# FACTORS INFLUENCEING FAMILY CAREGIVER

# BURDEN AT A TAIWANESE HOSPITAL

by

# Pi-Ming Yeh

A Dissertation Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in

Nursing

at

The University of Wisconsin-Milwaukee

August 2003

# FACTORS INFLUENCEING FAMILY CAREGIVER

### BURDEN AT A TAIWANESE HOSPITAL

by

Pi-Ming Yeh

A Dissertation Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in

Nursing

at

The University of Wisconsin-Milwaukee

August 2003

<u>6/20/03</u> Date 9/18/03 Date

ii

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

V

#### ABSTRACT

# FACTORS INFLUENCEING FAMILY CAREGIVER BURDEN AT A TAIWANESE HOSPITAL

by

#### Pi-Ming Yeh

# The University of Wisconsin-Milwaukee, (2003) Under the Supervision of Dr. Mary Wierenga

In Taiwan, most of the hospitalized patients have their relatives with them 24 hours a day. New family caregivers are usually poorly prepared to take on their role, and little literature demonstrates that nurses assess the burden of family caregivers in the hospital. The purpose of this study was to examine cancer patients' dependency, caregivers' factors, and family support that predict outcomes of family caregiver burden, including impact on health, schedule, and finances in the hospitals in Taiwan.

A multivariate descriptive design was used. This study was conducted with 91 Chinese family caregivers of patients diagnosed with cancer in the Chung-Shan Medical University Hospital in Taiwan. These family caregivers were asked to complete structured questionnaires. The instruments used to collect data were Sociodemographic Data Questionnaire, Caregiver Reaction Assessment, Family Caregiving Factors Inventory, and Psychological Well-Being Scale.

Data were analyzed using descriptive statistics, t-test, MANOVA, Pearson-Product Moment Correlation and hierarchical multiple regression analyses. The results indicated that patients' ADL dependency had a significantly positive relationship with impact on visits to family and friends and time for relaxation components of the Impact on Schedule Subscale. Family caregivers who had higher scores of psychological well-being, quality of relationship between family caregivers and care receivers, and knowledge of caregiving had lower impact on health scores. Family caregivers' psychological well-being also had a negative relationship with impact on finances. Caregivers' psychological well-being and quality of relationship with care receivers were significantly negative associated with impact on relaxation. Family caregivers who had more knowledge of caregiving had less impact on visits to family and friends. Family caregivers who had less family support had more impact on health, finances, visits to family and friends, and time for relaxation.

The first model variables accounted for 59% of the variance in impact on health. Older caregivers, poorer health status after being a caregiver, lower scores of psychological well-being, lower scores of quality of relationship, and lack of family support were found to predict significantly greater impact on health. The second model variables accounted for 21.3% of the variance in impact on finances. Family income and lack of family support were significant predictors for impact on finances. Family caregivers who had higher family income and family support had lower impact on finances. Recommendations for future research, nursing practice, and health policy are also included.

		6/20/03
Major Professor	0	Date

iv

© Copyright by Pi-Ming Yeh, 2003 All Right Reserved

# DEDICATION

# Glory to God

# Peace and Joy to the People on the Earth

# TABLE OF CONTENTS

ABSTRACTiii
LIST OF FIGURESxi
LIST OF TABLESxii
ACKNOWLEDGEMENTSxiii
CHAPTER
I. INTRUDUCTION
Background and Significance1
Purpose of Study5
Theoretical Framework5
Research Questions
Definitions of Terms10
Significance11
Summary11

### **II. REVIEW OF LITERATURE**

Family Caregiver Burden	12
Care Receiver Dependency of Daily Activities	.16
Family Caregiver Characteristics	20
Family Caregiver Psychological Well-Being	.24
Quality of Relationship between Family Caregiver and Care Receiver	26
Knowledge of Caregiving	28
Support Resources	.31
Summary	. 32

# **III. METHODOLOGY**

	Research Design
	Sample and Setting
	Instruments
	Socio-Demographic Questionnaire
	The Index of ADL40
	Psychological Well-Being Scale41
	Knowledge of Caregiving Subscale42
	Caregiver Reaction Assessment (CRA)43
	Esteem Subscale of CRA44
	Lack of Family Support Subscale of CRA45
	Data Collection Procedures
	Questionnaire Translation45
	Pilot Study46
	Main Study47
	Data Analysis Procedures
	Possible Reasons for Low Reliability50
	Solutions for Low Reliability51
	Summary55
I	V. RESULTS
	Description of Family Caregivers55
	Description of Care Receivers61
	Descriptive Statistics for Major Variables

### Analysis of Research Questions

Research Question 1	67
Research Question 2	68
Research Question 3	70
Research Question 4	71
Revised Conceptual Model	80
Summary	81

### V. SUMMARY, DISCUSSION AND RECOMMENDATIONS

Summary of the Study	
Measurements	83
Discussion of Results	86
Revised Conceptual Model	99
Limitations	99
Recommendations	
Research	101
Practice	103
Policy	104
Summary	105
REFERENCES	106
APPENDICES	

Appendix A: Demographic Questionnaire	112
Appendix B: The Index of ADL	115
Appendix C: Psychological Well-Being Scale	117
Appendix D: Knowledge of Caregiving	120

Appendix E: Caregiver Reaction	n Assessment	122
Appendix F: Data Collection To	ol (English Version)	125
Appendix G: Data Collection To	ool (Chinese Version)	132
Appendix H: Permission Letters	s to Conduct the Study	138
Appendix I: Information Sheet (	(English and Chinese Version)	140
Appendix J: Human Subjects Ap	pproval Document	144
Appendix K: Permission to use	Measurement Tools	146
VITA		150

# LIST OF FIGURES

Figure 1: A conceptual model of factors influencing family caregiver burden at a
Taiwanese hospital6
Figure 2: The revised conceptual model for factors influencing family caregiver
burden at a Taiwanese hospital80

# LIST OF TABLES

Table 1: Summary Information for the Data Collection Instruments
Table 2: Procedure of Data Analysis
Table 3: Caregiver Characteristics
Table 4: Independent Samples t-test between Not Staying & Staying in the hospital for
a long time if nurses can provide a complete care60
Table 5: Patient Characteristics
Table 6: Patient Dependency64
Table 7: Descriptions of Major Variables
Table 8: Pearson Correlations Between Caregiver Characteristics and
Major Variables
Table 9: Pearson Correlation between Care Receiver's ADL dependence and Impact on
Health, Finances, Visits, and Relaxation67
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,         Finances, Visits, and Relaxation
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,Finances, Visits, and RelaxationFinances, Visits, and Relaxation69Table 11: Pearson Correlation between Lack of Family Support and Impact on Health,
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,         Finances, Visits, and Relaxation         Table 11: Pearson Correlation between Lack of Family Support and Impact on Health,         Finances, Visits, and Relaxation
Table 10: Pearson Correlation between Caregiver Factors and Impact on Health,         Finances, Visits, and Relaxation         Table 11: Pearson Correlation between Lack of Family Support and Impact on Health,         Finances, Visits, and Relaxation         70         Table 12: Hierarchical Multiple Regression of Impact on Health.         73
<ul> <li>Table 10: Pearson Correlation between Caregiver Factors and Impact on Health, Finances, Visits, and Relaxation</li></ul>
<ul> <li>Table 10: Pearson Correlation between Caregiver Factors and Impact on Health, Finances, Visits, and Relaxation</li></ul>

#### ACKNOWLEDGEMENTS

I have been very fortunate to have the support of many people as I worked on this project. It is my pleasure to be able to thank those who worked closely with me and helped me to ensure its completion.

First and foremost, I must thank my dissertation committee members, Dr. Mary E. Wierenga, Dr. Sally Lundeen, Dr. Christine R. Kovach, Dr. Jane B. Leske, and Dr. Joan M. Jones, for their guidance and support during my four years' study in the Ph. D. program in Nursing at the University of Wisconsin— Milwaukee. The committee members' guidance has been like a lighthouse, which shows me the right direction in my academic pursuits.

I would like to especially thank my major professor, Dr. Wierenga, for her tireless support, guidance, and enthusiasm. Not only has she shared her expert knowledge with me, but also, with her devotion to teaching and research, she is a model of the kind of professor I aspire to be. If it had not been for her support and encouragement, I would not have successfully fulfilled all the requirements for the doctoral degree.

I also want to express my sincere gratitude to Professor Su-Chuan Yuan, the Dean of Nursing Department in Chung-Shan Medical University Hospital in Taiwan, and five head nurses, Mrs. Shu-Mei Tsai, Yu-Ping Liu, Yueh-Chiao Tsai, I-Lin Lai, and Yu-Hua Chan, for assisting me in data collection. To Mrs. Cythia Han and Yanmei Jiang, I would like to extend appreciation for helping me proofread my dissertation. My appreciation also goes to all the participants in this study for their time and efforts. Without their cooperation, this study would not have been possible.

My work has been generously supported by Dr. Barbara Given, Dr. Carol Ryff, and Dr. Yea-Ing Lotus Shyu for permitting me to use their questionnaires. To biostatistician Sheryl Kelber, I would like to express my gratitude for constantly and unselfishly helping me with methodology and data analysis.

Over the years, my parents, Ting-Chin Yeh and Hsia-Tzu Lin, have been

supporting me in so many ways. I want to express my deepest appreciation to them for all they have done and have enabled me to do. I also thank my brothers, Pi-Chung Yeh, Pi-Hsin Yeh, and Pi-Li Yeh, who have always been interested in and supported what I do. My thanks also go to the church members in Milwaukee Chinese Christian Church for their encouragement, support, and prayers, which helped me immensely in my life and academic pursuit. I also want to express my sincere thanks to all of the teachers in Chung-Shan Medical University for their support and encouragement during these years. To Bley family Leroy, Joan, and Amy, I would like to express my gratitude for their love to be my host family.

Finally, I own more than thanks to my husband, Cheng-Huei Chao, and my dear children, Chung-Yun Chao and Hsin-Yun Chao, for their love, understanding, and support which exist in endless reserve. They have always been there for me during both good times and bad times.

#### CHAPTER I

#### INTRODUCTION

This chapter provides an introduction to the proposed research, including background and significance of the problems, purpose of study, theoretical framework, research questions, and definitions. The purpose of this study is to examine factors influencing cancer patients' family caregiver burden in the hospital in Taiwan.

#### **Background and Significance**

The population of Taiwan aged 65 and over will increase from 1.6 million in 1995 to 3.4 million in 2020, and to 5.5 million in the year 2035 (Manpower Planning Department, R. O. C., 1996). This rapid increase in the number of elderly in the Taiwanese population increases the need for family caregivers both in the hospital and at home. Many families of hospitalized patients experience severe caregiving and financial burden. Family caregivers in the U.S.A. and Taiwan have similar experiences with regard to the impact on their health, schedule, and finances (Chou, 2000; Given et al., 1992; Liu, Hwu, & Lee, 1998; Yeh, 1995). In the U.S.A., families of the young, poor, and functionally dependent patients are most likely to report loss of some or most of the family's savings (Covinsky et al., 1994).

In most Chinese families, the concept of Chinese "Hsiao" (filial piety) is an important factor in family caregiving. Hsiao is defined as "being nice and obedient to your parents, pleasing your parents and caring for them" and "not putting shame on parents and bringing honor to them" (Sheu, 1997, p. 71). Most adult children strongly believe that helping and caring for parents is their responsibility of being Hsiao and being a child. Family caregivers who have higher scores of filial obligation have lower caregiver burden and higher caregiving involvement (Chou, 1998; Chou, LaMontagne, & Hepworth, 1999).

About 88% of the Taiwanese family caregivers lived with care receivers (Chiu, Pai, Tang, & Wang, 1996; Qin, You, & Huang, 1999; Wu, Hu, & Yao, 1991), and 84.5% of the family caregivers took care of the care receivers for 24 hours a day and 7 days every week (Chiu et al., 1996). Fifty to five percent of the family caregivers had no family member to help them care for the patient during the week (Chiu et al., 1996), and 31.9% to 55.7% of the family caregivers perceived that after providing caregiving, their own health status had deteriorated (Lin, Ku, Leu, Chen, & Lin, 1996; Wu et al., 1991). The burden and stress of family caregivers also affected the caregivers' life satisfaction (Acton, 1997).

Because the filial concept of supporting parents remains very important in Taiwan (Yeh, 1997), most elderly people live with their children, especially with their son's family. The living arrangements of elderly persons reflect their health as well as their family cultural ties (U. S. Department of Health and Human Services [U.S. DHHS], 1999). Older non-married persons who live alone (the majority of whom are widowed) in general have better health than non-married persons who do not live alone (U.S. DHHS, 1999). In the U.S.A., 32% of the elderly (age greater than 65 years old) live alone, 47% live with a spouse, 17% with other relatives, and 4% live with non-relatives (U.S. DHHS, 1999). In the USA, 47% of elderly women live alone, and 62% of elderly men lived with a spouse. This disparity is due to the fact that women have a longer life span (79.4 years) than men (73.6 years) (U.S. DHHS, 1999). Because Taiwanese culture and country area are different from U.S.A., in Taiwan, 62.93% of the elderly (age > 65 years old) live with

adult children, 18.7% with a spouse, 14.52% alone, 2.42% with other relatives, and 1.19% in institutions (Yeh, 1997).

Family caregivers receive very little information from health professionals concerning their patient's health problems and care needs at home (Brereton, 1997; Driscoll, 2000). The family caregivers' health and employment status are often not considered in their patients' discharge plans (Brereton, 1997; Driscoll, 2000). Family caregivers who are present with their care receivers when they receive information concerning post-discharge care experience a decrease in anxiety during their care receivers' convalescence at home, and greater satisfaction with the information they receive. Their patients experience fewer medical problems post-discharge (Brereton, 1997; Driscoll, 2000). New family caregivers usually are poorly prepared to take on their role, and they lack the information and skills to provide good care (Brereton, 1997). Failure to include family members in discharge planning has been shown to place elders at risk for readmission to the hospital (Bull, 1992; Bull, Jervis, & Her, 1995; Cummings, 1999; Kee & Borchers, 1998). Nurses play an important role in helping family caregivers, but currently lack a systematic assessment and intervention approach for helping family caregivers prepare for their new role (Brereton, 1997).

Caregivers of patients diagnosed with cancer were the population of this study. Cancer is a very severe disease in Taiwan. From 1982 to 2000, cancer was the leading cause of death in Taiwan (Department of Health, 2001). There were 5,532 cancer inpatients in 1995 and this number has increased to 9,394 cancer inpatients in 1999 in the National Taiwan University Hospital. In Taiwan, patients being treated for cancer have hospital stays of two to four weeks (National Taiwan University Hospital, 1999). Cancer

can cause changes in patients' functional ability, bodily functions, appearance, employment status, family and social role, and self-image. These changes also impact the lives of family caregivers (Siegel et al., 1991). Patients with cancer may become dependent on others for daily activities.

In Taiwan, most of the hospitalized patients have relatives or foreign laborers with them 24 hours a day. When a family member is sick and stays in a hospital from one week to one month, the first impact on a family caregiver is role engaging. Role engaging occurs primarily before discharge and is the process the caregiver uses to prepare for and begin the role of caregivers (Shyu, 2000b). In the stage of role engaging, family caregivers need health information including information about the care receivers' condition, caregiving skills, symptom monitoring and management, personal care delivery, emergency management, and support resources (Shyu, 2000c).

The factors that influence family caregiver burden have been demonstrated in many studies, but the literature does not demonstrate that nurses apply this knowledge to assess the burden of family caregivers in the hospitals. In the clinical situation, nurses need an easy and simplified model to assess family caregiver burden when developing a discharge plan for family caregivers in Taiwan. In this study, the predictors of impact on family caregiver health, schedule, and finances were examined with hospitalized cancer patients in Taiwan. The findings of this study can help nurses to understand the factors that influence the health, schedule, and finances of the family caregivers of cancer patients in the hospital in Taiwan.

#### Purpose

The purpose of this study was to examine hospitalized cancer patients' dependency, caregivers' factors, and family support that predict outcomes of family caregiver burden, including impact on health, schedule, and finances in Taiwan.

#### **Theoretical Framework**

The theoretical framework (Figure 1) for this study is based on a modification of the caregiving model proposed by Given, Collins, and Given (1988). They identified factors influencing caregivers' responses to patients including the patients' symptoms and dependencies, the caregivers' characteristics and social roles, the social support, financial resources and health care services available within the caregiving environment, and quality of prior relationship between family caregivers and patients. They also developed a measure, Caregiver Reaction Assessment, to describe these responses (Given et al., 1992).

Figure 1 illustrates the conceptual model for this study. Patients' ADL dependency was a predictor of caregiving burden. Caregivers' factors, including psychological wellbeing, quality of relationship with care receivers, and knowledge of caregiving, were also examined. Because the participants of this study were in the hospital, they were assumed to have similar access to health care services, so only family support was considered as an influencing factor of caregiver burden in the caregiving environment. Family caregiver burden was measured by impact on health, schedule, and finances.

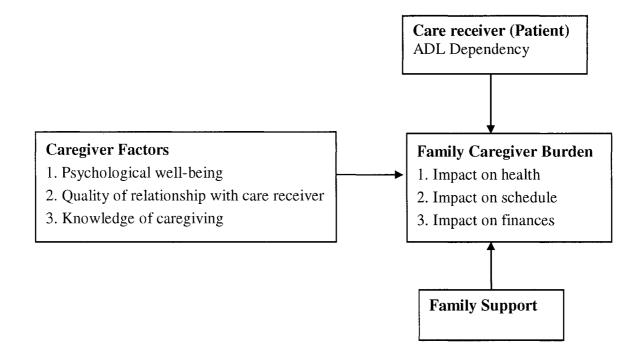


Figure 1. A conceptual model of factors influencing family caregiver burden at a Taiwanese hospital

According to previous research, family caregiving burden is affected by the amount of assistance needed for activities of daily living (ADL), such as getting in/out of bed, getting to/using toilet, getting dressed/undressed, eating, walking, and instrumental activities of daily living (IADL), such as shopping, cooking/preparing meals, by the care receivers (Danielson, Hamel-Bissell, & Winstead-Fry, 1993; Given, Given, Helms, Stommel, & DeVoss, 1997; Given et al., 1999; Chou, 2000; Shyu, 2000b; Wright & Leahey, 2000). Family caregivers' characteristics (Danielson et al., 1993; Montgomery et al., 1985; Given et al., 1988; Uhlenberg, 1996; Acton, 1997; Wright & Leahey, 2000), physical health, psychological well-being (Given et al., 1988; Uhlenberg, 1996; Acton, 1997), quality of relationship between caregivers and care receivers (Danielson et al., 1985; Given et al., 1988; Shyu, 2000b; Wright & Leahey, 2000), and knowledge of caregiving activities (Danielson et al., 1993; Uhlenberg, 1996; Shyu, 2000b) are significantly associated with family caregiver burden. Support resources can relieve the burden experienced by a family caregiver (Danielson et al., 1993; Given et al., 1988; Uhlenberg, 1996; Acton, 1997; Chou, 2000; Shyu, 2000b; Wright & Leahey, 2000).

In this study, the participants cared for cancer patients in the hospital in Taiwan. Family caregivers were asked to report the type and the amount of ADL that they needed to provide. Assistance with IADL does not become necessary until the patient is discharged and therefore was not considered in this study. Many Western studies have examined the factors influencing family caregiver burden described above. In those studies, most family caregivers were providing care in the community. The phenomenon of family members taking care of patients in the hospital has not been reported in Western studies.

Most of the studies associated with family caregiving in Taiwan were conducted in the community and the populations were family caregivers of elderly care receivers (Chiu et al., 1996; Qin, You, & Huang, 1999; Shyu, Archbold, & Imle, 1998; Shyu, 2000a; Shyu, 2000b; Shyu, 2000c; Weng, Ma, Zhang, & Zheng, 2002; Wu, Hu, & Yao, 1991), stroke care receivers (Lin, Liu, & Hung, 1999; Zhong & Huang, 1998), domiciliary palliative care (Hu, Chen, Chen, Lin, & Lin, 2001; Hu et al., 1999). Few studies have examined family caregivers of cancer patients in the hospital, and no study was found that examined the relationships among the psychological well-being of family caregivers, the quality of the relationship between family caregiver and patients, the knowledge of family caregivers, and family support associated with family caregiver burden, including impact on health, schedule, and finances among cancer patients' family

caregivers in the hospital in Taiwan. Because it is not suitable to generalize findings from Western research to Taiwanese families without considering cultural differences, research needed to be conducted to examine the impact of caregiving on Taiwanese caregivers themselves. Hence, the purpose of this study was to identify and describe variables influencing cancer patients' family caregiver burden in hospitals in Taiwan.

#### **Research Questions**

- 1. What is the relationship between the care receiver's dependence for activities of daily living and family caregiver burden?
  - (1) What is the relationship between the care receiver's dependence for activities of daily living and impact on family caregivers' health?
  - (2) What is the relationship between the care receiver's dependence for activities of daily living and impact on family caregivers' schedule?
  - (3) What is the relationship between the care receiver's dependence for activities of daily living and impact on family caregivers' finances?
- 2. What is the relationship between the caregiver factors and family caregiver burden?
  - (1) What is the relationship between the family caregivers' psychological well being and impact on family caregivers' health?
  - (2) What is the relationship between the family caregivers' psychological well being and impact on family caregivers' schedule?
  - (3) What is the relationship between the family caregivers' psychological well being and impact on family caregivers' finances?
  - (4) What is the relationship between the family caregivers and care receivers quality of relationship and impact on family caregivers' health?

- (5) What is the relationship between the family caregivers and care receivers quality of relationship and impact on family caregivers' schedule?
- (6) What is the relationship between the family caregivers and care receivers quality of relationship and impact on family caregivers' finances?
- (7) What is the relationship between the knowledge of caregiving and impact on family caregivers' health?
- (8) What is the relationship between the knowledge of caregiving and impact on family caregivers' schedule?
- (9) What is the relationship between the knowledge of caregiving and impact on family caregivers' finances?
- 3. What is the relationship between family support and family caregiver burden?
  - (1) What is the relationship between family support and impact on family caregivers' health?
  - (2) What is the relationship between family support and impact on family caregivers' schedule?
  - (3) What is the relationship between family support and impact on family caregivers' finances?
- 4. How much of family caregiver burden will be predicted by care receiver's dependence for activities of daily living, caregiver factors, and family support?
  - (1) How much impact on family caregivers' health will be predicted by care receiver's dependence for activities of daily living, caregiver factors, and family support?

- (2) How much impact on family caregivers' schedule will be predicted by care receiver's dependence for activities of daily living, caregiver factors, and family support?
- (3) How much impact on family caregivers' finances will be predicted by care receiver's dependence for activities of daily living, caregiver factors, and family support?

#### **Theoretical Definitions of Variables**

#### Family Caregiver Burden

Family caregiver burden is the subjective perception of the caregiver's health status, the impact on caregiver's schedule, and the impact on the caregiver's finances (Given et al., 1992). Impact on caregiver's health has been defined as the caregiver's feeling of decline in physical health (Given et al., 1992; Nijboer et al., 2000). Impact on caregiver's schedule has been defined as the extent to which caregiving tasks influence the usual activities of the caregiver (Given et al., 1992; Nijboer et al., 2000). Impact on caregiver's finances has been defined as the financial tension on the caregiver as a result of the caregiving situation (Given et al., 1992; Nijboer et al., 2000).

