                  = you feel very much

1. Has assisting your patient that you think should be given, but you can not do?

No ..... Go item. 2

Not Sure ..... Go item. 2

Yes

What is it? (please specified).....

How does it interfere your mind?

1. Not at all             2. A little bit             3. Somewhat

4. A quite bit          5. Very much

2. Has assisting your patient that you think should be given, but after that you thought you shouldn't do?

No ..... Go item. 3

Not Sure ..... Go item. 3

Yes

What is it? (please specified).....

How does it interfere your mind?

1. Not at all             2. A little bit             3. Somewhat

4. A quite bit          5. Very much

3.....

4.....

5.....

6.....

7. How do you feel your patient's health situation increase more help that make your family conflict?

1. Not at all

2. A little bit

3. Somewhat

4. A quite bit

5. Very much

### Part 3: Increased Tension Assessment Form

Please indicate whether or not you have each increased tension by check  $\checkmark$  in , then please  $\checkmark$  in , which corresponds to the amount tension that you feel.

- Not at all                    = you feel not at all  
 A little                      = you feel a little  
 Somewhat                  = you feel somewhat  
 Quite a bit                 = you feel quite a bit  
 Very much                  = you feel very much

Has assisting your patient .....	Not at all	A little bit	Some what	Quite a bit	Very much
1. Decrease time for yourself					
2. Increased the stress in your relationship with him/her					
3. Decrease your private time					
4. Increase his or her try to make you do thing that you don't want to do					
5. Decrease your relax activities					
6. Increase the number of unreasonable requests made of you					
7. Increase the stress in your life					
8. Decrease your rest time or travel time					
9. Increase the nervousness and depression you have concerning your relationship with him or her					
10. Take advantage of you					
11. Decrease your personal work time					

**Part 3 (Continued)**

Has assisting your patient .....	Not at all	A little bit	Some what	Quite a bit	Very much
12. Need help more than necessary					
13. Increase your anxiety about things					
14. Decrease time to meeting friends and relatives					

**Part 4: Global Strain**

Please indicate whether or not you have each global strain by check  $\checkmark$  in , then please  $\checkmark$  in , which corresponds to the amount global strain that you feel.

- |             |   |                      |
|-------------|---|----------------------|
| Not at all  | = | you feel not at all  |
| A little    | = | you feel a little    |
| Somewhat    | = | you feel somewhat    |
| Quite a bit | = | you feel quite a bit |
| Very much   | = | you feel very much   |

1. How confined do you feel because of all of the caregiving things that you do for your family member?

- |                                       |  |
|---------------------------------------|--|
| <input type="checkbox"/> 1. None      | <input type="checkbox"/> 2. A little bit |
| <input type="checkbox"/> 3. Somewhat  | <input type="checkbox"/> 4. Quite a bit  |
| <input type="checkbox"/> 5. Very much |  |

2. How often would you say that taking care of your family member is very difficult?

- |                                       |  |
|---------------------------------------|--|
| <input type="checkbox"/> 1. None      | <input type="checkbox"/> 2. A little bit |
| <input type="checkbox"/> 3. Somewhat  | <input type="checkbox"/> 4. Quite a bit  |
| <input type="checkbox"/> 5. Very much |  |

3. How much stress do you feel because all of your obligations, including taking care of your family member?

- |                                       |  |
|---------------------------------------|--|
| <input type="checkbox"/> 1. None      | <input type="checkbox"/> 2. A little bit |
| <input type="checkbox"/> 3. Somewhat  | <input type="checkbox"/> 4. Quite a bit  |
| <input type="checkbox"/> 5. Very much |  |

4.....

5.....

6.....

7. If your patient needs more caring, how much do you feel confidence more than now?

- |                                       |                                      |
|---------------------------------------|--------------------------------------|
| <input type="checkbox"/> 1. None      | <input type="checkbox"/> 2. A little |
| <input type="checkbox"/> 3. Somewhat  | <input type="checkbox"/> 4. A lot    |
| <input type="checkbox"/> 5. Very much |                                      |



## Appendix F

### Informed Consent Form

Study Title: The Relationships of Preparedness and Mutuality to Role Strain of Thai Family Caregivers of Patients with Head and Neck Cancer Receiving Treatments

Investigator: Miss Duangsuda Wongchuay

My name is Duangsuda Wongchuay, I am a master's student of the Faculty of Nursing, Prince of Songkla University, Hat Yai, Songkhla Thailand. I have studied in the Adult and Aging International Nursing Program. I am conducting a study to investigate the relationships of preparedness and mutuality to the role strain of Thai family caregivers of patients with HNC receiving treatments. This study fulfills the requirement of the master program of Nursing Faculty at the Prince of Songkla University, Hat Yai, Songkhla Thailand.

The study and its procedures have been approved by the appropriate person and Institutional Review Board (IRB) of Faculty of Nursing and Faculty of Medicine, Prince of Songkla University, Thailand. The information gathered will be used to complete a research report. The information may not have benefit for you directly, but it will be useful for nursing care in a clinical setting. It also can help nurses to be able to well prepare family caregivers' knowledge and caregiving skill, enhance mutuality and reduce caregiver role strain during providing care for HNC patients receiving treatments. The questionnaires will take approximately 30 minutes to complete answer.

Your participation in this study is voluntary. You have the right to participate or not participate. Whether, you participate or not, your family will continue to receive good care as other patients. Even you're willing to participate in this time. However, during answer the questionnaires, you feel discomfort. The researcher is willing to help you such as provide comfort and encourage the opportunity to relax. You also have the right to withdraw or withhold at any time that you want without telling a reason the researcher.

All information and your replies in connection with this study will be confidential information. Your information will not be distributed to a public. Only the researcher and the advisors are able to access the data. The information will be destroyed after finishing the study.

Finally, you should make sure that you understand all of questionnaires and willing to inform consent to participate in this study. You are free to ask any question according to the study and being a subject.

.....	.....	.....
(Name of Participant)	(Signature of Participant)	Date
.....	.....	.....
(Name of Researcher)	(Signature of Researcher)	Date
.....	.....	.....
(Name of Witness)	(Signature of Witness)	Date

If you have any questions, please contact:

Miss Duangsuda Wongchuay

Master of Nursing Science (International Program)

Faculty of Nursing, Prince of Songkla University

Hat Yai, Songkhla,

Thailand

Tel: (083) 1848403

E-mail: Tang\_psu@hotmail.com

## Appendix G

### Ethical Approval



SUB.EC 53-011-19-6-3

คณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์  
 ตำบลคลองหอยโข่ง อำเภอหาดใหญ่  
 จังหวัดสงขลา 90110

หนังสือรับรองนี้ให้ไว้เพื่อแสดงว่า

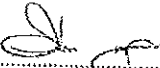
โครงการวิจัยเรื่อง : ความสัมพันธ์ของความพร้อมในการดูแลและความสัมพันธ์ทางเชื้อจุลินทรีย์ในคนจากเวรระเบียบ  
 ผู้ดูแลผู้ป่วยมะเร็งศีรษะและลำคอขณะได้รับการรักษา

หัวหน้าโครงการ : นางสาวดวงศุภา วงศ์ช่วย

ภาควิชาคณะ : คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

ได้ผ่านกระบวนการพิจารณารับรองจากคณะกรรมการพิจารณาจริยธรรมการวิจัยในคนจากเวรระเบียบ  
 และถึงส่งตรวจจากหน่วยงานผู้วิจัย ของคณะแพทยศาสตร์ มหาวิทยาลัยสงขลานครินทร์ แล้ว

ให้ไว้ ณ วันที่ 2 พฤศจิกายน 2552

  
 .....ประธานอนุกรรมการ  
 (รองศาสตราจารย์นายแพทย์วิระกมล จันทน์ดียิ่ง)  
 รองคณบดีฝ่ายวิจัย