#### Activities of Daily Living (ADL)

Normal functions associated with taking care of oneself, such as getting in/out of bed, getting to/using toilet, getting dressed/undressed, eating, walking (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963).

#### Caregivers' Factors

1. Caregivers' psychological well-being includes measures of autonomy, environmental mastery, personal growth, positive relations with others, purpose in life

and self-acceptance (Ryff, 1989).

2. Quality of the relationship between caregivers and care receivers means the caregivers' attitudes towards the care receiver relevant to the tasks they perform (Given, 1992).

3. Caregivers' knowledge of caregiving means the caregivers' understanding of the needs and abilities of the care receiver (Shyu, 2000a).

#### Family Support

Family support means the caregivers' perception of family members' help, mental support, and ability to work together with the caregivers (Given et al., 1992).

#### Significance

The findings of this study may help clinical practice nurses identify information to be included in a discharge plan for cancer patients and their family caregivers. The results of this study will contribute to the scientific base on burden in family caregivers, as well as to educate policymakers and the general public about the impact on the family caregivers of cancer patients in the hospital.

#### Summary

This chapter provided an introduction to the proposed research, including background and significance, purpose, theoretical framework, research questions, and definitions of terms. A research model based on previous literature was applied to guide this study. The purpose of the study was to examine factors influencing family caregiver burden at a Taiwanese hospital.

#### CHAPTER II

#### **REVIEW OF THE LITERATURE**

This chapter contains a critical review of the literature, organized according to the conceptual model of factors influencing family caregiver burden in the hospital in Taiwan discussed in Chapter I. The model describes the relationships between patients' dependency for ADL, caregiver factors (psychological well-being, quality of relationship with care receiver, and knowledge of caregiving), family support, and family caregiver burden. Previous studies of family caregiver burden are described. The relationships between predictors and family caregiver burden are illustrated in the following sections, according to cancer or non-cancer patients.

#### **Family Caregiver Burden**

#### Descriptions of Family Caregiving Burden

Family caregiving burden has been defined and categorized in a number of different ways. Although caregiving experiences have been reported as negative, positive, or neutral concepts (Hunt, 2003; Klein, 1989), this study focused on the negative consequences of being a family caregiver. Family caregiver burden has been defined as "the oppressive or worrisome load borne by people providing direct care for the chronically ill" (Hunt, 2003). This study focused on the impact on caregivers' health, schedule, and finances when caregivers cared for cancer patients as representative of caregiving burden. Family caregiver burden and changes in family roles had a negative effect on their quality of life (McCorkle et al., 1993).

Researchers have reported family caregiver burden in different ways, depending on the approaches they utilized to assess the burden. The burden of family caregivers has been considered from multiple dimensions. From the physical health perspective, caregiver muscle strain and back pain were common (American Association of Retired Persons [AARP]; The Travelers Foundation, 1988; Weng, Ma, Zhang, & Zheng, 2002). From the mental and emotional perspective, caregiver burden included caregivers' stress (Chen, 1997; Wright, Clipp, & George, 1993; Weng et al., 2002), strain (Robinson, 1983), helplessness (Chiu et al., 1996; Lin, Liu, & Hung, 1999; Weng et al., 2002), and depression (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000; Given et al., 1992). Financially, caregivers paid the costs for care receivers, including medical care, long-term care, home care, and the loss of productivity (Chen, 1997; Ernest, & Hay, 1994). Family caregivers have also experienced social burdens (e.g., divorce risk, changes in life style and job, isolation and loneliness) (Chen, 1997; Chiu et al., 1996; Lin, Liu, & Hung, 1999; Weng et al., 2002).

Burden also could be described as subjective or objective (Montgomery, Gonyea, & Hooyman, 1985). Subjective burden was defined as the respondent's attitudes toward or emotional reactions to the caregiving experience. Objective burden was defined as the extent of disruptions or changes in various aspects of the caregivers' life and household (Montgomery et al., 1985).

Given et al. (1992) assessed the reactions of family caregivers from the perspectives of caregiver esteem, lack of relative/friend support, impact on health, impact on schedule, and impact on finances. Similar to Given et al., some researchers described family caregivers' burden from multiple dimensions of caregiving tasks provided by the caregiver, employment burden (e.g., reduced work time), financial burden, physical burden (e.g., sleep disruption), social burden (reduced socialization), and caregiving time (Chen, 1997; Chou, 1998; Chou et al., 1999; Siegel et al., 1991; Stull, Kosloski, & Kercher, 1994). Employment burden and financial burden refer to the impact on family caregiver's finances. Physical burden can be described as the impact on family caregiver's health. Social burden and time burden reflect the impact on family caregiver's schedule.

Based on the review of literature, this study utilized a working definition of family caregiver burden, which stemmed from Given et al.'s research: The Caregiver Reaction Assessment for caregivers to persons with chronic physical and mental impairments (Given et al., 1992). Family caregiver's burden includes the impact on health, schedule, and finances of people providing direct care to family members with cancer. These three concepts are central to family caregiver burden, and they are clear and easy to measure.

#### Mechanisms of Family Caregiver Burden

The mechanisms of family caregivers' burden have been explored using both quantitative and qualitative studies. Quantitative studies have been discussed in the theoretical framework (Figure 1) presented in chapter I. In the qualitative research, Ayres (2000) reported that caregivers used expectations, explanations, and strategies to interpret their circumstances in the context of their lives, to identify those circumstances that required interventions, to select strategies to manage those circumstances, to predict the outcome of a strategy, and to make sense of the events that occurred. Expectations, explanations, and strategies interacted in caregivers' stories. Explanations about the past, present, and future events were influenced by expectations and can be used to design strategies for the fulfillment of caregiver's expectation (Ayres, 2000).

When family caregivers perceived differences between the real situation and their expectation, the differences became a stressor, causing the family caregivers to remain in an arousal situation (Erickson et al., 1998). Family caregivers found the explanations or strategies to deal with the differences in order to regain equilibrium. If they could not find reasonable explanations or suitable strategies to modify the situation, caregiving burden was produced (Erickson et al., 1998).

Shyu et al. (1998) also put forward a similar concept. Their research showed how Taiwanese family caregivers of frail elders found a balance point in the caregiving process. First, family caregivers recognized and weighed the competing needs. Second, they used multiple flexible strategies to adjust their stressors. When family caregivers could not recognize and weigh the competing needs, they used ineffective and fixed strategies, so their burden increased during the caregiving process (Shyu et al., 1998).

As families developed through their life span, stress was often greatest at transitional points from one stage to another as families rebalanced, refined, and realigned their relationships (Carter & McGoldrick, 1999). Shyu described three stages of role preparedness of family caregivers as role engaging, role negotiating, and role settling during the transition from hospital to home (Shyu, 2000b). Role engaging was defined as the process the caregiver and the care receiver used to prepare for and begin the role of caregiver or care receiver. It occurred before the care receiver was discharged from the hospital and usually began immediately after the care receiver was hospitalized. Role negotiating was defined as the process that the caregiver and the care receiver went through before arriving at a stable pattern of caregiving interaction. This phase occurred immediately after the care receiver's discharge from the hospital. Role settling was defined as the process through which the caregiver and the care receiver established a stable pattern of caregiving interactions. This phase occurred after the role-negotiating phase (Shyu, 2000b). At different phases, family caregivers had different levels of caregiving burden (Nijboer et al., 2000).

In summary, family caregivers' burden, defined as a negative concept in this study, was measured by impact on health, schedule, and finances. Family caregivers used expectations, explanations, and strategies to find a balance point in the caregiving process, and expectations, explanations, and strategies may be influenced by care receivers' ADL dependency, caregivers' psychological well-being, quality of relationship with care receivers, and knowledge of caregiving, and family support. According to role preparedness, the level of family caregivers' burden changes over time. The relationships between predictors and family caregivers' burden will be discussed in the following sections.

#### **Care Receiver Dependency of Daily Activities**

Patients' ADL dependency has a significant impact on family caregiver burden. When patients' ADL dependency is higher, the family caregiver have heavier burden. The level of family caregiver burden caused by ADL depends on patients' diseases, cognitive level, and mobility. Patients with the diagnosis comprised the non-cancer patients categorizing stroke, Alzheimer's disease, cognitive impairment, neurological disease, and senility. The relationships between patients' ADL dependency and family caregiver burden are described as follows, according to non-cancer patients and cancer patients.

#### **Non-Cancer Patients**

#### Impact on Health

The impact on caregiver's health was determined by a variety of factors. Chiu, et al. (1996) reported that 96% of the family caregivers took care of the care receivers for 7 days a week and at least 12 hours a day. Fifty percent of family caregivers needed to take on additional housework, and more than half of the participants had no assistance from family members during weekdays and over weekends (Chiu et al., 1996). The dependencies of elderly care receivers increased the hours of care provided, resulted in caregivers' perception of role overload, and led to caregiver depression (Yates, Tennstedt, & Chang, 1999).

Family caregivers of spinal injury patients at home had higher physical burden (e.g., change positions, bathing, etc.), especially for totally dependent and severely dependent patients (Weng et al., 2002). Caregiving tasks were associated with care receivers' dependency for ADLs. Caregivers' tasks, the number of hours per week the caregivers spent performing each task, had a positive association with objective burden (Montgomery et al., 1985). The objective burden was measured by the change (a lot more to a lot less) of amount in a caregiver's life, e.g., the amount of time, privacy, money, personal freedom, energy, time for social activities, vacation activities, and a caregiver's health and the relationship with families (Montgomery et al., 1985).

Liu et al. (1998) studied the burden of primary caregivers of stroke patients at a hospital and their burden-related factors in Taiwan. They reported that lower levels of patients' dependency were associated with lower physical burden. Lower physical and psychological burdens were associated with lower numbers of caregiving days (Liu et al.,

1998).

Care recipient's cognitive impairment was negatively associated with family adaptability, cohesion, and decision-making satisfaction and positively related to family conflict. Adaptability and decision-making satisfaction were negatively associated with family caregivers' depression (Deimling, Smerglia, & Schaefer, 2001). Although Deimling et al. measured families' adaptability, cohesion, conflict, and decision-making satisfaction, only one family caregiver for each family answered these questions. The researcher should consider whether a single caregiver could objectively report a family's situation.

Caregiver burden and antecedent variables (elder ADLs, elder IADLs, elder has some form of dementia, total tasks performed) were significantly correlated (Stull et al., 1994). There was a significant negative relationship between the general well-being of physical health and caregiver burden. Physical, financial, and social burdens were stronger predictors of adult day care and considering nursing home placement, but not significant with chore/homemaker service (Stull et al., 1994).

#### Impact on Schedule

Caregiving tasks put caregivers on care receivers' time schedule. Therefore, freedom or the lack of freedom might be the central concept explaining both the positive relationship between objective burden and the performance of certain types of tasks and the negative correlation between objective burden and the number of family members who assisted (Montgomery et al., 1985).

#### **Cancer Patients**

#### Impact on Health

The impact cancer patients had on caregivers' health differed based on cancer patient's stage of illness, the symptoms, and the amount of time spent on caregiving. The major physical symptoms of the end stage cancer patients, ranked by prevalence and severity, were pain, dysphagia, weakness, cognitive impairment, and nausea (Hu et al., 1999). Increasing care receivers' symptoms and dependency of IADL were positively correlated with the perceived impact on caregivers' health (Given et al., 1997). Caregivers who reported high numbers of symptoms among care receivers in the baseline data tended to have higher average levels of depression (Given et al., 1997). This did not extend to the second observation six months later (Given et al., 1997).

Hu, Chen, Chen, Lin, and Lin (2001) explored how caregivers' burden changed during the first four weeks after a loved one with cancer was discharged from the hospital. They reported that the caregivers' burden scores at the time of the patients' discharge from the hospital were higher than the scores at 1, 2, 4 weeks post-discharge. The scores of caregiver burden were higher among caregivers providing more than 12 hours per day than those providing fewer than 12 hours per day (Hu et al., 2001).

#### Impact on Schedule

Increasing care receivers' symptoms and dependency of IADL were positively correlated with perceived impact on caregivers' daily schedule (Given et al., 1997). Caregivers' daily schedule was also impacted by care receivers' ADL and the number of hours spent on caregiving per day (Given et al., 1997). In summary, the review of literature shows that increasing care receiver dependencies of ADL and IADL influenced the caregiver's daily schedule, had an impact on the caregiver's health, and increased depression in caregivers, especially care receivers' new ADL or IADL dependencies. However, no study has reported the relationship between patients' ADL dependency and the impact on finances. Care receivers' cognitive status was associated with the level of care receivers' dependency. After six months, the caregiver's time schedule adjusted and the impact on the schedule decreased (Given et al., 1999). Demands of care on the caregiver (physical and psychological) had a direct positive effect on caregiving involvement that increased caregiving burden (Chou, 1998; Chou, LaMontagne, & Hepworth, 1999). Cancer patients' symptoms were the main reasons for caregivers' depression. Therefore, family caregivers of cancer patients might have psychological burden (Given et al., 1992; Given et al., 1997; Given, McCorkle, Given, Kozachik, & Cimprich, 2002; Hu et al., 1999). Family caregiver burden of stroke patients and elderly people were focused on physical burden (Liu et al., 1998; Montgomery et al., 1985).

#### **Family Caregiver Characteristics**

The association between family caregivers' burden and family caregivers' age, gender, income, education, health status, the length of caregiving experience, psychological well-being, quality of relationship between caregivers and patients, and knowledge of caregiving are discussed in this section.

Research conducted with family caregivers found that most caregivers were female, married, spouse, or adult children, and well educated with an income range from \$25,000 to 34,000 (Acton, 1997; Given et al., 1992). For a sample of cancer patient caregivers, the mean age of family caregivers ( $\underline{N} = 276$ ) was 55.1 ( $\underline{SD} = 12.4$ ) and the mean duration of care was 2.1 years ( $\underline{SD} = 3.9$ ). The mean age of family caregivers ( $\underline{N} = 185$ ) was 61.9 ( $\underline{SD} = 11.5$ ) for caregivers of a physically impaired elderly sample and the mean duration of care was 5.6 years ( $\underline{SD} = 6.9$ ) (Given et al., 1992). In Taiwan, the mean age of stroke patient family caregivers was 43.4 years old ( $\underline{SD} = 13.98$ ), 64.9 % female, 81.9 % married, 80.8 % without college diploma (Liu et al., 1998); monthly family income was less than NT\$ 40,001 (44.5%), NT\$ 40,001 to 80,000 (29.1%), and greater than NT\$ 80,000 (23.6%) (Chiu, Pai, & Shyu, 1997).

As the basis for designing a service program, Qin, You, and Huang (1999) explored the stress and the needs of 378 family caregivers of elderly people in Taichung, Taiwan. Most family caregivers of elderly people in Taichung, Taiwan were spouses (41.5%), female (59.6%), 40 to 50 years old (31.4%), elementary school educated (28.5%), unemployed (57.3%), married (88%), and believed in Taoism (39.9%) and Buddhism (29.3%). Thirty-two percent of the participants reported family income per month at the range of NT\$40,000 to 60,000 and 29.6% of the participants earned NT\$ 20,000 to 40,000. More than half of the family caregivers reported their health status as very good and good, and only 6.9% of participants felt that their health status was worse after being a caregiver. The average caregiving experience was one year and five months (Qin, You, & Huang, 1999).

#### <u>Age</u>

Caregivers' characteristics (age, relationship to the elderly, caregiver's employment status, family income) were significantly associated with subjective burden. Younger, employed caregivers had demands that conflicted with the caregiver role, and therefore were more apt to experience strain (Montgomery et al., 1985). Some studies have shown a negative correlation between caregiver strain and age and a positive correlation between employment and strain (Robinson, 1983; Montgomery et al., 1985), but Shyu reported that younger caregivers had significantly better overall caregiving consequences (Shyu, 2002). There were no significant differences in family caregivers' strain by gender (male and female), relationship (wife, husband, daughter, son, other family members, and non-family members), or varying degrees of self-perceived health status (Robinson, 1983).

Older caregivers experienced less negative impact from disrupted schedules, and appeared to have less negative caregiving experience over time (Nijboer et al., 2000). Young caregivers tended to report a higher (i.e., more negative) impact on disrupted schedules and continued to do so over time (Nijboer et al., 2000). Family caregivers with higher age had higher scores in the hardiness, resources, and coping (Leske & Jiricka, 1998).

#### Gender

Women, including wives, daughters, and daughters-in-laws, comprised the largest group of caregivers in both the U.S.A. and Taiwan (Chiu et al., 1997; Given et al., 1992; Liu, et al., 1998; Shyu et al., 1998; Wu, Hu, & Yao, 1991). Women divide their time between caring for their own children and families and their aging parents. Adult children who currently were caring for their own children might experience higher levels of stress as they attempted to care simultaneously for family members with diverse needs (Given, Collins, & Given, 1988). Some women quit work to care for family members. Women who did not have stable employment appeared to suffer the most stress from caregiving (Given et al., 1988). Caregivers' characteristics affected the reactions of caregivers about the demands of care (Given et al., 1997). Female caregivers consistently were more depressed than their male counterparts (Given et al., 1999).

### Income and Education

Few studies reported the relationships between family caregiver burden and income as well as education. However, overtime caregivers with low to middle level education reported a decreasing trend of negative impact on finances, while the opposite trend was observed in the highest educated group (Nijboer et al., 2000).

Participants in the highly educational group (higher than vocational schooling and university) derived less self-esteem from providing care over time (Nijboer et al., 2000). Family caregivers with middle and high education had a decreasing negative impact on disrupted schedule over time, but there was no significant difference in the participants with primary school education (Nijboer et al., 2000).

#### Health Status

Family caregivers' health status was a main influencing factor for family caregiver burden of frail elderly (Wu, Hu, & Yao, 1991). Female caregivers reported a higher impact on physical strength than male caregivers of cancer patients (Nijboer et al., 2000). Caregivers' physical or mental health was more important in the decision to institutionalize a family member than an actual change in patient status (Given et al., 1988; Uhlenberg, 1996). People who had more severe physical and mental disabilities were unable to be care providers (Uhlenberg, 1996).

## Length of Caregiving Experiences

Time was a very important factor in the adjustment of family caregivers. Family caregivers with caregiving experience of less than six months had higher caregiving burden than the caregivers with caregiving experiences of more than two years (Hu et al., 2001). During the first six-month observation period, an increase in care receivers' new dependencies was positively associated with higher levels of caregiver depression (Given, Given, Stommel, & Azzouz, 1999). After six months, caregivers' time schedules were adjusted and the impact on their schedules were decreased (Given et al., 1999; Nijboer et al., 2000).

## Family Caregiver Psychological Well-being

Family caregivers not only faced caregiving tasks in their lives, but also faced normative life-span development and related issues. Psychological well-being was an important internal resource to support family caregivers, when they coped with the stressors in their lives.

Young adults had better perceptions of positive future change than middle-aged adults and older adults (Ryff & Heidrich, 1997). In terms of psychological well-being, older adults had higher scores in environmental mastery and positive relationships than middle-aged adults and young adults. Young adults had higher scores in personal growth and purpose in life than middle-aged adults and older adults. Middle-aged adults had higher scores in autonomy than young adults (Ryff & Singer, 1996).

Acton (1997) studied affiliated-individuation (AI) as a mediator of stress and burden in caregivers of adults with dementia. Affiliation was defined as Safety and Security and Love and Belongingness, e.g., "acceptance by others, safety, connection to others, sharing with others, and trust" (Acton & Miller, 1996, p. 253). Individuation meant Esteem, Self-Esteem, and Self-Actualization, e.g., "accepting own value or worth, recognizing own strengths, finding options and choices, making decisions, and sensing accomplishment" (Acton & Miller, 1996, p.253). Acton demonstrated that caregivers with higher levels of stress and burden had lower levels of life satisfaction, while caregivers with higher levels of AI had higher levels of life satisfaction. The effect of stress and burden on life satisfaction decreased when following an intervention in caregivers with higher levels of AI (Acton, 1997).

Family caregiver burden was related to a person's self-perception. Rosenberg's (1986) Self-Concept Theory suggested that an individual's judgment of his or her selfworth was based on how well actual self-perceptions matched ideal self-perceptions (Rosenberg, 1986). Heidrich (1994) utilized Self-Concept Theory in a longitudinal survey, the results of which showed that actual and ideal self-conceptions were predicted by depression, but not generally by physical health status (Heidrich, 1994).

When the level of prior family stressors, strains, and transitions increased, the level of hardiness, resources, problem-solving communication, family well-being, and family adaptation significantly decreased (Leske & Jiricka, 1998). Hardiness was a significant factor that increased in resources, coping, problem-solving communication, family well-being, and family adaptation. There was a positive relationship between problem-solving communication and family adaptation (Leske & Jiricka, 1998). Problem-focused coping (e.g., seeking social support or planful problem-solving) could decrease caregiving burden, but emotion-focused coping (e.g., distancing or escapeavoidance) increased caregiving burden (Chou, 1998; Chou, LaMontagne, & Hepworth,

1999). Caregivers who had more realistic self-expectations provided significantly better quality of care, and had better caregiver outcome, and family outcome (Shyu, 2002; Uhlenberg, 1996).

Lin, Ku, Leu, Chen, and Lin (1996) investigated 122 family caregivers of hepatoma patients and suggested family caregivers' individual and environmental stresses were associated with their physical, psychological health and social activities. Emotional-oriented coping behavior was a significant influencing factor on family caregivers' physical and psychological health. Family caregivers' stress and coping behaviors explained 56.38% of the variance in health status (Lin, Ku, Leu, Chen, & Lin, 1996).

In summary, the psychological well-being of family caregivers was related to a person's self-concept and hardiness that influenced role adjustment of a family caregiver. The role adjustment can influence a family caregiver's burden and life satisfaction. Quality of Relationship between Family Caregiver and Care Receiver

The quality of relationship between caregivers and care receivers has been reported as the main influencing factor on family caregiver burden (Given et al., 1988; Given, et al., 1997; Wu et al., 1991) and affected the reactions of caregivers about the caregiving tasks (Given, et al., 1997; Chou, 1998; Chou et al., 1999). There was a positive relationship between filial obligation and caregiving involvement. Family caregivers who had more caregiving involvement have heavier caregiving burden (Chou, 1998; Chou et al., 1999). Those caregivers with more filial obligation had lower caregiving burden (Chou, 1998; Chou et al., 1999). Lower physical burdens were associated with better interaction between primary caregivers and patients (Given et al., 1999; Liu et al., 1998).

Adult child caregivers reported a significantly higher level of conflict within their family environment, whereas spouse caregivers reported a high mean level of depression (Deimling et al., 2001) and caregiving strain (Lee, Hills, Kaplan, & Johnson, 1998). Compared with spouse caregivers, non-spouse caregivers had higher scores on depression at each observation (Given et al., 1999).

Corbeil, Quayhagen, and Quayhagen (1999) tested stress-adaptation intervention effects on the interactions of 87 dementia caregiver-patient dyads and reported that the improvement in caregiver satisfaction of dyadic interaction was attributed to a reduction of the behavioral stressor effects through increased use of a problem-focused coping strategy, that was, positive reassessment of the stressful situation (Corbeil et al., 1999). The quality of relationships between caregivers and elderly care receivers mediated the association between caregiving tasks and caregiver perception of depression (Yates, Tennstedt, & Chang, 1999).

Family caregivers who used religious or spiritual coping approaches had better quality of relationships with care receivers. The quality of relationships also decreased the level of depression and the caregiver burden of family caregivers (Chang, Noonan, & Tennstedt, 1998).