## Appendix H

## Permission of Instrument Use



มหาวิทยาลัยมหิดล
เลขที่ 2147
วันที่ 16 มิ.ย. 53
ปี 53

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

25/25 ถนนพหลโยธินสาย 4 ศาลายา นครปฐม 73170  
โทร. 0-2441-4125 ต่อ 109-111 โทรสาร 0-2441-9834

ที่ ศธ 0517.02/ 0504

วันที่ 19 มกราคม 2553

เรื่อง อนุญาตให้ใช้เครื่องมือวิจัย

เรียน ศพช. คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์

อ้างถึง หนังสือ ที่ ศธ 0521.1.05/3901 ลงวันที่ 13 พฤศจิกายน 2552

ตามที่ น.ส.ดวงศุภา วงศ์ช่วย นักศึกษาหลักสูตรพยาบาลศาสตรมหาบัณฑิต (หลักสูตรนานาชาติ) คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลานครินทร์ มีความประสงค์จะขออนุญาตใช้เครื่องมือวิจัย คือ

- 1) แบบวัดความสัมพันธ์สำนึกถือ (Mutuality Assessment Form)
- 2) แบบวัดความพร้อมในการดูแล (Preparedness Assessment Form)
- 3) แบบวัดความเครียดในบทบาทผู้ดูแล (Caregiver Role Strain Assessment Form)

ของ นางสาววิไลพร ทรชรศ ซึ่งเป็นส่วนหนึ่งของวิทยานิพนธ์ตามหลักสูตรพยาบาลศาสตรมหาบัณฑิต สาขาวิชาการพยาบาลผู้ใหญ่ คณะพยาบาลศาสตร์ และบัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล พ.ศ. 2546 เรื่อง " THE FACTORS INFLUENCING CAREGIVER ROLE STRAIN OF CEREBROVASCULAR DISEASE PATIENTS' WIVES. " ซึ่งมี รศ.ดร.สาขนิณ เกษมกิจวัฒนา ทำหน้าที่อาจารย์ที่ปรึกษาวิทยานิพนธ์เป็นหลัก

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล ได้พิจารณาแล้วไม่ขัดข้องอนุญาตให้ น.ส.ดวงศุภา วงศ์ช่วย ใช้เครื่องมือวิจัยดังกล่าวได้เนื่องจากเป็นการศึกษาวิจัยทางด้านวิชาการ แต่ทั้งนี้ขอให้โปรดระบุให้ชัดเจนว่าใช้เครื่องมือวิจัยทุกแบบสอบถามหรือบางส่วน และให้ระบุวัตถุประสงค์วิจัยดังกล่าวมาจากวิทยานิพนธ์ของนักศึกษา หลักสูตรพยาบาลศาสตรมหาบัณฑิต มหาวิทยาลัยมหิดล ถ้าหากมีการละเมิดเกิดขึ้น ข้าพเจ้ายินยอมให้คณะพยาบาลศาสตร์ ดำเนินการตามกฎหมาย และขอให้ดำเนินการชำระค่าบริการขอใช้เครื่องมือวิจัยดังกล่าวข้างต้น จำนวน 200 บาท (สองร้อยบาทถ้วน) ค่าเครื่องมือวิจัย 1 ชุด โดยส่งมอบให้ส่งจ่าย ป.ฉ. ศิริราช ในนาม

หลักสูตรบัณฑิตศึกษา (เพื่อการขอใช้เครื่องมือวิจัย)

คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล

เลขที่ 2 ถนนพหลโยธิน แขวงศิริราช

เขตบางกอกน้อย กรุงเทพมหานคร 10700

โทร. 0-2419-7466-80 ต่อ 1411, 1412

จึงเรียนมาเพื่อโปรดทราบ และดำเนินการต่อไปด้วย จักขอพระคุณยิ่ง

ขอแสดงความนับถือ

(รองศาสตราจารย์ ดร.ทญ. หันยวีร์ เล็กกุกอร์)

รองคณบดีฝ่ายวิชาการ

ปฏิบัติงานแทน คณบดีบัณฑิตวิทยาลัย

หมายเหตุ ผู้ที่นำผลคั้งเครื่องมือวิจัยที่หลักสูตรฯ ให้ผลิตต่อหลังเวลา 8.30-14.30 น.

## Appendix I

Table II

*The Frequency and Percentage of Caregiver Related to Preparedness of Caregiving (N= 80)*

	Preparedness of Caregiving				Not at all				Not too well				Somewhat well				Pretty well				Very well			
	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%	n	%
1. Take care of patient's physical needs	0	0	3	3.7	18	22.5	22	27.5	37	46.3														
2. Take care of patient's emotional needs	0	0	8	10.0	22	27.5	25	31.3	25	31.3														
3. Find out about and set up services of patient	0	0	9	11.3	24	30.0	32	40.0	15	18.7														
4. Manage the stress of caregiving	0	0	11	13.7	28	35.0	32	40.0	9	11.3														
5. Make caregiving activities pleasant for both caregivers and their patient	0	0	4	5.0	23	28.7	38	47.5	15	18.7														
6. Respond to and handle emergencies that involve him or her	8	10.0	16	20.0	27	33.7	15	18.7	14	17.5														
7. Get the help and information you need from the health care system	0	0	10	12.5	24	30.0	23	28.7	23	28.7														
8. Overall, to care for patients	0	0	0	0	30	37.5	21	26.2	29	36.3														

Table 12

The Frequency and Percentage of Caregiver Related to Mutuality (N= 80)

	Not at all		A little		Somewhat		Quite a bit		A great deal	
	n	%	n	%	n	%	n	%	n	%
1. See eye to eye (Agree on things)	3	3.7	13	16.3	19	23.7	21	26.3	24	30.0
2. Feel close to patient	0	0	1	1.3	12	15.0	24	30.0	43	53.7
3. Enjoy sharing past experiences with patient	7	8.7	13	16.3	22	27.5	23	28.7	15	18.7
4. Perceive in patient's appreciating	3	3.7	8	10.0	21	26.3	23	28.7	25	31.3
5. Attached to patient	0	0	3	3.7	8	10.0	18	22.5	51	63.7
6. Received help from patient	0	0	14	17.5	13	16.3	29	36.3	24	30.0
7. Like to sit and talk with patient	0	0	9	11.3	15	18.7	32	40.0	24	30.0
8. Feel love for patient	0	0	1	1.3	10	12.5	15	18.7	54	67.5
9. Share the same values	0	0	5	6.3	30	37.5	30	37.5	15	18.7
10. Get comfort from patient	6	7.5	15	18.7	20	25.0	29	36.3	10	12.5
11. Laugh together	0	0	24	30.0	18	22.5	31	38.7	7	8.7
12. Confide in patient	5	6.3	25	31.3	19	23.7	18	22.5	13	16.3
13. Receive emotional support from patient	4	5.0	2	2.5	33	41.3	30	37.5	11	13.7
14. Enjoy the time spend together	0	0	3	3.7	21	26.3	21	26.3	35	43.7
15. Perceived the patient's expression regarding feeling of warmth toward caregivers	1	1.3	8	10.0	15	18.7	29	36.3	27	33.7

Table 13

The Frequency, Percentage, Mean, and Standard Deviation of Caregiver Related to Role Conflict (N= 80)