Sebern (2002) described the relationship between patients and family caregivers as "shared care," which referred to a pattern of interdependent interaction consisting of communication, negotiation, and reciprocity. Forty-nine percent of family caregivers considered themselves caregivers, and 36% considered themselves as both a caregiver

and a care receiver (Sebern, 2002). Communication skills were very important in improving the quality of relationship between caregivers and care receivers (Coeling, Biordi, & Theis, 2003).

In summary, the quality of relationship between family caregivers and care receivers is associated with the role of family caregivers and influences caregiving tasks. Caregivers who had a better relationship with care receivers had better overall caregiving consequences (including quality of care, caregiver outcome, and family outcome) (Shyu, 2002).

# Knowledge of Caregiving

It was necessary to possess skills and knowledge to be a family caregiver (Uhlenberg, 1996). Family caregivers who had more knowledge and better skills of caregiving experienced lower physical burdens (Liu et al., 1998; Weaver, Perloff, & Waters, 1998). Family caregivers who had higher mutuality and preparedness had lower strain from direct caregiving tasks and tension, but mutuality and caregiving preparedness were not associated with financial burden and role conflict (Archbold, Stewart, Greenlick, and Harvath, 1990).

Caregivers' self-perceptions about good care included caregiving mastery, selfefficacy, competence, and preparedness. These concepts referred to caregivers' perceptions on how well they could provide care (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Family caregivers with more caregiving self-efficacy, skill mastery, and problem-focused coping had lower caregiving burden (Chou, 1998; Chou et al., 1999) and low level of depression (Yates, Tennstedt, & Chang, 1999).

Family caregivers who had more involvement in discharge planning had significantly higher scores on satisfaction, preparedness, and perception of care continuity two weeks following the elder's hospitalization than those who had little or no involvement in planning. Caregivers who had more involvement in discharge planning also accepted the caregiving role more easily (Bull, Hansen, & Gross, 2000). Caregivers who had more knowledge of caregiving have been shown to have better overall caregiving outcomes (Shyu, 2002).

Some researchers explored how to improve family caregivers' knowledge of caregiving and decrease family caregivers' burden. Archbold et al. (1995) designed the PREP system of nursing interventions to increase preparedness (PR), enrichment (E), and predictability (P) in families providing care to older people. Based on mean scores on the Care Effectiveness Scores (CES), caregivers in the experimental group reported greater perceived changes in preparedness for caregiving, enrichment in caregiving, and predictability than caregivers in the control group (Archbold et al., 1995).

Ostwald, Hepburn, Caron, Burns, and Mantell, (1999) developed a 14-hour training workshop for primary caregivers and their families to provide information and to enhance caregiving skills and mastery. This was a three-year randomized trial of a psychoeducational intervention targeting primary caregivers of community-dwelling persons with dementia. In the intervention group, the scores of caregivers' burden in follow-up were statistically significantly lower than posttest scores. However, in the control group, the follow-up scores of caregivers' burden were higher than posttest scores. Caregivers in the intervention group were able to achieve a reduction in their

negative reactions to the disruptive behaviors displayed by their family members (Ostwald et al., 1999).

Pasacreta, Barg, Nuamah, and McCorkle (2000) found the results of participant characteristics before and after four months' attendance at a Family Caregiver Cancer Education Program (FCCEP). The FCCEP included information on how to manage cancer patients' symptoms, improve technical competence, and administer medication at home. The results indicated that four months after the intervention, there was significant improvement in caregivers' health status, knowledge of caregiving, and assessment of role. They became well informed about caregiving, comfortable about interacting with patients, well informed about community resource availability, and confident in their ability to provide care (Pasacreta et al., 2000).

Given et al. (2002) studied 118 caregivers of cancer patients in an experimental group and 119 in a control group to determine whether a cognitive-behavioral intervention influenced the level of caregiver assistance with patients' symptoms. At the baseline, the experimental group and the control group reported equal numbers of patients' symptoms, but after 10 weeks of intervention, the experimental group reported lower numbers of pain and fatigue than the control group, as well as fewer patients' symptoms and less depression than the control group (Given et al., 2002).

The review of literature shows that a caregiver's knowledge about taking care of a care receiver is associated with the level of family caregiver burden and the role preparedness of caregiving. These studies demonstrated that improving caregivers' knowledge of caregiving increased their caregiving mastery, self-efficacy, competence, and preparedness. Therefore, family caregivers' physical burden, caregiving strain, and

tension were decreased as well as patients' symptoms, depression, pain, and fatigue were improved.

## Support Resources

Given et al. (1988) identified three important factors in a caregiving environment, as (a) perceived social support; (b) community services available; and (c) the financial conditions imposed by caregiving. Receipt of social support, which was extremely important for caregivers, included two broad types: emotional and instrumental (Given, et al., 1988). Both quality of support (feeling loved, feeling that one can count on others, having a confidant) and quantity of support (having a network available to provide aid in times of need) were associated with better health, both physical and emotional, in old age (Heidrich & Ryff, 1996).

In Taiwan, about 65% of the patients had coverage for home care from health insurance; 58.2% of the patients from regional hospital-based home-care agencies received home-care services (Chiu et al., 1997). The needs of family caregivers in the community were caregiving information (e.g., medical care, social welfare, and advance technologic equipment), patients' treatment and caring, social support, family support, physical assistance needs (e.g., church members, volunteers, and home care nurses, etc.), mental support needs (e.g., religion, consultation, sympathy, encouragement, and respect), and financial support (e.g., handicap benefits) (Chiu et al., 1996; Hu, et al., 1999; Weng, Ma, Zhang, & Zheng, 2002; Zhong & Huang, 1998).

Caregivers with high levels of emotional support had low level of depression (Yates et al., 1999). There was a negative correlation between objective burden and the number of family members who assisted (Montgomery et al., 1985). An alternative care

provider was a main influencing factor for the family caregiver burden of frail elderly (Wu et al., 1991). Family caregivers who had higher support systems had lower physical and psychological burdens (Liu et al., 1998; Shyu, 2002).

The mean burden scores of the community-dwelling older adults receiving geriatric evaluation and management (GEM) declined, while the mean scores of the usual care control caregiver group increased (Weuve, Boult, & Morishita, 2000). There was a significant difference between intervention group and control group in the mean burden scores at 12 months after interventions (Weuve et al., 2000).

In summary, the support resources include social support, community services, as well as financial conditions. The support resources could decrease the objective burden, and physical and psychological burden.

### **Summary of the Literature Review**

This chapter provided a broad literature review about family caregiver burden in both Taiwan and the U.S.A. Research has demonstrated that major variables linked to the family caregiver burden were patients' ADL dependency, family caregivers' psychological well-being, quality of relationship with care receivers, knowledge of caregiving, and family support. Some variables in these studies have consistently revealed their influences on caregiver burden that has been illustrated in the Figure 1. As a whole, these studies suffer from some conceptual and methodological issues that make it difficult to generalize the predictors of caregiver burden.

### **Conceptualization**

Three issues in conceptualization of caregiver burden are important. First, the absence of a standard usage of the term "family caregiver burden" has resulted in diverse

ways to identify family caregiver burden. Thus, the components of family caregiver burden should be categorized and standardized. Second, few studies showed sufficient theoretical support. The advantages of using theories to lead research are to distinguish fact from pseudofact, to structure converging facts from a number of fields, and to give direction to practice (Ellis, 1968). Third, the relationships between predictors and caregiver burden were influenced by care receivers' diagnosis, dependency, and caregivers' age, income, health, and experiences about caregiving. Thus, these covariate variables may confound the results of family caregiver burden. These variables have been controlled in this study and described in the chapter III.

### Methodology

Five methodology issues need to be carefully considered in caregiver burden studies. First, most studies have focused on a homogeneous sample that was mainly female, or family caregivers of patients with a certain diagnosis. Some studies had small sample sizes and had convenience samples obtained from community agencies. The sample size and the nature of the sample restrict the generaliziability of the results. Second, some studies used many questionnaires in the investigation, which may cause fatigue in the respondent and decrease the willingness to answer the questions. Adequate number of items will assist the researcher to get the true reflection of the phenomena and good internal consistency reliability. Third, most of the research used a cross-sectional design. There are many problems in inferring changes and trends over time using a crosssectional design. Many changes in the phenomena over time make it questionable to assume that differences in the behaviors, attitudes, or characteristics of different age groups are the result of the passage through time rather than the result of cohort or

generational differences (Polit & Hungler, 1999). Therefore, the studies using a crosssectional design are too weak to explain the causal inference. Fourth, many studies used multivariate descriptive design that also does not allow examining the issues of causality. Fifth, some instruments had good validity and reliability when they were developed and applied in the U.S.A., but they had lower internal consistency reliability after translated and applied in Taiwan. Taiwanese researchers should consider the culture issues when using questionnaires from the U.S.A.

Few experimental studies demonstrated significant differences between the experimental and control group. There are more studies that demonstrated significant differences between pre- and post-test in the same group but that is a weaker research design. The majority of prior research in Taiwan focuses on the conceptual development, descriptive research, and correlational research, but little research has been done regarding development of measures, and no quasi-experimental or experimental research has been conducted on the family caregivers.

When patients stay in the hospital, nurses and doctors usually focus on the treatments of patients, ignoring the assessment of the burden of family caregivers. The burden of family caregivers is dynamic and can be influenced by many domains as described above. The review of literature reveals that many studies about the factors of family caregiver burden have been done in the community, but there is little literature describing family caregivers' burden while the patient is still hospitalized. The purpose of this study was to examine cancer patients' dependency, caregivers' factors, and family support that predict outcomes of family caregiver burden, including impact on health, schedule, and finances in a Taiwanese hospital.

# CHAPTER III

## METHODOLOGY

## **Research Design**

A multivariate descriptive design was used to describe the relationships among care receiver dependency, caregiver factors, family support, and family caregiver burden. A multivariate descriptive design is used in nursing, medical, and social science research when the problems to be addressed are not amenable to experimentation (Polit & Hungler, 1999). This design is an efficient and effective means of collecting a large amount of data about a problem area and examining a relationship that has been deduced from an established theory (Polit & Hungler, 1999), while not adequately examining issues of causality. The relationships among selected variables were examined in order to confirm the conceptual framework and to establish a foundation for future nursing research and interventions.

## Sample and Setting

A convenience sample of 91 primary caregivers of hospitalized patients diagnosed with cancer was recruited in the oncology rooms and the general medical and surgical rooms (no hospice room) in Chung-Shan Medical University Hospital in Taichung, Taiwan. Cancer is a severe disease in Taiwan. In Taiwan, patients being treated for cancer have a hospital stay from two to four weeks (National Taiwan University Hospital, 1999). During the hospitalization, this disease will cause patients to be dependent on others for daily activities. Family members reside in the hospital and provide care for the patient.

The sample size was determined by Power Analysis Computer Software (Borenstein, Rothstein, Cohen, Schoenfeld, & Berlin, 2000) for regression models: The significance level set  $\alpha$  at .05 and power (1- $\beta$ ) at .80; estimating the four covariates (age, income, health status after caregiving, the length of caregiving experience) yielding an R-squared of .06; five independent variables (patients' ADL, caregivers' psychological well-being, quality of relationship with patients, knowledge of caregiving, family support) yielded an additional R-squared (R<sup>2</sup> change) of 0.13. In other words, in step one the four covariates were entered accounting for 6% of the variance; in step two, the five independent variables explained an additional 13% of the variance. The sample size needed to be 90 participants using these criteria (Borenstein et al., 2000).

The four covariates used in estimating sample size were based on the factors found in the literature, which were known to contribute to family caregiver burden. The family caregivers' characteristics that were known to be associated with caregiver burden were age, income, health status after caregiving, and the length of caregiving experience. Effect size for multiple regression was defined as Explained Variance/Error Variance (Borenstein et al., 2000). When the effects of covariates were taken out of the error variance, the denominator became smaller; consequently the effect size became bigger, resulting in a smaller sample size estimate (Lipsey, 1990). When used for a single set of variables, effect size was equal to  $R^2/(1-R^2)$ . Cohen provided the following conventions for research in the social sciences: Small effect size = .02, Medium effect size = .15, Large effect size = .35. These would correspond to  $R^2$  values of about .02, .13, and .26 (Borenstein et al., 2000). In the pilot study, these four covariates yielded an R-squared of 0.345 and the five independent variables yielded an additional R-squared of 0.328. The proportion of the variance found in the pilot study (.345) was larger than the proportion used in this estimate of sample size (.06). Therefore, 90 participants provided adequate

power for this study.

The primary caregiver sampling criteria were defined as a family member who (a) was at least 18 years old, (b) was able to read and write Chinese, (c) had the primary responsibility for providing care to the patient in the hospital for at least five days per week and at least 6 hours per day, (d) provided care for a patient diagnosed with cancer who needed assistance with at least one ADL, such as getting in/out of bed, getting to/using toilet, getting dressed/undressed, eating, walking, and (e) was not in a hospice unit.

## Instruments

Data for this study were obtained from five questionnaires: Socio-demographic Questionnaire, Activities of Daily Living (ADL) Index (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), Psychological Well-Being Scale (Ryff, 1989), Family Caregiving Factors Inventory (FCFI) (Shyu, 2000a), and Caregiver Reaction Assessment (CRA) (Given et al., 1992). Two of the CRA subscales, Esteem and Lack of Family Support, were used as separate variables. Internal consistency reliability estimates for each instrument using Cronbach alpha were obtained in the pilot study and this study. Results were summarized in Table 1.

# Family Caregiver and Care Receiver Socio-Demographic Questionnaires

The Family Caregiver Socio-Demographic Questionnaire was developed by the investigator and used to collect information about the caregiver, such as age, gender, marital status, education, religion, number of children, relationship with care receiver, family member, length of caring, health status, employment and income (See Appendix A).

There was an additional question to explore a special phenomenon in Taiwanese hospitals. Patients had their family caregivers' stay with them in the hospitals for 24 hours a day. Family caregivers were asked to answer "Yes" or "No" to the question "If nurses provided total care to the patients, do you think family caregivers need to stay in the hospital for a long time?" If family caregivers answered "Yes," they could describe their reasons why they wanted to stay in the hospital.

The Care Receiver Socio-Demographic questionnaire was developed by investigator and was used to collect information about a care receiver, such as age gender, born year, marital status, education, diagnosis, and mobility (See Appendix A).

Variables	Instruments	Items	Cronbach Alpha coefficients			Range of Scores
				Previous Study	This Study	
Patients' Depe	ndency					
Patients'	Index of	5	.97	.90 <sup>a</sup>	.94	5-20
Dependency	$ADL^{a}$					
Caregivers' Fa				1		
Caregiver's	Psychological	18	.79	.8388 <sup>b</sup>	.77	18-108
Psychological	Well-being					
Well-being	Scale <sup>b</sup>					
Quality of	Esteem	5	.75	.90 <sup>c</sup>	.79	5-25
relationship	Subscale in	-				
between a	the CRA <sup>c</sup>					
patient and a						
family						
caregiver				1		
Knowledge of	Knowledge	7	.87	.91 <sup>d</sup>	.83	7-35
caregiving	of the Care					
	Receiver					
	Subscale in the FCFI <sup>d</sup>					
Family Suppor						
Family	Lack of	5	.57	.85 <sup>c</sup>	.71	5-25
Support	Family			.7680 <sup>e</sup>		
	Support					
	Subscale of					
	the CRA <sup>c</sup>					
Family Caregi				0.00		,
Impact on	Impact on	4	.77	$.80^{\circ}$	.73	4-20
Health	Health					
	Subscale of the CRA <sup>c</sup>					
Impact on	Impact on	5	.78	.82 <sup>c</sup>	.52	5 75
Impact on Schedule	Schedule of	5	./0	.02	.34	5-25
Schedule	the CRA <sup>c</sup>					
Impact on	Impact on	3	.77	.81°	.75	3-15
Finances	Finances of	5	• / /	.01	.15	5-15
	the CRA <sup>c</sup>					

 Table 1

 Summary Information for the Data Collection Instruments

<sup>a</sup>Katz, Ford, Moskowitz, Jackson, & Jaffe (1963). <sup>b</sup>Ryff (1989). <sup>c</sup>Given et al. (1992). <sup>d</sup>Shyu (2000a). <sup>e</sup>Yeh (1995).

# Index of ADL

Care receiver's activities of daily living dependency was measured by the Index of Independency in Activities of Daily Living (Index of ADL) developed by Katz, Ford, Moskowitz, Jackson, and Jaffe in 1963. The Index of ADL was developed to study the results of treatment and prognosis in the elderly and chronically ill. More than 2,000 evaluations of 1,001 individuals demonstrated use of the Index as a survey instrument, as an objective guide to the course of chronic illness, as a tool for studying the aging process, and as an aid in rehabilitation teaching (Katz et al., 1963). In this study, caregivers were asked to answer the care receivers' dependencies of activities of daily living (ADL) for five items, such as getting in/out of bed, getting to/using toilet, getting dressed/undressed, eating, walking (from 1= no help needed to 4 = can not do it; alpha = .90) (Stull, Kosloski, & Kercher, 1994). The total score is 20, and the lowest score is 5. Higher scores indicate higher dependency of care receivers (see Appendix B).

Stull et al. (1994) reported the internal consistency reliability of ADL Index was .90. Katz et al. (1963) examined the validity of ADL index and found that patients who were graded as more dependent needed more frequent assistance. Degree of assistance appeared to be an ordered characteristic inherent in the Index. Patients who were graded as independent in all but one of these function (e.g., bathing and/or dressing) received assistance at isolated times in a given day, while those in the higher dependency at more frequent intervals. Seventy-nine percent of the patients graded as higher dependent were receiving non-family attendant care, but only 45% of those graded as more independent needed non-family attendant care (p < 0.002). The order of recovering function was also reported from more to less dependent with an ordered sequence of improvement. The

construct validity of the ADL index was demonstrated. In this study, the Cronbach's alpha was .94.

## Family Caregiver Psychological Well-being

Caregivers' psychological well-being was measured by the 18 item Psychological Well-being Instrument (Ryff, 1989). Six concepts including autonomy, environmental mastery, purpose in life, personal growth, positive relations with others, and self-acceptance were assessed by this questionnaire. Reversed items were included in the items that were used in this study. The items were scored on a six point Likert-type scale ranging from (1) strongly disagrees to (6) strongly agree. All of the items' scores were summed to provide one score. Higher scores indicate better psychological well-being. The maximum total score possible is 108, and the minimum score possible is 18 (See Appendix C). In previous research internal consistency reliability for each subscale based on a sample of 321 adults (age ranging from 19.53 to 74.96 years) revealed a high degree of reliability for each subscale with Cronbach's alphas ranging from .83 to .91(Ryff, 1989). In this study, a total score was used and the Cronbach's alpha was .77.

Evidence for the validity of the scale was examined by confirmatory factor analyses (Ryff & Keyes, 1995). The confirmatory factor analyses included three indices of the overall fit of five models. The results indicated that each of the six factors belonged to a single conceptual domain called well-being (Ryff & Keyes, 1995), which is why a total score was used in this study.

The definition of caregivers' psychological well-being include autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance (Ryff, 1989; Ryff, 1995; Ryff & Singer, 1996; Ryff & Singer, 1998).

Autonomy is self-determination, independency, and the ability to resist social pressures, to think and act in certain ways. Environmental mastery means a sense of being able to manage the situation; control complex external activities. Personal growth is a feeling of self development, growing, expanding and open to new experiences. A positive relation with others means having a warm, pleasing, trusting relationships with others. Purposes in life are the goals of life and a sense of direction. Self-acceptance means possessing an optimistic attitude toward the self (Ryff, 1989; Ryff, 1995; Ryff & Singer, 1996; Ryff & Singer, 1998).

# Knowledge of Caregiving

Shyu (2000a) developed the Family Caregiver Factor Inventory for home health assessment of elders in Taiwan, including caregiving resources, caregiver selfexpectations, caregiving task difficulty, and knowledge of the care receiver subscales. The subscale of knowledge of the care receiver was used to measure the caregiver's knowledge level about how to take care of the care receiver. The alpha of internal consistency reliability was .91. Confirmatory factor analysis was used to examine construct validity. The result of factor analysis demonstrated an excellent overall fit. There are 7 items in this subscale. Participants were asked to rate each item on a fivepoint Likert scales ranging from 1= completely not understanding, to 5 = understanding completely. The total score is 35, and the lowest possible score is 7 (See Appendix D). In this study, the internal consistency reliability was .83.

# **Caregiver Reaction Assessment**

The Caregiver Reaction Assessment (CRA), developed by Given et al., (1992), includes 24 items and consists of the following five subscales: (a) Caregiver's Esteem, (b) Lack of Family Support, (c) Impact on Health, (d) Impact on Schedule, and (e) Impact on Finances. Participants were asked to rate each item on a five-point Likert scale ranging from strongly agree (5) to strongly disagree (1). There are 6 reversed questions in the CRA.

Family caregivers' burdens were measured by the 12-item subscales of Impact on Health, Impact on Schedule, and Impact on Finances. Possible ranges of subscale scores are as follow: Impact on Health = 4 to 20, Impact on Schedule = 5 to 25, and Impact on Finances 3 to 15. Higher scores indicate higher burden.

The items in the Esteem subscale are associated with the caregivers' feeling about the caregiving tasks and the interaction between caregivers and care receivers. This subscale was used to measure the quality of the relationship between caregivers and patients. There are a total of seven items, the highest possible score is 35, and the lowest possible score is seven. Higher scores indicate better quality of relationship between family caregivers and patients. The Lack of Support subscale was used to measure the friend and relative support. There are a total of five items in that subscale. The highest possible score is 25, and the lowest score is five. Higher scores indicate lower support resources (see Appendix E).

In previous research internal consistency reliability for each subscale based on a sample of 377 caregivers of cancer or Alzheimer's patients revealed a high degree of reliability for each subscale with Cronbach's alphas ranging from .80 to .90. Given et al.

(1992) reported the internal consistencies of the sub-scales: caregiver's Esteem seven items (alpha = .90), Lack of Support five items (alpha = .85), Impact on Health four items (alpha = .80), Impact on Schedule five items (alpha = .82), and Impact on Finances three items (alpha = .81). In this study, internal consistency reliabilities were as follows: Esteem = .77, Lack of Support = .71, Impact on Health = .73, Impact on Schedule = .52, and Impact on Finances = .75.

Construct validity support was evidenced through establishment of stable factor structures across comparison groups: diseases (Alzheimer's & cancer), patient-caregiver relationships (spouses vs. nonspouses), and three cross-sectional comparisons. The results of the comparison were highly significant, large, and remarkably stable over time (Given et al., 1992). Also, the construct validity of the CRA instrument has been supported by correlations between the CRA subscales and depression. These correlations were consistent with the notion that specific caregiver burdens may result in overall caregiver depression (Given et al., 1992).

Esteem Subscale of CRA. The esteem subscale of CRA was associated with the caregivers' feeling about the meaning of the caregiving process and the interaction between caregivers and care receivers, so this subscale was used to measure the quality of the relationship between caregivers and care receivers. The total number of items is 7, the highest possible score is 35, and the lowest possible score is 7. Higher scores indicate better quality of relationship between family caregivers and patients. Esteem subscale (alpha = .90) developed by Given et al. (1992) was described in the CRA (See Appendix E). In this study, the Cronbach's alpha was .79.