The amount of role conflict that you feel	No Role		Yes					M	SD					
	Not at all		A little bit	Somewhat	Quite a bit	Very much								
	n	%	n	%	n	%	n			%				
1. Caring for patient interfere with your ability to involved in spouse activities	14	17.5	35	43.7	27	33.7	3	3.7	0	0	1	1.3	0.56	0.73
2. Caring for patient interfere with your ability to involved in parent activities	7	8.7	33	41.3	29	36.3	9	11.3	2	2.5	0	0	0.73	0.79
3. Caring for patient interfere with your ability to involved in child activities	23	28.7	33	41.3	20	25.0	2	2.5	2	2.5	0	0	0.53	0.73
4. Caring for patient interfere with your ability to involved in sister/brother activities	13	16.3	41	51.3	22	27.5	3	3.7	1	1.3	0	0	0.46	0.66
5. Caring for patient interfere with your ability to involved in grandfather/ grandmother activities	37	46.3	19	23.7	23	28.7	1	1.3	0	0	0	0	0.58	0.55
6. Caring for patient interfere with your ability to involved in aunt/ uncle activities	30	37.5	28	35.0	21	26.3	1	1.3	0	0	0	0	0.48	0.61
7. Caring for patient interfere with your ability to involved in friend activities	36	45.0	22	27.5	18	22.5	4	5.0	0	0	0	0	0.59	0.66

Table 13 (Continued)

The amount of role conflict that you feel	No Role		Yes								M	SD		
	Not at all		A little bit		Somewhat		Quite a bit		Very much					
	n	%	n	%	n	%	n	%	n	%				
8. Caring for patient interfere with your ability to involved in work activities	11	13.7	16	20.0	27	33.7	20	25.0	5	6.3	1	1.3	1.25	0.95
9. Caring for patient interfere with your ability to involved in homework activities	4	5.0	32	40.0	40	50.0	4	5.0	0	0	0	0	0.63	0.59
10. Caring for patient interfere with your ability to involved in student activities	78	97.5	0	0	2	2.5	0	0	0	0	0	0	1.00	0.00
11. Caring for patient interfere with your ability to involved in religion activities	12	15.0	32	40.0	28	35.0	5	6.3	3	3.7	0	0	0.69	0.80
12. Caring for patient interfere with your ability to involved in social activities	10	12.5	26	32.5	36	45.0	5	6.3	3	3.7	0	0	0.79	0.76
13. Caring for your patient interfere with your ability to involved in self care	3	3.7	36	45.0	36	45.0	2	2.5	1	1.3	2	2.5	0.66	0.82
14. Caring for your patient interfere with your ability to involved in other responsibility	3	3.7	35	43.7	40	50.0	2	2.5	0	0	0	0	0.57	0.55



Table I4

The Frequency, Percentage, Mean, and Standard Deviation of Caregiver Related to Mismatched Expectation (N= 80)

Amount of Mismatch that you feel	Not sure		No		Yes							M	SD				
					Not at all		A little bit		Somewhat		Quite a bit			Very much			
	n	%	n	%	n	%	n	%	n	%	n			%	n	%	
1. Assist your patient that you think should be given, but you can not do	7	8.7	66	82.5	3	3.8	2	2.5	0	0	0	0	0	2	2.5	0.14	0.67
2. Assist your patient that you think should be given, but after that you thought you shouldn't do	8	10.0	66	82.5	3	3.8	3	3.7	0	0	0	0	0	0	0	0.04	0.20
3. Assist your patient done by him/herself, but you think you should help to do	11	13.7	60	75.0	2	2.5	5	6.7	2	2.5	0	0	0	0	0	0.13	0.42
4. Want your patient do without your help?	3	3.7	66	82.5	3	3.8	3	3.7	3	3.7	2	2.5	0	0	0	0.19	0.63
5. Feel your patient had more expectation in yourself	0	0	0	0	20	25.0	28	35.0	18	22.5	6	7.5	8	10.0	1.42	1.23	
6. Blame yourself about a behavior you have directed towards your patient	0	0	0	0	72	90.0	6	7.5	2	2.5	0	0	0	0	0	0.12	0.40
7. Feel your patient's health need more help that make your family conflict	0	0	0	0	61	76.3	17	21.3	2	2.5	0	0	0	0	0	0.26	0.50

Table 15

The Frequency, Percentage, Mean, and Standard Deviation of Caregiver Related to Increased Tension (N= 80)