Lack of Family Support Subscale of CRA. The Lack of Family Support subscale (alpha = .85) developed by Given et al. (1992) was described in the CRA. The Lack of Family Support subscale of CRA was used to measure the friend and relative support. There are 5 items, the highest possible score is 25, and the lowest possible score is 5. Higher scores indicate lower support resources. The coding scheme range from 1=Strongly disagree to 5=Strongly agree (See Appendix E). In this study, the Cronbach's alpha was .71.

## **Data Collection Procedures**

## **Questionnaire Translation**

The translated version of questionnaires must satisfy two sets of requirements. First, they must meet the basic standards set for all measures, translated or not. That is, they must be valid, reliable, legal, and cost-effective (i.e., possess utility). Second, they must meet requirements for equivalence relative to the source language measure (Behling & Law, 2000). Not only must they possess acceptable levels of semantic and conceptual equivalence, but they and the procedures through which they are administered must also minimize problems created by lack of normative equivalence (Behling & Law, 2000).

All structured questionnaires were translated into Chinese by the researcher and back translated from Chinese to English by an independent translator, Mrs. Cynthia Han who is a Taiwanese American and has a Master's degree in English as a Second Language in the USA. Discrepancies between the researcher and Mrs. Han were identified and repetition of the translation procedure continued until all discrepancies were resolved.

### Pilot Study

The pilot study assisted the researcher to refine data collection plans with respect to the sample, instruments, and procedures to be followed. The structured questionnaires were modified based on the pilot study. Thirty participants returned the questionnaires. The internal consistency reliabilities of the instruments are summarized in Table 1. Most of these instruments had good internal consistency reliabilities, except the Lack of Family Support Subscale of the CRA, with Cronbach  $\alpha < .70$ . The approaches to improve the internal consistency reliability for the Caregiver Reaction Assessment (Given et al., 1992), especially the Lack of Family Support Subscale, are described as follow.

There was a significant difference of internal consistent reliability on the Lack of Family Support subscale between the original version and the version translated into Chinese. The alpha reliability for the American participants in the original CRA was .85, but .57 for Taiwanese participants in the pilot study. This difference may have been due to the fact that the items were modified from a negative meaning to a positive meaning to fit this research. Therefore, these items' semantic, conceptual, and normative equivalences were changed (Behling & Law, 2000). Based on the pilot study, the researcher used the Chinese version of the Lack of Family Support subscale (Given et al., 1992) that was translated by Yeh in 1995. The Chinese version of the Lack of Family Support subscale was used to study the burden of family caregivers with elderly families in Taiwan. The Cronbach Alpha coefficients were .76 (time 1) and .80 (time 2).

### Main Study

A convenience sample of 91 primary caregivers of hospitalized patients diagnosed with cancer was recruited in the oncology units and the general medical and surgical units in Chung-Shan Medical University Hospital in Taichung, Taiwan. The caregivers of cancer patients in hospice units were excluded. This formal study was processed after School of Nursing in University of Wisconsin Milwaukee Institutional Review Board (IRB) approved the proposal. Approval of the study protocols was also obtained from Chung-Shan Medical University Hospital in Taiwan.

Associated Professor Yuan, Su-Chuan (the Dean of nursing department in Chung-Shan Medical University Hospital) agreed to assist the researcher in the collection of data. She held a meeting with the five head nurses of Chung-Shan Medical University Hospital in Taiwan to introduce the research and train them in data collection. After answering questions about the study, the training procedures included: how to collect data; how to respond to participants' questions; and how to maintain the neutral attitude of a researcher. The goal of these training procedures was to collect consistent data with reliability and validity. Every head nurse practiced the procedures with another head nurses and Associated Professor Yuan supervised the practice procedure. Five head nurses recruited participants according to the criteria. Then the head nurses contacted the participants to explain the purpose of this study and request their consent to complete the questionnaires.

Interested primary family caregivers were given an envelope that included the questionnaires, an information sheet, and a small paper card. The questionnaires, either completed or not completed, were placed in their envelope and put in a big box in the

nurse station. Submission of the completed questionnaires implied consent to participate in the study. The participants did not put their names on the questionnaires. The primary family caregiver wrote his/her name and room number on the small paper card. They put the small paper card in another small box and the primary nurse gave them a gift to thank them for their efforts and time. Every two weeks, the researcher contacted the Associate Profession Yuan and collected the completed questionnaires. Data for this study were obtained from structured questionnaires.

#### **Data Analysis Procedures**

The analyses were conducted using the Statistic Package for the Social Sciences (SPSS) PC + Version 11.0 (Cronk, 1999). Descriptive statistics (mean, <u>SD</u>, range, frequency, percent) were used to describe the study sample. T-test was also used to examine the differences between group variables. The internal consistency reliabilities for the measures were computed for this study. Pearson-Product Moment Correlation, multivariate analysis of variance (MANOVA), and hierarchical multiple regression analyses were used to examine the questions.

Initially, the distributions of each continuous variable were analyzed for severe skew. All questionnaires used in this study were at the ordinal level of measurement. In this study these scales have been treated as interval level because: (a) there was no severe skew in the distributions; (b) conceptually each of these variables could be considered to roughly approximate equal distances between measures on each scale; and (c) evidence exists that treating such scales as interval measures is not likely to introduce major distortions (Polit, p. 9, 1996).

The assumptions of Pearson's r include random sampling, bivariate normal distribution, and homoscedastic scores. The first assumption of random sampling was violated because a convenience sample was recruited. The second assumption, bivariate normal distribution, scores on variable X were normally distributed for each value of variable Y, and vice versa. Finally, the scores were homoscedastic (homogeneity of variance) that is, for each value of X, the variability of the Y scores was about the same, and vice versa. Failure to meet the last two assumptions generally has only a small effect on the validity of the statistical test, particularly when the sample size is at least 25 to 30 (Polit, 1996, p. 227).

The assumptions for multiple regression include multivariate normality, homoscedastic, and linearity (Polit, 1996, p. 282). To assess this assumption, the five independent variables (patients' dependency, caregivers' psychological well-being, quality of relationship with patients, knowledge of caregiving, and family support) were plotted individually against the caregiver burden (impact on health, schedule, and finances) in a scatter diagram to visually examine its linear relationship with caregiver burden.

Pearson Correlation analysis was used to answer the first three questions. Hierarchical Multiple Regression and MANOVA were used to answer the fourth question. Patients' ADL, family caregivers' Psychological Well-being, Quality of Relationship, Knowledge of caregiving, and Family Support are independent variables. Family caregiver burden including impact on health, schedule, and finances was the dependent variable. The procedures of data analysis are summarized in the Table 2. In scoring the instruments, the method of mean substitution was used to compute scores for participants with missing data who completed at least 80% of the questions in a scale or subscale. Participants who did not complete 80% of the responses for an instrument were excluded from all analysis using that instrument. Only one participant returned the questionnaires with less than 80% of completion. The other 91 participants completed over 80% of the responses on each questionnaire. Statistical significance was established at p < .05. Only the variables that were statistically significant are displayed.

# Low Reliabilities

Low reliabilities were found on these subscales: Lack of Family Support Subscale (alpha = .69), Impact on Finances Subscale (alpha = .67), and Impact on Schedule Subscale (alpha = .52). The possible reasons and solutions for the low reliabilities are described as follows.

- Few questions per subscale: Lack of Family Support Subscale has five items.
   Impact on Finances Subscale has three items. Impact on Schedule Subscale has five items.
- (2) Cultural differences: American instruments were translated and used in Taiwan.
  People with different cultures may have different responses to the same questionnaire (Triandis, 1994). Most adult children in Taiwan strongly believed that helping and caring for parents was an unavoidable responsibility of being Hsiao and being a child (Chou, 1998; Chou, LaMontagne, & Hepworth, 1999).
- (3) The pilot study used a six-point Likert scale, which was adjusted to a five point scale for the study: 1= Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly agree. With the five-point scale, participants were permitted to have a neutral response. Therefore, they did not need to commit

themselves to provide a definite answer: agree or disagree. Agree or disagree responses can not be distinguished. This may have been an influencing factor contributing to the low reliability.

(4) The study sample was a homogeneous sample in regard to their role as caregivers of cancer patients (hospice patients excluded) while the pilot study was comprised of caregivers of both stroke and cancer patients. Heterogeneous samples have higher reliabilities than homogeneous samples (Waltz, Strickland, & Lenz,, 1991, p. 168).

Solution one. The following procedures were undertaken to manage the low reliabilities. The researcher examined the corrected item to total correlation. Items with low alpha levels that question was not internally consistent with the subscale, so the item was deleted.

For the Lack of Family Support Subscale (alpha = .69) one item was deleted from CRA "Since caring for him/her, I feel my family has abandoned me." The alpha for the adapted subscale is .71. For Impact on Finances Subscale (alpha = .67) one item was deleted from CRA "My financial resources are adequate to pay for things for care giving." The alpha for the adapted subscale is .75.

The subscales of Impact on Finances and Lack of Family Support were recalculated using the method of mean substitution for the excluded variable. (i.e. the mean score for the scale for each person was used for the excluded question). This was done to maintain the range of scores for each subscale so that the findings of this study can be compared to other studies using the same instrument. Pearson Product Moment correlations and Hierarchical Multiple Regressions were recalculated using the adapted subscales.

Solution two. The Impact on Schedule Subscale is made up of five questions with higher scores indicating higher schedule burden of family caregivers. A five point Likert scale: 1= Strongly disagree, 2 = Disagree, 3 = Neither agree nor disagree, 4 = Agree, 5 = Strongly agree was used as response to the questions on the Impact on Schedule Subscale. The Cronbach alpha for the Impact on Schedule Subscale was 0.52. The alpha value could not be improved by eliminating items from the scale; therefore the total score for the Impact on Schedule Subscale was not used in the analysis. The scale lacked internal consistency; therefore an item analysis was performed. Each questions were combined to create three groups disagree, neither agree nor disagree and agree, in order to examine the relationship of each of the five predictor variables. The participants who answered strongly disagree and disagree were combined to make up the disagree group and participants who answered strongly agree and agree belonged to the agree group.

The relationships between each grouped response were examined using the MANOVA procedure with each of the five-predictor variables (patients' ADL dependency, caregivers' psychological well-being, quality of relationship, knowledge of caregiving, and lack of family support) as dependent variables. There were no significant differences between the groups in regard to questions 4 "My activities are centered around care of him/her", question 8 "I have to stop in the middle of work" or question 14 "I eliminate things from my schedule since caring for him/her." There was a significant difference between the groups of respondents for question 11 "I visit family and friends

less since I have been caring for him/her" and question 18 "The constant interruptions make it difficult to find time for relaxation" of Impact on Schedule. Therefore, questions 11 (Impact on Visits) and 18 (Impact on Relaxation) were used to represent the impact on schedule and their MANOVA results were displayed separately.

### Summary

This research used a multivariate descriptive design to examine cancer patients' dependency, caregivers' factors, and family support that predict outcomes of family caregiver burden, including impact on health, schedule, and finances in the hospitals in Taiwan. The reliability and validity of data collection tools have been introduced in this chapter. Setting and participants, instruments, pilot study, questionnaire translation, the procedure of main study, and the procedure for data analysis were also presented in this chapter as well as the possible reasons and solutions for three low reliability subscales were described.

Table 2 Data Analysis Procedures

	Variables	Statistic Approaches		
Question 1.	ADL	Ι	Pearson Product Moment	
What is the relationship		-	Correlation	
between the care receiver	Impact on Health	D		
dependency for activities of	Impact on Finances	D		
daily living and family	Fewer Visits	D		
caregiver burden?	Less Relaxation	D		
Question 2.				
What is the relationship	Psychological Well-being	Ι	Pearson Product Moment	
between the caregiver factors	Quality of Relationship	I	Correlation	
and family caregiver burden?	Knowledge of caregiving	Ι		
	Impact on Health Impact	D		
	on Finances	D		
	Fewer Visits	D		
	Less Relaxation	D		
Question 3.				
What is the relationship between family support and	Family Support	Ι	Pearson Product Moment Correlation	
family caregiver burden?	Impact on Health	D	Continuation	
family curegiver surden.	Impact on Finances	D		
	Fewer Visits	D		
	Less Relaxation	D		
Question 4-1 & 3	Less Relaxation	ν		
How much of family caregiver burden (impact on	ADL	I	A Hierarchical Multiple Regression	
health and finance) will be	Psychological Well-being	Ι	Regression	
predicted by care receiver	Quality of Relationship	I		
dependency for activities of	Knowledge of Caregiving	I		
daily living, caregiver factors,	Knowledge of Calegrying	I		
and family support?	Support Resources	Ι		
	Impact on Health	D		
	Impact on Finances	D		
Question 4-2	ADL	D	MANOVA	
What is the relationship		-		
between the five-predictor	Psychological Well-being	D		
variables and the impact on	Quality of Relationship	D		
schedule?	Knowledge of Caregiving	D		
	Support Resources	D		
	Impact on Visits	Ι		
	Impact on Relaxation	I		

# CHAPTER IV

# RESULTS

This chapter contains the findings of the data analysis guided by a conceptual model of factors influencing family caregiver burden in the hospital in Taiwan and the research questions for this study. This chapter includes four sections. The first section outlines the characteristics of family caregivers. The second section presents the characteristics of patients. The third section contains the descriptive statistics for the major variables. The fourth section includes the findings relevant to the research questions in this study.

Four major questions were examined in this study. The first question was what is the relationship between the care receiver dependency for activities of daily living and family caregiver burden? The second question was what is the relationship between the caregiver factors and family caregiver burden? The third question was what is the relationship between family support and family caregiver burden? The fourth question was how much of family caregiver burden will be predicted by care receiver dependency for activities of daily living, caregiver factors, and family support? Pearson Product Moment Correlations were calculated to answer the first three questions. The fourth question was analyzed by using a Hierarchical Multiple Regression and MANOVA. <u>Description of Family Caregivers</u>

Characteristics of the family caregivers in this study are presented in Table 3. A total of 91 subjects participated in the study. Of all the caregivers, 69 (75.8%) were female, 75 (82.4%) married, 76 (83.6%) had a high school education or less, and 48 (52.7%) were Buddhists. The age of family caregivers ranged from 19 to 78 years old

with a mean age of 46.65 years ( $\underline{SD} = 13.28$ ). The monthly income for 68 (74.8%) participants was below N\$ 30,000 (about \$ 857.14).

Sixty-eight (74.8%) of the caregivers took care of patients longer than six months. The average length of caregiving was 1.66 (SD = 2.45) years. Family caregivers reported their health status before caregiving as: 2 (2.2%) poor, 19 (20.9%) very good, and 5 (5.5%) excellent. Family caregivers reported their health status after caregiving: 7 (7.7%) very poor to poor, 13 (14.3%) very good, and 2 (2.2%) excellent. Paired-sample t-test demonstrated that family caregivers' health status after taking care of patients was significantly worse than before taking care of patients (t = 3.96, p < 0.001). Twenty (22%) of the family caregivers' reported that their health status was worse after being a caregiver, only one (1%) stated that it was improved, and others reported that their health status was the same.

Before being a caregiver, 35 (38.5%) caregivers had full time jobs, but after being a caregiver, only 12 (13.2%) had full time jobs. There was a significant difference in the work status between before and after being a caregiver ( $\underline{t} = -5.36$ ,  $\underline{p} < 0.001$ ). Thirty-four (37%) of the caregivers decreased the level of work status, 2 (2%) increased, and 55 (60%) did not change their work status. The amount of time worked for 58 (63.7%) of the caregivers was affected by being a caregiver.

Caregiver Characteristics (Total $N = 91$ ) Variable	<u>n</u>	%	M	SD
Gender Male	22	24.2		
Female	69	75.8		
Age (Range: 19-78) years			46.65	13.28
Marital Status				
Single (Never Married)	12	13.2		
Divorced	4	4.4		
Separated	0	0		
Widowed	0	0		
Married	75	82.4		
Education				
Elementary School and under	32	35.2		
Middle School	19	20.9		
High School	25	27.5		
Two-Year Technical School	10	11.0		
Undergraduate	5	5.5		
Graduate	0	0		
Religion				
Not Religious	18	19.8		
Buddhist	48	52.7		
Jewish	0	0		
Believe Jesus Christ	5	5.5		
Taoism	17	18.7		
Islam	0	0		
Others	3	3.3		
Children				
0	13	14.3		
1-3	57	62.6		
Over 3	21	23.1		
Relationship				
Friend	6	6.6		
Son	10	11.0		
Daughter	11	12.1		
Husband	11	12.1		
Wife	35	38.5		
Daughter in law	6	6.6		
Other relative	9	9.9		
Mother	2	2.2		
Father	1	1.1		

L

Table 3

$\sim$ ·	<u></u>	/ .* 1\
( aregiver	Characteristics	(continued)
		(Commucu)

	<u>n</u>	%	<u>M</u>	<u>SD</u>
Live with				
Alone	2	2.2		
Friend	1	1.1		
Parents	10	11.0		
Children	5	5.5		
Spouse	9	9.9		
Spouse and Children	45	49.5		
Spouse, Children and Parents	17	18.7		
Spouse and Parents	2	2.2		
Length of being a Caregiver				
(Range: 5 days to 17.25 years)			1.66 yea	rs 2.45 years
Less Six month	23	25.3		
Six month One year	33	36.3		
Over one year	35	38.5		
Health Status				
Before Caregiving			3.85	.97
Very poor	0	0		
Poor	2	2.2		
Fair	39	42.9		
Good	26	28.6		
Very good	19	20.9		
Excellent	5	5.5		
After Caregiving			3.54	.93
Very poor	1	1.1		
Poor	6	6.6		
Fair	44	48.4		
Good	25	27.5		
	13	14.3		
Very good				

Table	3
raute	5

-

Caregiver	Characteristics (continued)	
Variable		

Caregiver Characteristics (continued)				
Variable	<u>n</u>	%	M	<u>SD</u>
Work				
Before Caregiving			2.49	1.65
Full time	35	38.5		
Part time	27	29.7		
Retired	3	3.3		
Unemployed	1	1.1		
Do not work outside the home	25	27.5		
After Caregiving			3.35	1.62
Full time	12	13.2		
Part time	30	33.0		
Retired	4	4.4		
Unemployed	4	4.4		
Do not work outside the home	41	45.1		
Paired Sample t-test of work status	<u>t</u> = -5	5.36 р.	< .001	
between before and after caregiving				
Work Time Was Affected				
No	33	36.3		
Yes	58	63.7		
Monthly Income				
Below N\$ 10,000	29	31.9		
N\$10,000-19,999	18	19.8		
N\$20,000-29,999	21	23.1		
N\$30,000-39,999	15	16.5		
N\$40,000-49,999	3	3.3		
N\$50,000-59,999	3	3.3		
N\$60,000-69,999	0	0		
Above N\$ 70,000	2	2.2		
Hire a foreign labor to help				
No	86	94.5		
Yes	5	5.5		
Family caregivers need to spend a long time				
staying in the hospital				
No	38	41.8		
Yes	53	58.2		

An additional question was added to the Socio-Demographic Questionnaire. Family caregivers were asked to answer "Yes" or "No" to the question "If nurses provided total care to the patients, do you think family caregivers need to stay in the hospital?" There were significant differences between the family caregivers who thought it was important to stay in the hospital with the family members compared to those who did not think it was important. Family caregivers who felt the need to stay in the hospital had a higher income (t = -2.86, p < .01), better psychological well-being (t = -1.99, p < .05), and provided care to older patients (t = -2.25, p < .05) (See Table 4).

Table 4

Independent Samples t-test between Not Staying & Staying in the hospital for a long time if nurses can provide a complete care

Variable	Not Staying ( $\underline{n} = 38$ )		Staying	( <u>n</u> = 53)	
	<u>M</u>	<u>SD</u>	M	<u>SD</u>	<u>t</u>
Monthly Income	2.11	1.06	2.96	1.78	-2.86**
Patients' age	54.79	14.48	62.08	15.78	-2.25*
Psychological Well-being	73.21	10.49	77.98	11.79	-1.99*

\* p < .05 (2-tailed) \*\* p < .01 level (2-tailed) \*\*\* p < .001 level (2-tailed).

### Description of Care Receivers

Characteristics of the care receivers are provided in Table 5. Information about the 91 care receivers' data was reported by the caregivers. About 62.6% of the care receivers were male. The age of care receivers ranged from 15 to 87 years with a mean age of 59.03 years ( $\underline{SD} = 15.59$ ). Seventy-one (78%) of the care receivers were married, 52 (57.1%) had completed elementary school or less, and 48 (52.7%) were treated by chemotherapy. The largest diagnostic group was lung cancer ( $\underline{n} = 24$ ) followed by liver cancer ( $\underline{n} = 14$ ). The average number of care receivers' symptoms was 4.55 ( $\underline{SD} = 2.59$ ) for a range from 1 to 12. Fifty-five (60.4%) patients had loss of appetite, 52 (57.1%) felt fatigue, 41 (45.1%) had weight loss, and 39 (42.9%) felt pain (See Table 5).

Patients' ADL dependency is provided in Table 6 based on five activities. The number (<u>n</u>) indicates the number of patients, and the mean (<u>M</u>) indicates the average level of patients' ADL dependency. The average level of patients' ADL dependency for walking was 2.19 (<u>SD</u> = .94) for a range from 1 to 4. Seventy-eight (85.7%) of the care receivers were able to walk, 63.7% were able to walk with assistance (51.6% needed some help and 12.1% needed a lot of help), and 22% were able to walk without assistance. The average number of patients' total ADL dependency was 10.37 (<u>SD</u> = 4.33) for a range from 5 to 20. In general, they needed some help with ADL (See Table 6).

Table 5

-

Variable	<u>n</u>	%	M	<u>SD</u>
Gender Male	57	62.6		
Female	34	37.4		
Age (Range: 15 to 87) years			59.03	15.59
Marital Status				
Single (Never Married)	6	6.6		
Divorced	1	1.1		
Separated	0	0		
Widowed	13	14.3		
Married	71	78.0		
Education				
Elementary School and under	52	57.1		
Middle School	14	15.4		
High School	20	22.0		
Two-Year Technical school	3	3.3		
Undergraduate	2	2.2		
Graduate	0	0		
Diagnosis				
Lung Cancer	24	26.4		
Liver Cancer	14	15.4		
Colon Cancer	8	8.8		
Nasal Throat Cancer	7	7.7		
Cervical Cancer	6	6.6		
Oral Cancer	6	6.6		
Stomach Cancer	5	5.5		
Blood Cancer	5	5.5		
Esophageal Cancer	5	5.5		
Malignant Lymphoma	3	3.3		
Breast Cancer	2	2.2		
Bone Cancer	1	1.1		
Scalp Cell Cancer	1	1.1		
Ovary tumor	1	1.1		
Uterus Myoma	1	1.1		
Pancreatic cancer	1	1.1		
Small intestinal cancer	1	1.1		
Therapy				
Chemotherapy	48	52.7		
Radiation Therapy	29	31.9		
Surgery	21	23.1		
Symptom Therapy	16	17.6		
Thrombosis	3	3.3		

Table 5

Patient Characteristics (continued)

Variable	<u>n</u>	%	<u>M</u>	<u>SD</u>
Symptom				
Total Number of Symptoms			4.55	2.59
Loss of Appetite	55	60.4		
Fatigue	52	57.1		
Weight Loss	41	45.1		
Pain	39	42.9		
Dry Mouth	37	40.7		
Nausea & Vomiting	36	39.6		
Hair Loss	23	25.3		
Low Blood Counts	22	24.2		
Skin Changes (e.g., itchy skin)	21	23.1		
Respiratory Problems	20	22		
Loss of Concentration	19	20.9		
Food Taste Change	17	18.7		
Stomatitis	13	14.3		
Numbness or Tingling	11	12.1		
Halitosis	10	11		

Table 6

.

.

Patient Dependency Item	<u>n</u>	%	<u>M</u>	SD
Getting in/out of bed (1-4)			2.04	.84
No help needed	24	26.4		
Needs some help	45	49.5		
Needs a lot of help	16	17.6		
Can not do it	6	6.6		
Getting to/using toilet (1-4)			2.04	.97
No help needed	30	33.0		
Needs some help	37	40.7		
Needs a lot of help	14	15.4		
Can not do it	10	11.0		
Getting dressed/undressed (1-4)			2.16	.97
No help needed	25	27.5		
Needs some help	37	40.7		
Needs a lot of help	18	19.8		
Can not do it	11	12.1		
Eating (1-4)	14 A		1.93	1.06
No help needed	41	45.1		
Needs some help	28	30.8		
Needs a lot of help	9	9.9		
Can not do it	13	14.3		
Walking (1-4)			2.19	.94
No help needed	20	22.0		
Needs some help	47	51.6		
Needs a lot of help	11	12.1		
Can not do it	13	14.3		
Total Patient Dependency				
(Range 5-20)			10.37	4.33

### Descriptive Statistics for Major Variables

Table 7 provides descriptions of the major variables. The total scores of patients' ADL dependency, caregivers' psychological well-being, quality of relationship, knowledge of caregiving, lack of family support, impact on health, impact on schedule, and impact on finances were examined for normal distribution. Normal distributions produce a skewness statistic near zero (Brown, 1997). The absolute values of the skewness statistic for this study ranged from .03 to .79. Table 8 provides the Pearson's product-moment correlation between four caregiver's characteristics associated with caregiver burden (age, income, health status after caregiving, and the length of caregiving experience) and nine major variables. The purpose of using Pearson's product-moment correlation was to examine the relationship between two variables. The variables with significant Pearson's r were used in the Hierarchical Multiple Regression.

Variable	M	<u>SD</u>	Median	Min	Max
Patients' ADL dependency	10.37	4.33	10.00	5	20
Caregivers' psychological well-being	75.99	11.45	75.00	44	97
Quality of relationship	27.79	4.79	28.00	12	35
Knowledge of caregiving	28.12	4.23	28.00	18	35
Lack of family support	11.33	4.58	11.25	5 4	25 20
Impact on health Impact on finances	9.89 8.79	3.22 3.66	10.00 9.00	4	15
Impact on visits to family/friends	3.22	1.25	4.00	1	5
Impact on time for relaxation	3.00	1.20	3.00	1	5
*					

Descriptions of Major	· Variablee

Table 7

	1	2	3	4	5	6	7	8	9	10	11	12	13
1.Caregiver Age	1												
2.Caregiving Experience	.34***	1											
3. Health After Caregiving	13	04	1										
4. Income	10	.10	.37***	1									
5. ADL Dependency	01	.02	.18	.11	1								
6. Psy. Well Being	25*	13	.43***	.36***	.01	1							
7. Quality Relationship	.01	03	.37***	.10	22*	.35***	1						
8. Caregiving Knowledge	.03	.16	.16	.05	17	.30**	.37***	1					
9. Lack of Family Support	05	.14	28**	09	.13	29**	47***	17	1				
10. Impact on Health	.25*	.22*	52***	22*	.16	57***	55***	30**	.50***	1			
11. Impact on Finances	.15	.13	31**	28**	.02	31**	17	12	.35***	.52***	1		
12. Fewer Visits	.007	.02	13	.11	.27*	003	17	29**	.30**	.33****	.32**	1	
13. Less Relaxation	.18	.09	17	13	.40***	25*	26*	16	.37***	.47***	.36***	.42***	1

Table 8	
Pearson Correlations Between Caregiver Characteristics and Major Variables	

\* p < .05 (2-tailed) \*\* p < .01 level (2-tailed) \*\*\* p < .001 level (2-tailed).

## Research Question 1

The first question of this study was what is the relationship between the care receiver's dependency for activities of daily living and family caregiver burden? Family caregiver burden included impact on health, schedule, and finances. The results of the Pearson Correlation analysis are presented in Table 9. There were no significant relationships between the care receiver's dependency for activities of daily living and impact on health and finances.

There were significant positive relationships between the care receiver's ADL dependency and less time to visit family and friends ( $\underline{r} = .27$ ,  $\underline{p} < .05$ ) and less time for relaxation ( $\underline{r} = .40$ ,  $\underline{p} < .001$ ). Family caregivers whose care receiver had higher ADL dependency had less time to visit family and friends, and had less time for relaxation.

Table 9

Pearson Correlations between Care Receiver's ADL dependency and Impact on Health, Finances, Visits, and Relaxation

Variable	Impact on Health	Impact on Finances	Impact on Visits	Impact on Relaxation
Care receiver's ADL dependency	.16	.02	.27*	.40***

\* p < .05 (2-tailed) \*\* p < .01 level (2-tailed).

### **Research Question 2**

The second question of this study was what is the relationship between the caregiver factors and family caregiver burden? The results of the Pearson Correlation analysis are presented in Table 10. The caregiver factors included the family caregivers' psychological well-being, the quality of relationship between family caregivers and care receivers, and the knowledge of caregiving.

Impact on health was significantly associated with family caregivers' psychological well-being ( $\underline{r} = -.57$ ,  $\underline{p} < .001$ ), quality of relationship between family caregivers and care receivers ( $\underline{r} = -.55$ ,  $\underline{p} < .001$ ), and knowledge of caregiving ( $\underline{r} = -.30$ ,  $\underline{p} < .01$ ). Family caregivers who had higher scores of psychological well-being, the quality of the relationship between family caregivers and care receivers, and knowledge of caregiving had lower scores of impact on health (Table 10).

There was a significant negative relationship between family caregivers' psychological well-being and impact on finances( $\underline{r} = -.31$ ,  $\underline{p} < .01$ ). Family caregivers who had higher scores of psychological well-being had lower impact on finances scores. There was a negative relationship between caregivers' knowledge of caregiving and spending less time visiting family and friends ( $\underline{r} = -.29$ ,  $\underline{p} < 0.1$ ). Family caregivers who had better knowledge of caregiving had less impact on visits to family and friends. Caregivers' psychological well-being ( $\underline{r} = -.25$ ,  $\underline{p} < .05$ ) and quality of relationship with patients ( $\underline{r} = -.26$ ,  $\underline{p} < .05$ ) were negatively associated with impact on caregivers' relaxation. Family caregivers who had better psychological well-being or quality of relationship with patients had less impact on their relaxation (Table 10).

68

### Table 10

-

Variable	Impact on Health	Impact on Finances	Impact on Visits	Impact on Relaxation
Psychological well- being	57***	31**	003	25*
Quality of relationship	55***	17	17	26*
Knowledge of caregiving	30**	12	29**	16

Pearson Correlations between Caregiver Factors and Impact on Health, Finances, Visits, and Relaxation

\* p < .05 (2-tailed) \*\* p < .01 level (2-tailed) \*\*\* p < .001 level (2-tailed).

# Research Question 3

The third question of this study was what is the relationship between family support and family caregiver burden? The results of the Pearson Correlation analysis are presented in Table 11. The Lack of Family Support subscale was used in this question. There were significant positive relationships between lack of family support and impact on health ( $\underline{r} = .50$ ,  $\underline{p} < .001$ ), finances ( $\underline{r} = .35$ ,  $\underline{p} < .001$ ), visits to family and friends ( $\underline{r} = .30$ ,  $\underline{p} < .01$ ), and relaxation ( $\underline{r} = .37$ ,  $\underline{p} < .001$ ). Family caregivers who had less family support had a greater impact on health, finances, visits to family and friends, and relaxation.

Table 11

<u>Pearson Correlations between Lack of Family Support and Impact on Health, Finances,</u> <u>Visits, and Relaxation</u>

Variable	Impact on	Impact on	Impact on	Impact on
	Health	Finances	Visits	Relaxation
Lack of family support	.50***	.35***	.30**	.37***

 $\frac{p < .05 (2-tailed)}{p < .05 (2-tailed)} \approx p < .01 (2-tailed) \approx p < .001 (2-tailed).$ 

# Research Question 4

The fourth question of this study was how much of family caregiver burden will be predicted by the care receiver's dependency for activities of daily living, caregiver factors, and family support? Hierarchical Multiple Regression was used to analyze this question. Table 12 shows the results of the first model: impact on health and significant predictors. The order of entry for the predictors was according to the predictors' variances and significance: from stable to changeable variables and from caregivers' characteristics to the variables in the model. The purpose of this entry order was to control covariate variables' variances and separate entry in order to observe the  $\mathbb{R}^2$ change. Caregivers' age was entered on the first step, because age was the most stable variable. Income, health after being a caregiver, and patients' ADL dependency were entered on the second step. Total scores of caregivers' psychological well-being were entered on the third step. Total scores of quality of relationship between family caregivers and patients were entered on the fourth step. Total scores of caregiving knowledge were entered on the fifth step. Total scores of lack family support were entered on the sixth step.

As shown in Table 12, the model variables accounted for 59% of the variance in impact on health. In the first step, family caregiver's age had a significant increment 6%  $\underline{R}^2$  change (<u>F</u> change = 6.10, p < .05). In the second step, caregiver's income, health status after caregiving, and patient's ADL dependency had a significant increment 30%  $\underline{R}^2$ change (<u>F</u> change = 13.64, p < .001). In the third step, psychological well-being had a significant increment 11%  $\underline{R}^2$  change (<u>F</u> change = 18.10, p < .001). In the fourth step, quality of relationship between caregivers and patients had a significant increment 7% R<sup>2</sup> change (<u>F</u> change = 13.36, p < .001). In the fifth step, knowledge of caregiving had a non-significant increment  $0.1\% \underline{R}^2$  change (<u>F</u> change = .24, p > .05). In the sixth step, lack of family support had a significant increment  $4\% \underline{R}^2$  change (<u>F</u> change = 7.98, p < .01).

The statistic significance of  $\beta$  value was based on the <u>t</u> value. Older caregivers ( $\beta = .17, p < .05$ ), poorer health status after being a caregiver ( $\beta = -.26, p < .01$ ), lower scores of psychological well-being ( $\beta = -.26, p < .01$ ), lower scores of quality of relationship ( $\beta = -.22, p < .05$ ), and lack of family support ( $\beta = .23, p < .01$ ) were found to predict significantly greater impact on health. In the last step, lack of family support had a 4% increment to  $\underline{R}^2$  change (<u>F</u> change= 7.98, p < .01). This is a significant unique contribution to this model.

Step	Predictors	$\underline{\mathbf{R}}^2$ Change	<u>F</u> Change	β	<u>t</u>
I	Caregiver's Age	.06*	6.10*	.17*	2.34
II	Income	.30***	13.64***	.02	.19
	Health After Caregiving			26**	-2.91
	Total ADL Dependency			.12	1.58
III	Psychological Well-being	.11***	18.10***	26**	-2.98
IV	Quality of Relationship	.07***	13.36***	22*	-2.39
V	Caregiving Knowledge	.001	.24	05	63
VI	Lack Family Support	.04**	7.98**	.23**	2.83
	$\underline{\mathbf{R}}^2$	.59***			
	$\underline{F}(df = 8, 82)$	14.75***			

 Table 12

 Hierarchical Multiple Regression of Impact on Health with its Predictors

-

\* p < .05 (2-tailed) \*\* p < .01 (2-tailed) \*\*\* p < .001 (2-tailed).

A Multivariate Analysis of Variance was performed using patients' ADL dependency, caregivers' psychological well-being, quality of relationship, knowledge of caregiving, and lack of family support as dependent variables and responses to CRA question on visiting family and friends after grouping the responses. There was a significant difference between the participants in this study based on their response to this question (Wilks' Lamda =.789,  $\underline{F} = 2.11$ ,  $\underline{df} = 10$ , 168,  $\underline{p} = .026$ ). Post hoc comparisons using Tukey's honestly significant difference (Tukey's HSD) revealed a significant difference between the participants who had more time to visit family and friends compared to those who had less time in regard to patients' ADL dependency (mean difference = -2.68,  $\underline{p} < .05$ ), caregivers' knowledge of caregiving (mean difference = 2.37,  $\underline{p} < .05$ ), and lack of family support (mean difference = -2.57,  $\underline{p} < .05$ ). Respondents that agreed that they had less time to visit family and friends cared for patients with higher levels ADL dependency, had lower levels of knowledge about caregiving, and less family support than those who responded that visitation with family and friends had not decreased (see Table 13).

# Table 13

Descriptions of variables in MANOVA for Impact on Visits with 5 dependent variables Disagree (n = 30)Neither  $(\underline{n} = 14)$ Agree  $(\underline{n} = 47)$ Total ( $\underline{N} = 91$ ) M <u>SD</u> M SD M SD M <u>SD</u> **Patient ADL** Dependency 8.53 3.14 11.50 4.57 11.21 4.61 10.37 4.33 Caregiver Psycho. 77.70 9.99 70.93 10.44 75.99 76.40 12.37 11.45 Well-being Quality of Relationship 28.90 3.84 26.50 4.94 27.47 5.23 27.79 4.79 Knowledge of 3.58 27.57 5.63 27.30 3.94 28.12 4.23 Caregiving 29.67 Lack of Family 9.67 3.50 11.88 3.59 12.23 4.58 5.19 11.33 Support

Note. Bold words and numbers indicate significant differences.

A Multivariate Analysis of Variance was performed using patients' ADL dependency, caregivers' psychological well-being, quality of relationship, knowledge of caregiving, and lack of family support as dependent variables and responses to CRA question on relaxation after grouping the responses into three groups from five. There was a significant difference between the participants in this study based on their response (Wilks' Lamda = .663,  $\underline{F}$  = 3.84,  $\underline{df}$  = 10,168,  $\underline{p}$  = .000). Post hoc comparisons using Tukey's HSD revealed significant differences between participants who had more time for relaxation compared to those who had less time for relaxation in regard to patients' ADL dependency (mean difference = -3.71, <u>p</u> < .001), caregivers' quality of relationship (mean difference = 2.74, p < .05) and lack of support (mean difference = -3.73, p < .01). Respondents that had more difficulty finding time for relaxation had lower levels of quality of relationship, higher levels of patients' dependency, and less family support. Post hoc comparisons using Tukey's HSD revealed a significant difference between participants who had more time for relaxation compared to those who did not know whether they had time for relaxation or not (neutral responders) in regard to caregivers' psychological well-being (mean difference = 10.80, p < .001). Respondents that had more time for relaxation had higher psychological well-being than those who did not know whether they had time for relaxation or not (see Table 14).

Table 14

	Disagree	$r_{1}(n = 34)$	Neither	(n = 24)	Agree	(n = 33)	Total (	N = 91
	<u>M</u>	<u>SD</u>	<u>M</u>	$\underline{SD}$	M	<u>SD</u>	<u>M</u>	<u>SD</u>
Patient ADL Dependency	8.47	3.96	10.58	3.69	12.18	4.42	10.37	4.33
Caregiver Psycho. Well-being	81.09	10.27	70.29	8.11	74.88	12.64	75.99	11.45
Quality of Relationship	29.56	4.53	26.63	4.68	26.82	4.73	27.79	4.79
Knowledge of Caregiving	28.82	4.41	27.92	4.38	27.55	3.94	28.12	4.23
Lack of Family Support	9.34	3.80	11.77	4.44	13.07	4.75	11.33	4.58

Descriptions of variables in MANOVA for Impact on Relaxation with 5 dependent variables

Note. Bold words and numbers indicate significant differences.

Table 15 shows the results of the second model: impact on finances and significant predictors. The predictors were entered according to the predictors' variances and significance: from stable to changeable variables and from caregivers' characteristics to the variables in the model. The purpose of this entry order was to control covariate variables' variances and separate entry in order to observe the  $\mathbb{R}^2$  change. Caregiver's income and work time affected was entered on the first step, because income and work time were the most stable variables. Total scores of patient's ADL dependency were entered on the second step. Total scores of quality of relationship between family caregivers and patients were entered on the fourth step. Total scores of caregiving knowledge were entered on the fifth step. Total scores of lack of family support were entered on the sixth step.

As shown in Table 15, the model variables accounted for 21.3% of the variance in impact on finances. In the first step, family caregiver's income had a significant increment of 10%  $\underline{R}^2$  change (<u>F</u> change = 5.00, p < .01). In the third step, psychological well-being had a significant increment of 4%  $\underline{R}^2$  change (<u>F</u> change = 4.40, p < .05). In the sixth step, lack of family support had a significant increment of 6%  $\underline{R}^2$  change (<u>F</u> change = 6.60, p < .05).

Monthly income ( $\beta = -.22$ , p < .05) and lack of family support ( $\beta = .29$ , p < .05) were significant predictors for impact on finances in this model. In the last step, lack of family support had a 6% increment to  $\underline{R}^2$  change (<u>F</u> change= 6.60, p < .05). This is a significant unique contribution to this model. Family caregivers who had higher monthly income or more family support had lower impact on finances.

78

Step	Predictors	$\underline{\mathbf{R}}^2$ Change	<u>F</u> Change	β	<u>t</u>
I	Income	.10**	5.00**	22*	-2.04
	Work Time Affected			.10	.89
Π	Total ADL Dependency	.001	.14	.01	.10
III	Psychological Well-being	.04*	4.40*	16	-1.41
IV	Quality of Relationship	.003	.29	.06	.50
V	Caregiving Knowledge	.00	.003	01	10
VI	Lack Family Support	.06*	6.60*	.29*	2.57
	$\underline{\mathbf{R}}^2$	.213			
	$\underline{F}(df = 7, 83)$	3.20**			

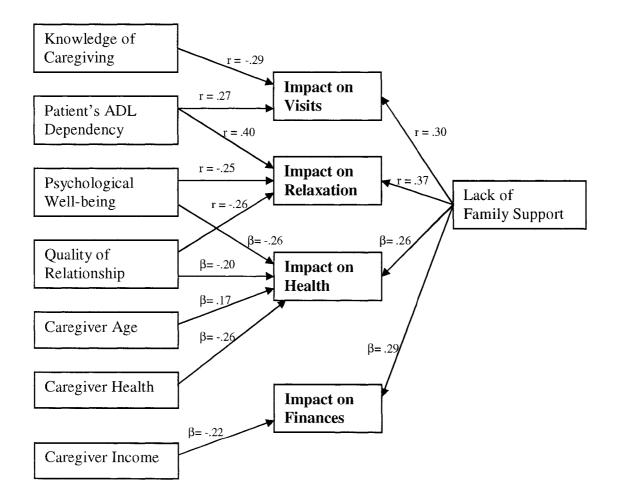
Table 15Hierarchical Multiple Regression of Impact on Finances with its Predictors

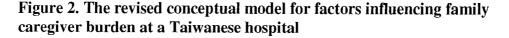
-

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

## Revised Conceptual Model

The revised conceptual model is shown in Figure 2. All estimated parameters were significant at p < 0.05. The conceptual model was modified based on the results of the hierarchical model of impact on health and finances as well as the MANOVA for impact on visits and relaxation. Pearson's r values were used to indicate the relationships between significant variables in the MANOVA for impact on visits and relaxation. Beta values were used to show the predictors in the hierarchical model of impact on health and finances.





#### Summary

The findings of this study were presented in this chapter. Descriptive statistics were used to examine demographic characteristics of the family caregivers, patients, and the major variables. A Pearson Product Moment Correlation matrix containing the caregivers' characteristics and major variables was generated and the relationships between them were examined. Hierarchical Multiple Regression analyses and MANOVA were used to answer the fourth question. The first model variables accounted for 59% of the variance in impact on health. The second model variables accounted for 21.3% of the variance in impact on finances. MANOVA showed the results of two significant variables (impact on visits to family and friends and time for relaxation). The revised conceptual model was proposed in this chapter.

# CHAPTER V

# SUMMARY, DISCUSSION, AND RECOMMENDATIONS

This chapter includes four sections. The first section contains a summary of the study including an overview of the study, research questions, methodology, data analysis techniques, and findings. The second section contains a discussion of measurements and recommendations. The third section includes discussion and interpretation of study findings related to the characteristics of participants and research questions. The fourth section includes the limitations of this study. The fifth section includes the recommendations for future research, as well as the implications for nursing practice, and health policy.

### Summary of the Study

The purpose of this multivariate descriptive study was to examine cancer patients' dependency, caregivers' factors, and family support that predict outcomes of family caregiver burden, including impact on health, schedule, and finances in a Taiwanese hospital. The conceptual framework of this study was developed from the model of factors influencing caregivers' responses to patients (Given et al., 1988).

A convenience sampling technique was used. Caregivers who met study criteria were recruited from Chung-Shan Medical University Hospital in Taichung, Taiwan. The study sample consisted of 91 primary family caregivers, 69 females and 22 males, with a mean age of 46.65 (SD = 13.28) years. The majority of caregivers were spouses and had a high school education or less. In general, most of the cancer patients in this study were male, could walk, and needed some help in ADL, with a mean age of 59.03 (SD = 15.59) years. The majority of patients were married and had a high school education or less.

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Data were analyzed using descriptive statistics, t-test, Pearson's product-moment correlation, MANOVA, and hierarchical multiple regression analyses. The relationships proposed by the model were partially supported.

# Measurements

This section contains the summary of measures and problems. In this study, the Activities of Daily Living (ADL) Index (Katz et al., 1963), Psychological Well-Being Scale (Ryff, 1989), Family Caregiving Factors Inventory (FCFI) (Shyu, 2000a), and Caregiver Reaction Assessment (CRA) (Given et al., 1992) were translated and back translated from English to Chinese. Two of the CRA subscales, Esteem and Lack of Family Support, were used as separate variables. The Esteem Subscale was used to measure the quality of relationship between family caregivers and care receivers. Lack of Family Support Subscale was used to measure lack of family support. Internal consistency reliability estimates for each instrument using Cronbach's alpha were obtained in the pilot study and this study. Results were summarized in Table 1.

Three subscales had low reliabilities: Lack of Family Support Subscale (alpha = .69), Impact on Finances Subscale (alpha = .67), and Impact on Schedule Subscale (alpha = .52) in the data analysis. After examining the summary of reliability statistics for each item's alpha in the Lack of Family Support Subscale, one question was eliminated to improve the alpha to .71. On the Impact on Finances Subscale CRA question 3 was deleted to improve the alpha to .75.

Reliability analysis on individual items demonstrated that the alpha value for the Impact on Schedule Subscale could not be improved by eliminating items from the scale. Therefore, the total score for the Impact on Schedule Subscale was not used in the analysis. Due to the distribution of responses, the Impact on Schedule responses were combined to create three groups: disagree, neither agree nor disagree, and agree, in order to examine the relationships of the five predictor variables. MANOVA was used to analyze the relationships between the five predictor variables and each question in the Impact on Schedule Subscale. Only two questions in the Impact on Schedule Subscale showed significant differences among the five predictor variables, so only these two questions' results were shown in the data analysis. The two questions are associated with visits to family and friends and time for relaxation. These two questions had significant results in the MANOVA, which were used in the data analysis instead of the total score of the Impact on Schedule Subscale.