The amount of tension that you feel	Not at all		A little bit		Somewhat		Quite a bit		Very much		M	SD
	n	%	n	%	n	%	n	%	n	%		
	1. Assisting patient has decreased your time	22	27.5	53	66.3	2	2.5	5	3.7	0		
2. Assisting patient has increased the stress in your relationship with him/her	50	62.5	25	31.3	5	6.3	0	0	0	0	0.44	0.61
3. Assisting patient has decreased your private time	37	46.3	42	52.5	0	0	1	1.3	0	0	0.56	0.57
4. Assisting patient has increased him or her that makes you do things you don't want to do	72	90.0	8	10.0	0	0	0	0	0	0	0.10	0.30
5. Assisting patient has decreased your relax activities	47	58.7	29	36.3	4	5.0	0	0	0	0	0.46	0.59
6. Assisting patient has increased a number of your unreasonable requests	67	83.7	7	8.7	5	6.3	1	1.3	0	0	0.25	0.63
7. Assisting patient has increased the stress in your life	38	47.5	27	33.7	10	12.5	4	5.0	1	1.3	0.79	0.94
8. Assisting patient has decreased your rest time or travel time	29	36.3	45	56.3	5	6.3	1	1.3	0	0	0.73	0.64
9. Assisting patient has increased your depression	60	75.0	16	20.0	4	5.0	0	0	0	0	0.30	0.56
10. Assisting patient has taken advantage of you	73	91.3	5	6.7	2	2.5	0	0	0	0	0.11	0.39
11. Assisting patient has decreased your personal work time	29	36.3	39	48.7	8	10.0	4	5.0	0	0	0.84	0.80
12. Assisting patient has needed help more than usual	55	68.7	16	20.0	8	10.0	1	1.3	0	0	0.44	0.73
13. Assisting patient has increased your anxiety	23	28.7	31	38.7	20	25.0	3	3.7	3	3.7	1.15	1.01
14. Assisting patient has decreased your time to meeting friends and relatives	25	31.3	42	52.5	10	12.5	3	3.7	0	0	0.89	0.76

Table 16

*The Frequency, Percentage, Mean, and Standard Deviation of Caregiver Related to Global Strain (N= 80)*

The amount of overall that you feel	Not at all		A little bit		Somewhat		Quite a bit		Very much		M	SD
	n	%	n	%	n	%	n	%	n	%		
	1. Feel lack of independence	34	42.5	44	55.0	2	2.5	0	0	0		
2. Feel difficult in caring your patient	23	28.7	41	51.3	13	16.3	3	3.7	0	0	0.95	0.78
3. Feel stress in your responsibility	21	26.3	36	45.0	21	26.3	1	1.3	1	1.3	1.06	0.83
4. Feel lack of patience in caring for patient	57	71.3	19	23.7	2	2.5	2	2.5	0	0	0.36	0.66
5. Feel bad from caring for patient	41	51.3	18	22.5	16	20.0	5	6.3	0	0	0.81	0.97
6. Feel difficult when patient had symptoms change	16	20.0	14	17.5	41	51.3	9	11.3	0	0	1.54	0.94
7. Feel confidence more than now	20	25.0	23	28.7	18	22.5	14	17.5	5	6.3	2.49	1.22

## VITAE

**Name** Miss Duangsuda Wongchuay

**Student ID** 5110420093

### Educational Attainment

Degree	Name of Institution	Year of Graduation
Bachelor of Nursing Science	Prince of Songkla University	2008

### Scholarship Award during Enrollment

2008-2010 Teacher Scholarship for the Degree of Master of Nursing Science  
(International Program), Faculty of Nursing, Prince of Songkla  
University, Songkhla, Thailand

### List of Publication and Proceedings

Wongchuay, D., Kitrungrrote, L., & Petpichetchian, W. (2010, July 3). *Preparedness of caregiving and caregiver role strain among family caregivers of patients with head and neck cancer receiving treatments*. Paper presented at the 2010 National Research Conference Proceedings, Songkhla, Thailand