There are several possible reasons for the low Cronbach's alpha on the Lack of Family Support Subscale, Impact on Finances Subscale, and the Impact on Schedule Subscale as described below. First, the number of items in each subscale is low. The Lack of Family Support Subscale has 5 items. The Impact on Finances Subscale has 3 items. The Impact on Schedule Subscale has 5 items. "Alpha is a function of test length. The longer the test, that is, the more items included, the higher the resulting alpha value (Waltz et al., 1991, p.167)." Researchers use subscales with few items is to increase the willingness of participants to answer the questions which will decrease threats to internal validity. Another reason is to decrease additional burden on the family caregivers who already spend a lot of time and effort on their sick family members.

84

A second reason is the cultural difference. American instruments were translated and used in Taiwan. The original questionnaire was applied in the community in the USA, but in this study, the Chinese version was used in the hospital in Taiwan. The living arrangements of elderly persons reflect their health as well as their family and cultural ties (U. S. Department of Health and Human Services [U.S. DHHS], 1999). The different family structures between the two countries influence the concept of family interaction and role expectation between parents and adult children. Most adult children in Taiwan strongly believe that helping and caring for parents is an unchangeable responsibility of being Hsiao and being a child (Chou, 1998; Chou, LaMontagne, & Hepworth, 1999). Based on these reasons, these five questions of Impact on Schedule might not fit into Taiwanese family caregivers.

The instruments with low reliability might not be culturally appropriate. For example, question 16 in the Lack of Family Support Subscale, which reads: Since caring for him/her, I feel my family has abandoned me, may not be culturally appropriate. Most of Taiwanese caregivers follow traditional culture. The traditional culture including filial piety (Sheu, 1997) and family cohesion (Carter & McGoldrick, 1999) teaches people that taking care of families is their responsibility, so they rarely use the term "being abandoned" to describe their lack of family support.

In this study, a translation and back-translation approach was used to translate the questionnaires. Using only one approach may not be enough to create a good questionnaire. Although this approach is popular and useful tool to develop a target language instrument, translation and back-translation is not an adequate test of the

equivalence of the target and source language documents, because this approach deals only with semantic equivalence (Behling & Law, 2000).

Another possible reason for the low Cronbach's alpha of Impact on Schedule is that the study sample was a homogeneous sample. They were caregivers of cancer patients (hospice patients excluded). While the pilot study was comprised of caregivers of both stroke and cancer patients, so the Cronbach's alpha of Impact on Schedule was higher than this study. A heterogeneous sample has higher internal consistency reliability than homogeneous sample, because "alpha is dependent upon the shape of the resulting distribution of test scores (Waltz et al., 1991, p. 168)." "When a skewed test-score distribution results, variance is usually less than that obtained when the distribution approximates a normal curve, and hence, alpha may be lower in value (Waltz et al., 1991, p. 168)."

In summary, the issues about low internal consistency reliability of subscales were discussed. Two specific questions in the CRA were introduced to replace the total scores of Impact on Schedule Subscale. The possible reasons for the low reliability included few items in the subscales, cultural difference, inadequate translation approaches, and homogeneous sample. The solutions for the low reliability included deleting items to increase alpha. In addition, MANOVA was used instead of the hierarchical multiple regression.

#### **Discussion of the Findings**

Discussion of the findings contains two sections, descriptive data and the results of the data analysis to answer the research questions.

86

### Descriptive Data

In this section findings related to the description of family caregivers and their care receivers are discussed.

#### Description of Family Caregivers

Most of the family caregivers in this study were spouses of the patients ( $\underline{n} = 46$ ), female ( $\underline{n} = 69$ ), married ( $\underline{n} = 75$ ), had a high school education or less ( $\underline{n} = 76$ ), and lived with spouse ( $\underline{n} = 73$ ). The age of family caregivers ranged from 19 to 78 with a mean age of 46.65 years ( $\underline{SD} = 13.28$ ). Monthly income for 68 (74.8%) participants was below N\$ 30,000 (about \$ 857.14). These findings are similar to previous studies in Taiwan (Chiu et al., 1996; Hu et al., 1999; Hu et al., 2001; Lin et al., 1996; Lin et al., 1999; Liu et al., 1998; Qin et al., 1999; Shyu, 2000a; Wu et al.,1991; Zhong & Huang, 1999).

In the U.S.A., most of the family caregivers also are females, married, and spouses of care receivers (Acton, 1997; Acton & Miller, 1996; Ayres, 2000; Given et al., 1992; Given et al., 1997; Given et al., 1999; Nijboer et al., 2000; Pasacreta et al., 2000; Schumacher et al., 2000), but American caregivers have higher education and income than Taiwanese caregivers. American caregivers only had 4% to 6% of the sample with less than a high school education, 49.9% to 59.2% had at least some college training, and 16% to 23% had income less than \$15,000 (Acton, 1997; Acton & Miller, 1996; Archbold et al., 1995; Given et al., 1992; Given et al., 1997; Nijboer et al., 2000; Ostwald et al., 1999).

Some previous studies reported that most of the primary caregivers were adult children of care receivers (Bull et al., 2000; Deimling et al., 2001; Weuve et al., 2000, Shyu, 2000b; Shyu, 2000c; Shyu et al., 1998), but in this study, only 23.1% of the caregivers were adult children of care receivers. The average age of these care receivers in the previous studies is older than the average age of this study's care receivers. There is an indication that older care receivers are taken care by their adult children, and the younger care receivers are taken by their spouse.

In this study, most of the spouse caregivers were in the stages of launching children and moving on or families with adolescents. Most of the adult children caregivers were in the stage of family with young children. These caregivers are vulnerable to increase stress as several development levels. Stress is often greatest at transition points from one stage to another in the developmental process as families rebalance, refine, and realign their relationships (Carter & McGoldrick, 1999).

The stress can be observed in the changes of family caregivers' health status, and work status. The family caregivers' health status after taking care of patients was significantly worse than before taking care of patients ( $\underline{t}$  = 3.96,  $\underline{p}$  < 0.001). This finding was similar to the previous study in Taiwan (Wu et al., 1991) and U.S.A. (Nijboer et al., 2000). There was a significant difference in the work status after being a caregiver compared to before being a caregiver ( $\underline{t}$  = -5.36,  $\underline{p}$  < 0.001). The amount of time worked was affected by being a caregiver for 58 (63.7%) of the caregivers. This finding was similar to previous study in Taiwan (Hu et al., 2001). Few previous studies have reported changes in the caregivers' health and work status after being a caregiver compared to before being a caregiver for 58 (63.7%) of the caregivers and work status after being a caregiver compared to before being a caregiver for 58 (63.7%) of the caregivers. This finding was similar to previous study in Taiwan (Hu et al., 2001). Few previous studies have reported changes in the caregivers' health and work status after being a caregiver compared to before being a caregiver for 58 are previous study and work status after being a caregiver compared to before being a caregiver of the status after being a caregiver compared to before being a caregiver for 58 are previous studies have reported changes in the caregivers' health and work status after being a caregiver compared to before being a caregiver. Caregivers' age may be related to their health status and work status. Younger caregivers have more impact on the time for work. In this study, older caregivers had more impact on their health and lower psychological well-being. The

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

discussion about impact on health and impact on finances is described with research question four.

In summary, most of the family caregivers in this study were spouses of the patients. About a quarter of the caregivers were their adult children. There is a tendency that older care receivers are taken care by their adult children, and the younger care receivers are taken by their spouse. The family caregivers' health and work status after taking care of patients were significantly worse than before taking care of patients.

# Description of Care Receivers

Most care receivers were male ( $\underline{n} = 57$ ) and married ( $\underline{n} = 71$ ). The finding is similar to the previous study in Taiwan (Zhong & Huang, 1999). The age of care receivers ranged from 15 to 87 with a mean age of 59.03 years ( $\underline{SD} = 15.59$ ). The finding is similar to the previous study in Taiwan (Liu et al., 1998; Zhong & Huang, 1999).

Most of the cancer patients were treated by chemotherapy in this study. The largest diagnostic group was lung cancer 24 (26.4%) followed by liver cancer 14 (15.4%). The average number of care receivers' symptoms was 4.55 (SD = 2.59). About 60.4% of cancer patients lost the appetite, 57.1% felt fatigue, and 45.1% had weight loss. Seventy-eight (85.7%) of the care receivers were able to walk, 63.7% were able to walk with assistance, and 22% were able to walk without assistance, so the average patients' dependency in ADL was not high. In general, the finding that they needed some ADL help is similar to the previous studies in Taiwan (Hu et al., 2001; Zhong & Huang, 1999). Compared with stroke and paralysis patients (Chiu et al., 1996; Wu et al., 1991), cancer patients' ADL dependencies were lower.

In summary, the characteristics of patients were male and married. Most of the cancer patients were treated by chemotherapy in this study. The major symptoms of cancer patients were lost the appetite, felt fatigue, and had weight loss. Most of the care receivers were able to walk, with or without assistance, so their ADL dependency were not high.

#### **Research Questions**

#### First Question

The first question of this study was what is the relationship between the care receiver's ADL dependency and family caregiver burden, which included impact on health, schedule, and finances. In this sample, family caregivers whose care receivers had higher ADL dependency had fewer visits to family and friends and more difficulty finding time for relaxation. Few previous studies reported the relationship between care receiver's ADL dependency and impact on visits to family and friends and time for relaxation. There was no significant relationship between the care receiver's ADL dependency and impact on health and finances.

Although many previous studies reported that there is a significant relationship between the care receiver's mobility and family caregiver burden (Danielson et al., 1993; Given et al., 1997; Given et al., 1999; Chou, 2000; Shyu, 2000b; Wright & Leahey, 2000; Montgomery et al., 1985), that finding was not supported in this study for health and finances, but was for aspects of impact on schedule.

There are four possible reasons for the differences. First, most patients in this study had a low level of ADL dependency and only needed some help or no help, but patients in other studies had higher levels of ADL dependency. Most patients could walk,

with or without assistance, so the significant influence of patients' dependency on family caregiver burden was decreased.

Second, most family caregivers had caregiving experience longer than six months. The average caregiving experience was  $1.66 (\underline{SD} = 2.45)$  years. During the first sixmonth observation period, an increase in care receivers' new dependencies was positively associated with higher levels of caregiver depression (Given et al., 1999). Caregivers who reported high numbers of care receivers' symptoms at baseline tended to have higher average levels of depression. This did not extend after the first six months (Given et al., 1997). In this study, most family caregivers were experienced decreasing the likelihood of finding a significant relationship between patients' ADL dependency and family caregiver burden.

Third, care receivers in this study were diagnosed with cancer. Most family caregivers of cancer patients focus on psychological problems (e.g., depression) (Given et al., 1997; Given et al, 1999), unlike the family caregivers of stroke, or cognitive patients who focus is on ADL assistance (Chou, 2000; Shyu, 2000b). Therefore, ADL dependency was less likely to be significantly related to impact on family caregivers' health and finances in this study.

Fourth, most of these previous studies measure patients' ADL and IADL as their mobility, but in this study only patients' ADL was used to assess their dependency. Because the participants were in-patient family caregivers, patients did not need shopping, housework, laundry, and financial management in the hospital. Without patients' IADL assessment might decrease the likelihood of association between patients' dependency and family caregivers' burden.

91

# Second Question

The second question of this study was what is the relationship between the caregiver factors (including psychological well-being, quality of relationship, and knowledge of caregiving) and family caregiver burden. Family caregivers with lower impact on finances had higher scores of psychological well-being. Low finances may be especially related to environment mastery that can influence caregivers' psychological well-being. Family caregivers who had better knowledge of caregiving had a lower impact on visits to family and friends. Family caregivers' knowledge of caregiving can increase caregivers' ability to help patients efficiently, so they can have more time to visit family and friends. Family caregivers' impact on their relaxation was less for those who had better psychological well-being or quality of relationship with patients. Family caregivers with better psychological well-being or quality of relationship with patients felt that they had more time for relaxation.

The result of this study is similar to the findings in several other studies, that family caregivers who have better psychological well-being experience a lower impact on their health (Acton, 1997; Chou, 1997; Chou, 1998; Chou et al., 1999; Shyu, 2000b). Most of the previous studies focused on the caregivers' hardiness (Chou, 1997), coping strategies (Chou, 1998; Chou et al., 1999; Shyu, 2000b), the process of adapting caregiving (Ayres, 2000; Shyu, 2000b; Shyu et al., 1998) and personal internal resources (Acton, 1997). Few studies explored the relationship between caregivers' psychological well-being and impact on their health. Psychological well-being is very important for family caregivers, because they not only face the caregiving tasks, but also they need to overcome many other issues in their lives simultaneously. Therefore, psychological wellbeing can help caregivers to maintain their health status. In this study, the significance of psychological well-being with caregivers' health has been supported.

The finding that family caregivers who have better quality relationships with their patients have a lower impact on their health is similar to other results reported in the literature (Chang et al., 1998; Chou, 1998; Chou et al., 1999; Corbeil et al., 1999; Liu et al., 1998; Yates, Tennstedt, & Chang, 1999; Shyu, 2002). The quality of relationships can be explained by filial obligation (Chou, 1998; Chou et al., 1999) and satisfaction with dyadic interaction (Corbeil et al., 1999).

Family caregivers who had better psychological well-being or quality of relationships with patients had less impact on their relaxation in this study. This may be related to patients' dependency. Only caregivers' quality of relationships with patients had a significant negative relationship with patients' ADL dependency, but there was not a significant association between caregivers' psychological well-being and patients' ADL dependency. That means that patients' ADL dependency can influence the quality of relationships between caregivers and patients, but patients' ADL dependency has no significant influence on caregivers' psychological well-being.

Few previous studies reported the relationship between caregivers' psychological well-being and impact on finances. In this study, family caregivers with better psychological well-being had a lower impact on their finances. The possible reason is that caregivers with better psychological well-being had higher income ( $\underline{r} = .36$ ,  $\underline{p} < .001$ ) in this study, so they had a lower impact on their finances.

The result of this study corroborates the findings in several other studies, that family caregivers with better knowledge of caregiving had a lower impact on their health.

93

Many studies have found that the knowledge of caregiving is inversely associated with impact on caregivers' health (Archbold et al., 1995; Bull et al., 2000; Chou, 1998; Chou et al., 1999; Liu et al., 1998; Shyu et al., 1998; Schumacher et al., 2000; Shyu, 2002; Yates et al., 1999; Ostwald et al., 1999).

Few previous studies reported the relationship between family caregivers' knowledge of caregiving and impact on visits to family and friends. In this study, family caregivers with more knowledge of caregiving had a lower impact on visits to family and friends. The possible reason is that caregivers with more knowledge of caregiving also had better caregiving mastery (Chou, 1998; Chou et al., 1999) and were more accepting the caregiving role (Bull et al., 2000). Therefore, they took care of patients more efficiently, and then they had more free time to visit their family or friends. Another possible reason is that family caregivers with more knowledge of caregiving also had better psychological well-being ( $\underline{r} = .30$ ,  $\underline{p} < .01$ ) and quality of relationship with patients ( $\underline{r} = .37$ ,  $\underline{p} < .001$ ) in this study. Therefore, visits to family and friends might not be a strong expectation (Ayres, 2000; Shyu, 1998) for family caregivers, and then the impact on visits to family and friends was decreased for them (Acton, 1997).

#### Third Question

The third question of this study was to examine the relationship between family support and family caregiver burden. Family caregivers with less family support had more impact on health, finances, visits to family and friends, and time for relaxation. The findings are similar to other results reported in the literature (Liu et al., 1998; Shyu, 2002; Weuve et al., 2000; Yates et al, 1999). Family support includes quality of support (feeling loved, feeling that one can count on others, having a confidant) and quantity of support (having a network available to provide aid in times of need) (Heidrich & Ryff, 1996). When caregivers get family support, they can have time to rest in order to restore their energy and health (Liu et al., 1998), which may help decrease caregivers' depression (Yates et al., 1999), and lessen the impact on their health and schedule. Little previous literature has reported the relationship between family support and impact on finances. The possible reason for this result is that family members might support caregivers in finances, so the impact on finances was decreased.

#### Fourth Question

Finding significant results in the analysis of the socio-demographic variables and the first three questions led to the final determination of variables used to predict family caregiver burden. The fourth question of this study was how much of family caregiver burden will be predicted by care receiver's ADL dependency, caregiver factors, and family support. In the first model, impact on health was predicted by caregivers' age, health status after being a caregiver, psychological well-being, quality of relationship, and family support. The model variables accounted for 59% of the variance in impact on health. The following variables were found to predict significantly greater impact on health: older caregivers, poorer health status after being a caregiver, lower psychological well-being scores, lower quality of relationship scores, and lack of family support.

In the second model, monthly income and family support accounted for 21.3% of the variance in impact on finances. Family caregivers who had higher income and family support had lower impact on finances.

MANOVA indicated that respondents who had fewer visits with family and friends after caregiving had higher levels of patients' ADL dependency, lower levels of knowledge about caregiving, and less family support than those who did not have fewer visits with family and friends. Respondents who had difficulty finding time for relaxation had lower levels of quality of relationship, higher levels of patients' dependency, and less family support. Respondents who had time for relaxation had higher psychological wellbeing than those who did not know how to express whether they had time for relaxation or not.

Lack of family support was a very important predictor for impact on health ( $\beta$  = .23, p < .01), finances ( $\beta$  = .29, p < .05), visits to family and friends, and relaxation. Family caregivers who had lower family support had more impact on health, finances, visits to family and friends, and relaxation. Others have reported that support resources can relieve the burden experienced by a family caregiver (Danielson et al., 1993; Given et al., 1988; Uhlenberg, 1996; Acton, 1997; Chou, 2000; Shyu, 2000b; Wright & Leahey, 2000).

Family caregivers' psychological well-being and health status after providing caregiving had the same effect ( $\beta = -.26$ , p < .01) on the impact on health. Family caregivers who had better psychological well-being and health status had a lower impact on their health. These results contribute to other findings on the relationship of psychological well-being in caregivers. Family caregivers who had good psychological well-being had better self-acceptance, positive relations with others, independency, life purpose, personal growth, and environmental mastery (Heidrich & Ryff, 1996). These personal characteristics were associated with the basic needs of human beings, e.g., safety/security, love/belongingness, esteem/ self-esteem, and self-actualization that can decrease the effects of stress and burden on life satisfaction (Acton, 1997).

The quality of the relationship between family caregivers and patients was a significant predictor of impact on health ( $\beta = -.22$ , p < .05) and relaxation. Family caregivers who had better quality of relationship with patients had a lower impact on their health and relaxation. Filial obligation (Chou, 1998; Chou et al., 1999; Yates, Tennstedt, & Chang, 1999) and good dyadic interaction (Corbeil et al., 1999) can decrease caregiving burden (Wu et al., 1991).

Family caregivers' age was a significant predictor for impact on health ( $\beta = .17$ , p < .05). Older family caregivers had more of an impact on their health. The results were similar to Shyu's study in Taiwan in which she reported that younger caregivers had significantly better overall caregiving consequences (Shyu, 2002), but in USA, younger, employed caregivers had demands that conflicted with the caregiver role and were therefore more apt to experience strain than older caregivers (Montgomery et al., 1985; Robinson, 1983).

Family caregivers' income was an important predictor of impact on finances ( $\beta$  = -.31, p < .01). Family caregivers who had higher income had a lower impact on their finances. Compared with previous studies in USA (Acton, 1997; Given et al., 1992) and in Taiwan (Chiu et al., 1997; Qin et al., 1999), most of the participants in this study had a low income. The monthly income for 68 (74.8%) participants was below N\$ 30,000 (about \$ 857.14). There were significantly positive relationships between income and family caregivers' health status (r = .37, p < .001) and psychological well-being (r = .36, p < .001). Family caregivers who had more income had better health status and psychological well-being. Family caregivers who reported low income not only had an

impact on their finances, but also on their health status. Few studies report the relationships between family caregiver burden and income.

In the first model, knowledge of caregiving was not a significant predictor. The possible reasons were that about 75% of the family caregivers had caregiving experience longer than six months. Patients' ADL dependency also was not a significant predictor in this model. The possible reason was that about 86% of the patients could walk. The two reasons might decrease the contributions of knowledge of caregiving and patients' ADL dependency to this model.

In summary, care receiver's ADL dependency was a significant predictor for impact on visits to family and friends and time for relaxation in this study. Family caregivers who had higher psychological well-being scores, quality of relationship between family caregivers and care receivers, and knowledge of caregiving had a lower impact on health scores. Family caregivers' psychological well-being also had a negative relationship with impact on finances. Family caregivers with more knowledge of caregiving had lower impact on their time to visit family and friends. Family caregivers with better psychological well-being and quality of relationship with patients had a lower impact on their time to relax. Family caregivers who had less family support had more impact on their health, finances, visits to family and friends, and relaxation.

Family support was a very important predictor for impact on health ( $\beta = .26, p < .01$ ), finances ( $\beta = .29, p < .05$ ) and impact on visits to family and friends, and relaxation. Family caregivers' psychological well-being and health status after providing caregiving had the same effect ( $\beta = .26, p < .01$ ) on the impact on health. The quality of the relationship between family caregivers and patients was a significant predictor of impact

on health ( $\beta = -.20$ , p < .05) and relaxation. Family caregivers' age was a significant predictor for impact on health ( $\beta = .17$ , p < .05). Family caregivers' income ( $\beta = -.22$ , p < .05) and lack of family support ( $\beta = .29$ , p < .05) were important predictors of impact on finances.

#### **Revised Conceptual Model**

The conceptual model of factors influencing family caregiver burden at a Taiwanese hospital has been examined based on these results. Five main predictors (patients' ADL dependency, family caregivers' psychological well-being, quality of relationship with care receiver, knowledge of caregiving, and family support) had significant relationships with family caregiver burden in these different impacts. The revised model was illustrated in the Figure 2 at the end of the chapter IV. The revised model indicates that lack of family support is the most important predictor for impact on caregivers' health, finances, time spent on visiting family and friends, and time for relaxation. Caregivers' psychological well-being and quality of relationship with patients are predictors of impact on health and relaxation. Caregivers' age and health status also are the predictors of impact on health. Caregivers' knowledge of caregiving is related to impact on visits with family and friends. Patients' ADL dependency is associated with impact on visits with family and friends and time for relaxation. Caregivers' income is a predictor of impact on finances.

#### Limitations

The participants in this study were a convenience sample, recruited from Chung-Shan Medical University Hospital, in the Taichung, Taiwan. The diagnosis of all of the care receivers was non-hospice cancer. Therefore there are limitations in the generalizability beyond a similar population. Also, the results of this cross sectional study describes the burden of family caregivers only while in a hospital. The multivariate descriptive design is used to observe and describe the natural phenomena rather than to infer cause-and-effect relationship (Polit & Hungler, 1999).

An additional limitation is the low reliabilities in the subscales of Lack of Family Support ( $\alpha = .69$ ), Impact on Finances ( $\alpha = .67$ ), Impact on Schedule ( $\alpha = .52$ ). The reasons and solutions for the low reliabilities have been discussed in the measurement section of this chapter. The instruments with low reliability might not be culturally appropriate, have too few items, employed with a too homogeneous group. The subjects in this study were limited in the family caregivers of cancer patients, over 18 years old, and being a family caregiver in a hospital at least 5 days. Therefore they had a homogeneous tendency with the majority having lower income and education that also contributes to the low reliability of subscale.

The low internal consistency reliability reflected the low consistency attitude of family caregiver's responses about Impact on Schedule subscale. The low internal consistency reliability could be a threat to internal validity, because the true of reality might not be reflected (Cook & Campbell, 1979). Potential type I error might be existed, because multiple statistics were used.

Most patients could walk, with or without assistance, so the significant influence of patients' dependency on family caregiver burden was decreased. In this study, most family caregivers were experienced decreasing the likelihood of finding a significant relationship between patients' ADL dependency and family caregiver burden as well as the relationship between caregivers' knowledge of caregiving and family caregiver burden.

In summary, the limitations include convenience sample, cross sectional and multivariate descriptive design, the low reliabilities in the subscales, low patients' ADL dependency, and longer than six months caregiving experiences. These limitations were discussed in this section.

#### **Recommendations and Implications**

Based on the findings of this study, this section contains the recommendations for future research, as well as implications for nursing practice and health policy.

## Recommendations for Future Research

Factors influencing family caregiver burden of chronic illness patients will be explored in the future. Participants should be recruited from several hospitals. A larger sample size randomly drawn from these hospitals would comprise a sample representative of the population. This would increase the generalizability of the study findings. The researchers also could compare family caregiver burden of other chronic illness patients who had more ADL dependency to further examine the relationship between patients' ADL dependency and family caregiver burden. In the sample criteria, the researchers should consider the length of caregiving experience. Previous studies reported that family caregivers with less than six months of caregiving experience had more caregiver burden than those with caregiving experience more than six months, but this study showed that family caregivers with longer caregiving experience had more impact on health. Using a longitudinal design, changes in family caregiver burden can be

measured over time. The effects of predictor variables found in this study should be examined to determine if they are significant predictors over time.

Because translation and back-translation focuses on dealing with semantic equivalence (Behling & Law, 2000), other solutions for the translating questionnaires should be used together. For example, Chang, Chau, and Holroyd (1999) compared Cronbach's alpha reliability coefficients, item to item agreement, and intraclass correlation coefficients between an English and Chinese version to increase the rigor of determining the equivalence between the Chinese and English versions of questionnaires (Chang, Chau, & Holroyd, 1999).

The researcher should carefully consider two other types of informationgathering methods before deciding to use the questionnaires and other self-report instrument (Behling & Law, 2000). The researchers also could prepare two different measurements to assess the same concept (Behling & Law, 2000). Adequate items should be included in the questionnaire to avoid low reliability (Waltz et al., 1991) and the threat to the internal validity (Cook & Campbell, 1979).

Modifications of the CRA instrument should be developed to insure the use of culturally sensitive measures. Taiwanese researchers could develop Taiwanese caregiver reaction assessment according to Taiwanese culture and norm. The developmental procedure of Given et al.'s CRA provides the cornerstone for the future researchers.

The results of this study could serve as a foundation for an intervention research to relieve family caregiver burden. The interventions may include (1) improving family caregivers' psychological well-being (2) improving quality of relationship between family caregivers and care receivers (3) increasing the knowledge of caregiving and (4)

motivating family support.

#### **Implications for Nursing Practice**

Based on the findings of this study, nurses should be aware of the family caregivers' physical and psychological well-being while providing care in the hospital and upon discharge. A systematic approach should be implemented to use in assessment, discharge plans, and evaluation. The discharge plans for family caregivers and patients should be explored. Nurses play three crucial roles in designing discharge plans: they function as observers, consulters, and educators. As observers, nurses should have the knowledge in how to assess caregivers' psychological well-being, quality of relationship with patients, knowledge of caregiving, and family support. A simplified check list can help nurses to collect information. As counselors, nurses should learn how to listen to and respond to family caregivers' questions according to their observation. They should also inspire family caregivers to explore and make use of their internal and external resources. Nurses should also provide information about support resources to family caregivers. As educators, nurses could motivate and improve family support by using brochures, videos, small-group discussions, and series of educational lessons to help family caregivers improve their psychological well-being, quality of relationship with patients.

Previous studies indicate that the knowledge of caregiving coudl be improved by discharge plans (Bull et al., 2000) and nursing interventions (Archbold et al., 1995; Ostwald et al., 1999). Knowledge of caregiving increased caregivers' preparedness (Archbold et al., 1995), caregiving mastery, self-efficacy, competence (Chou, 1998; Chou et al., 1999; Schumacher et al., 2000) and acceptance of the caregiving role (Bull et al., 2000), so the family caregivers had better caregiving outcomes (Bull et al., 2000; Shyu,

2002), and lower levels of depression (Yates et al., 1999). A series of caregiving lessons for family caregivers should be included in the nursing care plans or family caregivers' education. Evaluation of the effects on the lessons should be assessed at a suitable time to motivate family caregivers to learn the lessons. The results of the evaluation could be a cornerstone for future nursing practice and research.

A Family Caregiver Alliance should also be established in hospitals or in the community nursing center so that it can serve as a channel of two-way communication between family caregivers and the nurses and social workers.

#### **Implications for Health Policy**

In this study, caregivers with lower income and lack of family support experienced a greater impact on their finances. Family caregivers' health status and work status were also affected by being a caregiver. Policies should be made to the following:

1. Provide job protection for caregivers who take a leave of absence or leave the workplace temporarily to provide care.

2. Medical and insurance support for family members who provide care for patients should be included in state and federal benefits for health care.

3. Recruit volunteers to participate in the activities of caring for elders with disability and patients in the hospital and in the community. Establish a training center to train volunteers temporarily to relieve caregivers.

4. Use public media to provide family caregivers information about social resources to help them alleviate problems.

#### **Summary**

This chapter presented the summary and discussion of the study findings. The results of the four questions were discussed and illustrated in this chapter. Methodological issues associated with data collection, research design, and instruments were also discussed. Recommendation for future research, implication for nursing practices and health policies were suggested. The evaluation of the conceptual model of this study also was discussed.

## Reference:

- Acton, G. J. (1997). Affiliated-individuation as a mediator of stress and burden in caregivers of adults with dementia. *Journal of Holistic Nursing*, 15(4), 336-357.
- Acton, G. J., & Miller, E. W. (1996). Affiliated-Individuation in caregivers of adults with dementia. *Issues in Mental Health Nursing*, 17, 245-260.
- American Association of Retired Persons (AARP) and The Travelers Foundation (1988). A National Study of Caregivers: Final Report. Washington, DC: American Association of Retired Persons.
- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (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., Kirschling, J. M., Valanis, B. G., Brody, K. K., Schook, J. E., & Hagan, J. M. (1995). The PREP system of nursing interventions: A pilot test with families caring for older member. *Research in Nursing Health*, 18, 3-16.
- Ayres, L. (2000). Narratives of family caregiving: The process of making meaning. *Research in Nursing & Health*, 23, 424-434.
- Behling, O., & Law, K. S. (2000). *Translating Questionnaires and Other Research Instruments Problems and Solutions*. Thousand Oaks, CA: Sage.
- Borenstein, M., Rothstein, H., Cohen, J., Schoenfeld, D., & Berlin, J. (2000). Power for a test of the null hypothesis. *SamplePower* <sup>TM</sup> *Release* 2.0. SPSS Inc.
- Brereton, L. (1997). Preparation for family care-giving: stroke as a paradigm case. *Journal of Clinical Nursing*, *6*, 425-434.
- Brown, J. D. (1997). Statistics Corner. Questions and answers about language testing statistics: Skewness and Kurtosis. Shiken: JALT Testing & Evaluation SIG Newsletter, 1(1), 16-18. Retrieved March 17, 2003, from Internet Web Site: <a href="http://www.jalt.org/test/bro\_1.htm">http://www.jalt.org/test/bro\_1.htm</a>
- Bull, M. J. (1992). Managing the transition from hospital to home. *Qualitative Health Research*, 2, 27-41.
- Bull, M. J., Jervis, L. L. & Her, M. A. (1995). Hospitalized elders: the difficulties families encounter. *Journal of Gerontological Nursing*, 21, 19-23.
- Bull, M. J., Hansen, H. E., & Gross, C. R. (2000). Differences in family caregiver outcomes by their level of involvement in discharge planning. *Applied Nursing Research*, 13(2), 76-82.
- Carter, B., & McGoldrick, M. (1999). *The Expanded Family Life Cycle: Individual, Family, and Social Perspectives (3<sup>rd</sup> ed.)*. Needham Heights, MA: Allyn & Bacon.
- Chang, A. M., Chau, J. P. C., & Holroyd, E. (1999). Translation of questionnaires and issues of equivalence. *Journal of Advanced Nursing*, 29(2), 316-322.
- Chang, B. H., Noonan, A. E., & Tennstedt, S. L. (1998). The role of religion / spirituality in coping with caregiving for disabled elders. *The Gerontologist*, 38(4), 463-470.
- Chen, S. Y. (1997). A primary caregiver's pressure and coping mechanisms while the nasopharyngeal cancer patient is in the hospital. *Nursing of Veteran Hospital*, 14(3), 295-303. (in Chinese)
- Chiu, L., Pai, L. & Shyu, W. C. (1997). Factors determining family caregiver's satisfaction with home care in the Taipei metropolitan area. *Chinese Medical Journal (Taipei)*, 59, 28-36. (in Chinese)

- Chiu, L., Pai, L., Tang, K. Y., & Wang, S. P. (1996). Family caregivers' burdens and perceived need for home care services in the Taipei metropolitan area. *Chinese Journal Public Health (Taipei)*, 15(4), 289-302.
- Chou, K. R. (1998). Caregiver Burden: Structural Equation Modeling. *Nursing Research* (*in Taiwan*), 6(5), 358-371. (in Chinese)
- Chou, K. R. (2000). Caregiver Burden: A concept analysis. *Journal of Pediatric Nursing*, 15(6), 398-407.
- Chou, K. R., LaMontagne, L. L., & Hepworth, J. T. (1999). Burden experienced by caregivers of relatives with dementia in Taiwan. *Nursing Research*, 48(4), 206-214.
- Clyburn, L. D., Stones, M. J., Hadjistavropoulos, T. & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journal of Gerontology: SOCIAL SCIENCES*, *55B*(1), S2-S13.
- Coeling, H. V., Biordi, D. L., & Theis, S. L. (2003). Negotiating dyadic identity between caregivers and care receivers. *Journal of Nursing Scholarship*, 35(1), 21-25.
- Cook, T. D. & Campbell, D. T. (1979). *Quasi-experimentation: Design and analysis issues for field settings*. Boston: Houghton Mifflin.
- Corbeil, R. R., Quayhagen, M. P., & Quayhagen, M. (1999). Intervention effects on dementia caregiving interaction: A stress-adaptation modeling approach. *Journal of Aging and Health*, 11(1), 79-95.
- Covinsky, K. E., Goldman, L., Cook, E. F., Oye, R., Desbiens, N., Reding, D., Fulkerson, W., Connors, A. F., Lynn, J., & Phillips, R. S. (1994). The impact of serious illness on patients' families. *JAMA*, 272\_(23), 1839-1844.
- Cronk, B. C. (1999). *How to Use SPSS: A Step-by-Step Guide to Analysis and Interpretation*. Los Angeles, CA: Pyrczak Publishing.
- Cummings, S. M. (1999). Adequacy of discharge plans and rehospitalization among hospitalized dementia patients. *Health & Social Work*, 24(4), 249-259.
- Danielson, C. B., Hamel-Bissell, B., & Winstead-Fry, P. (1993). Families, Health, & Illness: Perspectives on Coping and Intervention. St. Louis, Missouri: Mosby.
- Department of Health, the Executive Yuan. (2001). *Health and vital statistics*. Taipei, Taiwan, ROC: Government Printing Office.
- Deimling, G. T., Smerglia, V. L., & Schaefer, M. L. (2001). The impact of family environment and decision-making satisfaction on caregiver depression: A path analytic model. *Journal of Aging and Health*, 13(1), 47-71.
- Driscoll, A. (2000). Managing post-discharge care at home: an analysis of patients' and their carers' perceptions of information received during their stay in hospital. *Journal of Advanced Nursing*, 31(5), 1165-1173.
- Erickson, M. E., Caldwell-Gwin, J. A., Carr, L. A., Harmon, B. K., Hartman, K., Jarlsberg, C. R., McCormick, J., & Noone, K. W. (1998). Helen C. Erickson, Evelyn M. Tomlin, Mary Ann P. Swain: Modeling and Role-Modeling. In A. M. Tomey & M. R. Alligood (4<sup>th</sup> Ed.), *Nursing Theorists and Their Work* (pp. 390-391). Salem, MA: Mosby Year book.
- Ernest, R.L. & Hay, J.W. (1994). The U.S. Economic and Social Costs of Alzheimer's Disease Revisited. *American Journal of Public Health*, 84(8), 1261-1264.
- Given, B. A., Given, C. W., Helms, E., Stommel, M. & DeVoss, D. N. (1997). Determinants of family care giver reaction: new and recurrent cancer. *Cancer Practician*, 5(1), 17-24.

- Given, C. W., Collins, C. E., & Given, B. A. (1988). Sources of stress among families caring for relatives with Alzheimer's Disease. *Nursing Clinics of North America*, 23(1), 69-82.
- Given, C. W., Given, B. A., Stommel, M., & Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression: Test using an inception cohort. *The Gerontologist*, 39(1), 76-85.
- Given, C. W., Given, B., Stommel, M., Collins, C., King, S. & Franklin, S. (1992). The caregiver reactions assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health*, *15*, 271-283.
- Given, B., McCorkle, R., Given, C. W., Kozachik, S., & Cimprich, B. (2002). Does emotional distress influence caregivers' assistance with cancer patients' symptoms: Results of a clinical trial. Research supported by Family Home for Cancer- A Community-Based Model. Grant # R01CA79280. From Speech at State of the Science Congress in Washington DC, September 26-29, 2002.
- Gresham, G. E., Duncan, P. W., & Stason, W. B. (1995). Post-stroke rehabilitation. Clinical Practice Guideline, No. 16. Rockville, MD: U. S. Department of Health and Human Services. Public Health Service, Agent for Health Care Policy and Research. AHCPR Publication No. 95-0662.
- Heidrich, S (1994). The Self, Health, and Depression in Elderly Women. Western Journal of Nursing Research, 16(5), 544-555.
- Heidrich, S. M., Ryff, C. D. (1996). The Self in Later Years of Life: changing perspectives on psychological well-being. In Sperry, Len; Prosen, Harry. Aging in the twenty-first century a developmental perspective, p.73-101, Garland Publishing, Inc. New York and London.
- Hu, L. C., Chen, M. L., Chen, M. C., Lin, C. C. & Lin, L. H. (2001). The caregiving burden and related factors of primary caregivers of metastatic cancer patients at home. *Chang Gung Nursing*, 12(4), 282-293 (in Chinese).
- Hu, W. Y., Chiu, T. Y., Chuang, R. D., Chen, C. Y., Dai, Y. T., & Chen, Y. C. (1999). The needs and satisfaction of main family caregivers in domiciliary palliative care. *Formosan Journal of Medical*, *3*, 527-537 (in Chinese).
- Hunt, C. K. (2003). Concept in caregiver research. *Journal of Nursing Scholarship*, 35(1), 27-32.
- Kahn, R. L., Goldfarb, A. I., Pollack, M., & Gerber, I. E. (1960). The relationship of mental and physical status in institutionalized aged persons. *American Journal of Psychiatry*, 117, 120-124.
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL: A standardized measure of Biological and Psychological Function. *Journal of the American Medical Association*, *185*, 914-919.
- Kee, C. C. & Borchers, L. (1998). Reducing readmission rates through discharge interventions. *Clinical Nurse Specialist*, 12(5), 206-209.
- Klein, S. S. (1989). Caregiver burden and moral development. *IMAGE: Journal of Nursing Scholarship*, 21 (2).
- Leading Causes of Death in the USA, (1998) http://infoplease.lycos.com
- Lee, J. R., Hills, G. A., Kaplan, S., & Johnson, P. M. (1998). Burden among caregivers of stroke patients in Taiwan. *Top Geriatric Rehabilitation*, 14(1), 74-83.

- Leske, J. S. & Jiricka, M. K. (1998). Impact of family demands and family strengths and capabilities on family well-being and adaptation after critical injury. *American Journal of Critical Care*, 7(5), 383-392.
- Lin, M. H., Ku, N. P., Leu, J. D., Chen, J. Y., & Lin, L. C. (1996). An exploration of the stress aspects in family caregivers of hepatoma patients. *Nursing Research*, 4(2), 171-185. (in Chinese)
- Lin, S. F., Liu, P. E., & Hung, H. C. (1999). Nursing experience of burdens of a family caregiver in home health care. *Hung Kuang Study Report*, 33(4), 1-20.
- Lipsey, M. W. (1990). *Design Sensitivity: Statistical Power for Experimental Research*. Newbury Park, CA: SAGE Publications.
- Liu, C. N., Hwu, Y. J., & Lee, M. J. (1998). The burden of primary caregivers' of stroke patients at hospital and its related factors. *Public Health*, 25(3), 197-210. (in Chinese)
- Manpower Planning Department, Council for Economic Planning & Development, Executive Yuan, Republic of China, (1996). *Projections of the Population of Taiwan Area. Republic of China 1995-2036*. Manpower Planning Department, Council for Economic Planning & Development, Executive Yuan, R. O. C., Taipei, Taiwan. (In Chinese)
- McCorkle, R., Yost, L. S., Jepson C. Malone D., Baird S, Lusk, E. (1993). A cancer experience: relationship of patient psychosicial responses to caregiver burden over time. *Psychooncology*, 2, 21-32.
- Montgomery, R. J. V., Gonyea, J. G., & Hooyman, N. R. (1985). Caregiving and experience of subjective and objective burden. *Family Relations*, 34, 19-26.
- Nijboer, C., Triemstra, M., Tempelaar, R., Mulder, M., Sanderman, R., & Bos, G. A. M. van den (2000). Patterns of caregiver experiences among patterns of cancer patients. *The Gerontologist*, 40(6), 738-746.
- Ostwald, S. K., Hepburn, K. W., Caron, W., Burns, T., & Mantell, R. (1999). Reducing caregiver burden: A randomized psychoeducational intervention for caregivers of persons with dementia. *The Geronlogist*, 39(3), 299-309.
- Pasacreta, J. V., Barg, F., Nuamah, I., & McCorkle, R. (2000). Participant characteristics before and 4 months after attendance at a Family Caregiver Cancer Education Program. *Cancer Nursing<sup>TM</sup>*, 23(4), 295-303.
- Polit, D. F. (1996). *Data Analysis & Statistics for Nursing Research*. Saratoga Springs, New York: Appleton & Lange.
- Polit, D. F., & Hungler, B. P. (1999). Nursing Research: Principles and Methods, 6<sup>th</sup> ed. Philadelphia, PA: Lippincott.
- Qin, Y., You, Y. H., & Huang, X. Q. (1999). The stresses and the needs of the primary caregivers of elderly people in Taichung. *Journal of Chinese Medical Social Work*, 7, 75-103 (in Chinese).
- Microsoft [Computer software]. (1996). Excel<sup>TM</sup>. Redmond, WA: Microsoft Corporation.
- National Taiwan University Hospital (1999). 1999 Cancer Statistics Review. Retrieved April 22, 2003, from <u>http://ntuh.mc.ntu.edu.tw/mre</u>
- Robinson, B. (1983). Validation of a caregiver strain index. *Journal of Gerontology, 38*, 344-348.
- Rosenberg, M. (1986). Conceiving the self. Malabar, FL: Robert E. Krieger.

- Ryff, C. D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57(6), 1069-1081.
- Ryff, C. D. (1995). Psychological well-being in adult life. *Current Directions in Psychological Science: A Journal of the American Psychological Society, 4*(4), 99-104.
- Ryff, C. D., & Heidrich, S. M. (1997). Experience and well-being: Explorations on domains of life and how they matter. *International Journal of Behavioral Development*, 20(2), 193-206.
- Ryff, C. D., & Keyes, C. L. M. (1995). The structure of psychological well-being revised. Journal of Personality and Social Psychology, 69(4), 719-727.
- Ryff, C. D., & Singer, B. (1996). Psychological well-being: Meaning, measurement, and implications for psychotherapy research. *Psychotherapy and Psychosomatics*, 65, 14-23.
- Ryff, C. D., & Singer, B. (1998). The contours of positive human health. *Positive Human Health*, 9(1), 1-28.
- Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: Development of the concept. *Research in Nursing & Health*, 23, 191-203.
- Sebern, M. (2002). Shared care describing & measuring a family caregiving interaction. Patient Centered Informational Interventions, University of Wisconsin-Madison. Funded by NINR T32 NR07102.
- Sheu, S. J. (1997). *Filial piety (Hsiao) and filial caregiving experiences of Chinese families in the San Francisco Bay Area.* Doctor of Philosophy Dissertation in School of Nursing, Graduate Division of the University of California, San Francisco.
- Shyu, Y. I., Archbold, P. G., & Imle, M. (1998). Finding a balance point: a process central to understanding family caregiving in Taiwanese families. *Research in Nursing & Health*, 21, 261-270.
- Shyu, Y.-I. L. (2000a). Development and testing of the Family Caregiving Factors Inventory (FCFI) for home health assessment in Taiwan. *Journal of Advanced Nursing*, 32(1), 226-234.
- Shyu, Y.-I. L. (2000b). Role tuning between caregiver and care receiver during discharge transition: An illustration of role function mode in Roy's adaptation theory. *Nursing Science Quarterly*, 13(4), 323-331.
- Shyu, Y.-I. L. (2000c). The needs of family caregivers of frail elders during the transition from hospital to home: a Taiwanese sample. *Journal of Advanced Nursing*, *32*(3), 619-625.
- Shyu, Y.-I. L. (2002). A conceptual framework for understanding the process of family caregiving to frail elders in Taiwan. *Research in Nursing & Health*, 25, 111-121.
- Siegel, K., Raveis, V. H., Houts, P., & Mor, V. (1991). Caregiver burden and unmet patient needs. *Cancer*, 68, 1131-1140.
- Stull, D. E., Kosloski, K., & Kercher, K. (1994). Caregiver burden and generic well-being: Opposite sides of the same coin? *Gerontologist*, 34, 88-94.
- Triandis, H. C. (1994). How to study cultures. *Cultural and Social Behavior*. New York: McGraw Hill.

- Uhlenberg, P. (1996). The burden of aging: A theortical framework for understanding the shifting balance of caregiving and care receiving as cohorts age. *The Gerontologist*, *36* (6), 761-767.
- U. S. Department of Health and Human Services (1999). *Health, United States, 1999 with Health and Aging Chart book.* Washington, DC: U.S. Government Printing Office.
- Waldman, A., & Fryman, E. (1964). Classification in homes for the aged. In Shore, H., & Leeds, M. (Eds.) (1964). *Geriatric Institutional Management*. New York: Putnam's.
- Waltz, C. F., Strickland, O. L., & Lenz, E. R. (1991). Measurement in Nursing Research (2nd ed). Philadelphia: F. A. Davis Company.
- Ware, J. E. JR., Davies-Avery, A., & Donald, C. A. (1978). Conceptualization and measurement of health for adults in the health insurance study: *Vol. V, General Health Perceptions*. Santa Monica, CA: Rand.
- Weaver, F. M., Perloff, L., & Waters, T. (1998). Patients' and caregivers' transition from hospital to home: Needs and recommendations. *Home Health Care Services Quarterly*, 17(3), 27-48.
- Weng, H. Q., Ma, J. N., Zhang, L. C., & Zheng, Y. X. (2002). The exploration of primary caregiver burden of spinal injury patients at home: Qualitative interviews and observation records of 15 pairs of caregivers and patients. *Long Term Care*, 5(2), 77-89 (in Chinese).
- Weuve, J. L., Boult, C., & Morishita, L. (2000). The effects of outpatient geriatric evaluation and management on caregiver burden. *The Gerontologist*, 40(4), 429-436.
- Wright, L. K., Clipp, E. C., & George, L. K. (1993). Health consequences of caregiver stress. *Medical Exercise and Nutritional Health*, 2, 181-195.
- Wright, L. M., & Leahey, M. (2000). Nurses and Families: A Guide to Family Assessment and Intervention (3 ed). Philadelphia, PA: F. A. Davis.
- Wu, S. L., Hu, H. C., & Yao, K. M. (1991). A study on the burdens and needs of primary caregiver of frail elderly in home care program. *Public Health*, 18(3), 237-248. Taiwan, R.O.C. (in Chinese).
- Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Psychological Sciences*, 54B(1), 12-22.
- Yeh, K. H. (1997). Changes in Taiwan people's concept of filial piety. In L. Y. Change, Y. H. Lu, & F. C. Wang (Eds.), *Taiwan society in 1990s: Taiwan Social Change Survey Symposium Series II* (Part 2, pp. 170-214). Taipei: Institute of Sociology, Academia Sinica (in Chinese).
- Yeh, S. H. (1995). *Caregiver burden and the changes in caregiving following nursing home placement in Taiwan*. Doctoral Dissertation, College of Nursing in the University of Utah.
- Zhong, Y. Q., & Huang, Z. W. (1998). The needs of primary caregivers of stroke patients in the community. *Chung-Tai Study Report*, 11, 29-55 (in Chinese).

APPENDIX A DEMOGRAPHIC QUESTIONNAIRE

Filling out this survey means that I am at least 18 years old and am giving my informed consent to be a participant in this study. CODE NUMBER:

## **Caregiver Characteristics:**

PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF.
(choose one number and check in the square)
<b>1. Gender :</b> 1. $\square$ Male 2. $\square$ Female
2. What year were you born?
<b>3.</b> Are you: 1. □ Single (Never Married) 2. □ Divorced 3. □ Separated
4. 🗌 Widowed 5. 🗌 Married
4. What is the highest grade you completed in school?
1. $\Box$ Elementary School and under 2. $\Box$ Middle School 3. $\Box$ High School
3. 🗆 Two-Year Technical school 4. 🗆 Undergraduate 5. 🗆 Graduate
5. Do you consider yourself 1.  Not Religious 2.  Buddhist 3.  Jewish
4. 🗆 Believe in Jesus Christ 5. 🗆 Taoism 6. 🗆 Islam 7. 🗆 Other
<b>6. How many children do you have?</b> 1. $\Box$ 0 2. $\Box$ 1-3 3. $\Box$ Over 3
7. You are care receiver's 1.  Friend 2. Son 3. Daughter
4. $\Box$ Husband 5. $\Box$ Wife 6. $\Box$ Daughter in law 7. $\Box$ Other relative
8. Whom do you live with?
1. $\Box$ Alone 2. $\Box$ Friend 3. $\Box$ Parents 4. $\Box$ Children 5. $\Box$ Spouse
6. 🗆 Spouse and Parents 7. 🗆 Spouse and Children 8. 🗆 Spouse, Children and Parents
9. How long have you been a caregiver? — Days — Months — Years
10. How is your Health Status?
Please choose one number to express your health status.
Before Caregiving
1. $\Box$ very poor 2. $\Box$ poor 3. $\Box$ fair 4. $\Box$ good 5. $\Box$ very good 6. $\Box$ excellent.
After Caregiving
1. $\Box$ very poor 2. $\Box$ poor 3. $\Box$ fair 4. $\Box$ good 5. $\Box$ very good 6. $\Box$ excellent.
11. How much do you work?
Before Caregiving
1. $\Box$ Full time 2. $\Box$ Part time 3. $\Box$ Retired 4. $\Box$ Unemployed
After Caregiving
1. $\Box$ Full time 2. $\Box$ Part time 3. $\Box$ Retired 4. $\Box$ Unemployed
Has the amount of time you work been affected by your need to be a caregiver?
1. $\Box$ No 2. $\Box$ Yes
12. Your Monthly Income is
1. □ Below N\$ 10,000 2. □ N\$10,000-19,999 3. □ N\$20,000-29,999

4. □ N\$ 30,000-39,999 5. □ N\$ 40,000-49,999 6. □ N\$50,000-59,999

7. □ N\$ 60,000-69,999 8. □ N\$ Above N\$ 70,000

Patient Characteristics:

- 1. Care Receiver's Gender: 1. 
  Male 2. 
  Female
- 2. What year was Care Receiver born? \_\_\_\_

## 3. Care Receiver's Marital Status:

1. □ Single (Never Married) 2. □ Divorced 3. □ Separated 4. □ Widowed 5. □ Married

5.  $\Box$  Married

## 4. What is the highest grade care receiver completed in school?

1. 
Elementary School and under 2. 
Middle School 3. 
High School

3.  $\Box$  Two-Year Technical school 4.  $\Box$  Undergraduate 5.  $\Box$  Graduate

## 5. What is care receiver's diagnosis?

1. 
Lung Cancer 2. 
Liver Cancer 3. 
Colon Cancer 4. 
Breast Cancer

5. □ Cervical Cancer 6. □ Bone Cancer 7. □ Stomach Cancer 8. □ Other \_\_\_\_

**6.** What treatments does the patient have in this hospitalization? (You can choose more than one item.)

1. □ Surgery 2. □ Radiation Therapy 3. □ Chemotherapy

**7. What symptoms and side effects does the patient have in this hospitalization?** (You can choose more than one item.)

1. □Pain 2. □Fatigue 3. □Loss of Appetite 4. □Weight Loss 5. □Nausea & Vomiting

6. □Food Taste Change 7. □Halitosis 8. □Stomatitis 9. □Dry Mouth 10. □Hair Loss

11. Dow Blood Counts 12. Skin Changes (e.g., itchy skin) 13. Numbness or

tingling in the hands or feet 14. Doss of Concentration 15. Respiratory Problems

## 8. Highest level of care receiver's mobility during hospitalization:

1.  $\Box$  Lie on the bed 2.  $\Box$  Can sit up, but needs help 3.  $\Box$  Can sit up without help

4.  $\Box$  Can walk, but needs help 5.  $\Box$  Can walk without help

APPENDIX B

## THE INDEX OF ACTIVITIES OF DAILY LIVING

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

## <u>Care Receiver Dependency of daily activities</u> Please choose each item that care receiver needs for assistance in daily activities

	No help	Needs some	Needs a lot of	Can not do it
	needed	help	help	
1. Getting in/out of bed	1	2	3	4
2. Getting to/using toilet	1	2	3	4
3. Getting dressed/undressed	1	2	3	4
4. Eating	1	2	3	4
5. Walking	1	2	3	4

Katz, Ford, Moskowitz, Jackson, & Jaffe, (1963)

## APPENDIX C

## PSYCHOLOGICAL WELL-BEING SCALE

## Psychological Well-Being (Ryff, 1989)

Definition: Caregivers' psychological well-being including autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance.

#### AUTONOMY

Definition: <u>High Scorer</u>: Is self-determining and independent; able to resist social pressures to think and act in certain ways; regulates behavior from within; evaluates self by personal standards.

<u>Low Scorer</u>: Is concerned about the expectations and important decisions; conforms to social pressures to think and act evaluations of others; relies on judgements of others to make in certain ways.

- 1. \*I tend to be influenced by people with strong opinions.
- 2. I have confidence in my opinions, even if they are contrary to the general consensus.
- 3. I judge myself by what I think is important, not by the values of what others think is important.

#### **ENVIRONMENTAL MASTERY**

Definition: <u>High Scorer</u>: Has a sense of mastery and competence in managing the environment; controls complex array of external activities; makes effective use of surrounding opportunities; able to choose or create contexts suitable to personal needs and values.

<u>Low Scorer</u>: Has difficulty managing everyday affairs; feels unable to change or improve surrounding context; is unaware of surrounding opportunities; lacks sense of control over external world.

- 4. In general, I feel I am in charge of the situation in which I live.
- 5. \*The demands of everyday life often get me down.
- 6. I am quite good at managing the many responsibilities of my daily life.

#### PERSONAL GROWTH

Definition: <u>High Scorer</u>: Has a feeling of continued development; sees self as growing and expanding; is open to new experiences; has sense of realizing one's potential; sees improvement in self and behavior over time; is changing in ways that reflect more self knowledge and effectiveness.

Low Scorer: Has a sense of personal stagnation; lacks sense of improvement or expansion over time; feels bored and uninterested with life; feels unable to develop new attitudes or behaviors.

- 7. I think it is important to have new experiences that challenge how you think about yourself and the world.
- 8. For me, life has been a continuous process of learning, changing, and growth.
- 9. \*I gave up trying to make big improvements or changes in my life a long time ago.

#### POSITIVE RELATIONS WITH OTHERS

- Definition: <u>High Scorer</u>: Has warm satisfying, trusting relationships with others; is concerned about the welfare of others; capable of strong empathy, affection, and intimacy; understands give and take of human relationships.
   <u>Low Scorer</u>: Has few close, trusting relationships with others; finds it difficult to be warm, open, and concerned about others; is isolated and frustrated in interpersonal relationships; not willing to make compromises to sustain important ties with others.
- 10. \*Maintaining close relationships has been difficult and frustrating for me.
- 11. People would describe me as a giving person, willing to share my time with others.
- 12. \*I have not experienced many warm and trusting relationships with others.

#### **PURPOSE IN LIFE**

Definition: <u>High Scorer</u>: Has goals in life and a sense of directedness; feels there is meaning to present and past life; holds beliefs that give life purpose; has aims and objectives for living.

Low Scorer: Lacks a sense of meaning in life; has few goals of aims, lacks sense of direction; does not see purpose of past life; has no outlook or beliefs that give life meaning.

- 13. \*I live life one day at a time and do not really think about the future.
- 14. Some people wander aimlessly through life, but I am not one of them.
- 15. \*I sometimes feel as if I've done all there is to do in life.

#### SELF-ACCEPTANCE

Definition: <u>High Scorer:</u> Possesses a positive attitude toward the self; acknowledges and accepts multiple aspects of self including good and bad qualities; feels positive about past life.

<u>Low Scorer</u>: Feels dissatisfied with self; is disappointed with what has occurred in past life; is troubled about certain personal qualities; wishes to be different than what one is.

- 16. When I look at the story of my life, I am pleased with how things have turned out.
- 17. I like most aspects of my personality.
- 18. \*In many ways, I feel disappointed about my achievements in life.

#### APPENDIX D

## KNOWLEDGE OF CAREGIVING

These questions were designed to find out the knowledge of family caregivers about caregiving that could be a reference for nurses to provide family caregivers and patients with a good discharge plan. Please remember that there are no right or wrong answers. According to what you know about the condition of the care receiver, please choose one answer that best describes your situation.

How well do you know him/her?	Completely	Not	Partly	Most	Completely
	Not	Understand	Understand	Understand	understand
	Understand				
1. Factors that influence care receiver's	1	2	3	4	5
physical condition (e.g. pressure sore)					
2. Care receiver's safety problems (ex. fall or	1	2	3	4	5
choke)					
3. Factors that influence of care receiver's	1	2	3	4	5
emotional state (ex. happy, sad, angry, or joy)					
4. Care receiver's cognitive ability (ex.	1	2	3	4	5
judgments of time, place, and person)					
5. Care receiver's personality	1	2	3	4	5
6. Care receiver's communication ability	1	2	3	4	5
7. Care receiver's comfort needs	1	2	3	4	5

(Shyu, 2000)

APPENDIX E

## CAREGIVER REACTION ASSESSMENT

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

Coding scheme ranged from 1=Strongly disagree to 5=Strongly agree.

\* indicates reverse scored question.

Factor 1: Caregiver's esteem

The higher scores express the better quality of relationships between caregivers and care receivers.

1. I feel privileged to care for \_\_\_\_\_.

7. \* I resent having to take care of \_\_\_\_\_.

9. I really want to care for \_\_\_\_\_.

12. I will never be able to do enough caregiving to repay \_\_\_\_\_.

17. Caring for \_\_\_\_\_makes me feel good.

20. Caring for \_\_\_\_\_is important to me.

23. I enjoy caring for \_\_\_\_\_.

Factor 2: Lack of family support

2. Others have dumped caring for \_\_\_\_\_ onto me.

6. It is very difficult to get help from my family in taking care of \_\_\_\_\_.

13. \* My family works together at caring for \_\_\_\_\_.

16. Since caring for \_\_\_\_\_, I feel my family has abandoned me.

22. My family (brothers, sisters, children) left me alone to care for \_\_\_\_\_.

Factor 3: Impact on Finances

Higher scores indicate higher financial burden of family caregiver.

3. \* My financial resources are adequate to pay for things that are required for caregiving.

21. Caring for \_\_\_\_\_ has put a financial strain on the family.

24. It's difficult to pay for \_\_\_\_\_'s health needs and services.

Factor 4: Impact on schedule

Higher scores indicate higher schedule burden of family caregiver.

4. My activities are centered around care of \_\_\_\_\_.

8. I have to stop in the middle of work.

11. I visit family and friends less since I have been caring for \_\_\_\_\_.

14. I have eliminated things from my schedule since caring for \_\_\_\_\_.

18. The constant interruptions make it difficult to find time for relaxation.

Factor 5: Impact on health

Higher scores indicate higher health burden of family caregiver.

5. Since caring for \_\_\_\_\_, it seems like I'm tired all of the time.

10. My health has gotten worse since I've been caring for\_\_\_\_\_.

15. \* I have enough physical strength to care for \_\_\_\_\_.

19. \* I am healthy enough to care for \_\_\_\_\_.

APPENDIX F

# DATA COLLECTION TOOL (ENGLISH VISION)

Filling out this survey means that I am at least 18 years old and am giving my informed consent to be a participant in this study. CODE NUMBER:

## **Caregiver Characteristics:**

<ul> <li>PLEASE ANSWER THE FOLLOWING QUESTIONS ABOUT YOURSELF.</li> <li>(choose one number and check in the square)</li> <li>1. Gender : 1. □ Male 2. □ Female</li> <li>2. What year were you born?</li> <li>3. Are you: 1. □ Single (Never Married) 2. □ Divorced 3. □ Separated</li> </ul>
4. $\Box$ Widowed 5. $\Box$ Married
4.What is the highest grade you completed in school?
1. $\Box$ Elementary School and under 2. $\Box$ Middle School 3. $\Box$ High School
3. 🗆 Two-Year Technical school 4. 🗌 Undergraduate 5. 🗆 Graduate
5. Do you consider yourself 1. 🗆 Not Religious 2. 🗆 Buddhist 3. 🗆 Jewish
4. 🗌 Believe in Jesus Christ 5. 🗌 Taoism 6. 🗌 Islam 7. 🗌 Other
<b>6. How many children do you have?</b> 1. $\Box$ 0 2. $\Box$ 1-3 3. $\Box$ Over 3
7. You are care receiver's 1. 🗆 Friend 2. 🗌 Son 3. 🗋 Daughter
4. $\Box$ Husband 5. $\Box$ Wife 6. $\Box$ Daughter in law 7. $\Box$ Other relative
8. Whom do you live with?
1. $\Box$ Alone 2. $\Box$ Friend 3. $\Box$ Parents 4. $\Box$ Children 5. $\Box$ Spouse
6. $\Box$ Spouse and Parents 7. $\Box$ Spouse and Children 8. $\Box$ Spouse, Children and Parents
9. How long have you been a caregiver? Days MonthsYears
10. How is your Health Status?
Please choose one number to express your health status.
Before Caregiving
1. $\Box$ very poor 2. $\Box$ poor 3. $\Box$ fair 4. $\Box$ good 5. $\Box$ very good 6. $\Box$ excellent.
After Caregiving
1. $\Box$ very poor 2. $\Box$ poor 3. $\Box$ fair 4. $\Box$ good 5. $\Box$ very good 6. $\Box$ excellent.
11. How much do you work?
11. How much do you work? Before Caregiving
<ul> <li>11. How much do you work?</li> <li>Before Caregiving</li> <li>1. □ Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving</li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>Has the amount of time you work been affected by your need to be a caregiver?</li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>Has the amount of time you work been affected by your need to be a caregiver? <ol> <li>No 2. □ Yes</li> </ol> </li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>Has the amount of time you work been affected by your need to be a caregiver? <ol> <li>No 2. □ Yes</li> </ol> </li> <li>12. Your Monthly Income is</li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>Has the amount of time you work been affected by your need to be a caregiver? <ol> <li>No 2. □ Yes</li> </ol> </li> <li>12. Your Monthly Income is <ol> <li>Below N\$ 10,000 2. □ N\$10,000-19,999 3. □ N\$20,000-29,999</li> </ol> </li> </ul>
<ul> <li>11. How much do you work?</li> <li>Before Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>After Caregiving <ol> <li>Full time 2. □ Part time 3. □ Retired 4. □ Unemployed</li> </ol> </li> <li>Has the amount of time you work been affected by your need to be a caregiver? <ol> <li>No 2. □ Yes</li> </ol> </li> <li>12. Your Monthly Income is</li> </ul>

Patient Characteristics:

1. Care Receiver's Gender: 1. 
Male 2. 
Female

2. What year was Care Receiver born?

## 3. Care Receiver's Marital Status:

1. □ Single (Never Married) 2. □ Divorced 3. □ Separated 4. □ Widowed 5. □ Married

## 4. What is the highest grade care receiver completed in school?

1. □ Elementary School and under 2. □ Middle School 3. □ High School

3. □ Two-Year Technical school 4. □ Undergraduate 5. □ Graduate

## 5. What is care receiver's diagnosis?

1. □ Lung Cancer 2. □ Liver Cancer 3. □ Colon Cancer 4. □ Breast Cancer

5. □ Cervical Cancer 6. □ Bone Cancer 7. □ Stomach Cancer 8. □ Other \_\_\_\_

# **6. What treatments does the patient have in this hospitalization?** (You can choose more than one item.)

1. □ Surgery 2. □ Radiation Therapy 3. □ Chemotherapy

**7. What symptoms and side effects does the patient have in this hospitalization?** (You can choose more than one item.)

1. □Pain 2. □Fatigue 3. □Loss of Appetite 4. □Weight Loss 5. □Nausea & Vomiting

6. DFood Taste Change 7. Halitosis 8. Stomatitis 9. Dry Mouth 10. Hair Loss

11. Dow Blood Counts 12. Skin Changes (e.g., itchy skin) 13. Numbness or

tingling in the hands or feet 14. 
Loss of Concentration 15. 
Respiratory Problems

8. Highest level of care receiver's mobility during hospitalization:

- 1.  $\Box$  Lie on the bed 2.  $\Box$  Can sit up, but needs help 3.  $\Box$  Can sit up without help
- 4.  $\Box$  Can walk, but needs help 5.  $\Box$  Can walk without help

## Care Receiver Dependency of daily activities

Please choose each item that care receiver needs for assistance in daily activities (draw a circle around the number)

	No help needed	Needs some help	Needs a lot of help	Can not do it
Getting in/out of bed	1	2	3	4
Getting to/using toilet	1	2	3	4
Getting dressed/undressed	1	2	3	4
Eating	1	2	3	4
Walking	1	2	3	4

Katz, Ford, Moskowitz, Jackson, & Jaffe, (1963)

The following set of questions deals with how you feel about well-being in your life. Please remember that there are no right or wrong answers.

Circle the number that best describes your	Strongly	Disagree	Disagree	Agree	Agree	Strongly
present agreement or disagreement with each	Disagree	Somewhat	Slightly	Slightly	Somewhat	Agree
statement						
1. I tend to be influenced by people with strong						
opinions.	1	2	3	4	5	6
2. I have confidence in my opinions, even if						
they are contrary to the general consensus.	1	2	3	4	5	6
3. I judge myself by what I think is important,						
not by the values of what others think is	1	2	3	4	5	6
important.						
4. In general, I feel I am in charge of the						
situation in which I live.	1	2	3	4	5	6
5. The demands of everyday life often get me						
down.	1	2	3	4	5	6
6. I am quite good at managing the many						
responsibilities of my daily life.	1	2	3	4	5	6
7. I think it is important to have new						
experiences that challenge how you think	1	2	3	4	5	6
about yourself and the world.						
8. For me, life has been a continuous process of						
learning, changing, and growth.	1	2	3	4	5	6
9. I gave up trying to make big improvements or						
changes in my life a long time ago.	1	2	3	4	5	6
10. Maintaining close relationships has been						
difficult and frustrating for me.	1	2	3	4	5	6
11. People would describe me as a giving						
person, willing to share my time with others.	1	2	3	4	5	6
12. I have not experienced many warm and						
trusting relationships with others.	1	2	3	4	5	6
13. I live life one day at a time and do not really						
think about the future.	1	2	3	4	5	6
14. Some people wander aimlessly through						
life, but I am not one of them.	1	2	3	4	5	6
15. I sometimes feel as if I have done all there is						
to do in life.	1	2	3	4	5	6
16. When I look at the story of my life, I am						
pleased with how things have turned out.	1	2	3	4	5	6
17. I like most aspects of my personality.						
	1	2	3	4	5	6
18. In many ways, I feel disappointed about my						
achievements in life.	1	2	3	4	5	6

(Ryff, 1989)

Circle the number that best describes your present agreement or disagreement with each statement	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
1. I feel privileged to care for him/her.					
	1	2	3	4	5
2. Others have dumped caring for him/her onto					
me.	1	2	3	4	5
3. My financial resources are adequate to pay					
for things that are required for caregiving.	1	2	3	4	5
4. My activities are centered around care of					
him/her.	1	2	3	4	5
5. Since caring for him/her, it seems like I'm				<u></u>	
tired all of the time.	1	2	3	4	5
6. It is very difficult to get help from my family					
in taking care of him/her.	1	2	3	4	5
7. I resent having to take care of him/her.					
	1	2	3	4	5
8. I have to stop in the middle of work.					
	1	2	3	4	5
9. I really want to care for him/her.					
	1	2	3	4	5
10. My health has gotten worse since I've been					
caring for him/her.	1	2	3	4	5
11. I visit family and friends less since I have					
been caring for him/her.	1	2	3	4	5
<ol> <li>I will never be able to do enough caregiving to repay him/her.</li> </ol>	1	2	3	4	5
13. My family works together at caring for					
him/her.	1	2	3	4	5
(Given et al., 1992)	•	,	I.	•	1

The following set of questions deals with how you feel about caregiving. Please remember that there are no right or wrong answers.

(Given et al., 1992)

statement	Disagree		Agree nor Disagree	Agree	Strongly Agree
14. I have eliminated things from my schedule					
since caring for him/her.	1	2	3	4	5
15. I have enough physical strength to care for					
him/her.	1	2	3	4	5
16. Since caring for him/her, I feel my family					
has abandoned me.	1	2	3	4	5
17. Caring for him/her makes me feel good.					
	1	2	3	4	5
18. The constant interruptions make it difficult					
to find time for relaxation	1	2	3	4	5
19. I am healthy enough to care for him/her.					
	1	2	3	4	5
20. Caring for him/her is important to me.					
	1	2	3	4	5
21. Caring for his/her has put a financial strain					
on the family.	1	2	3	4	5
22. My family (brothers, sisters, children) left					
me alone to care for him/her.	1	2	3	4	5
23. I enjoy caring for him/her.					
	1	2	3	4	5
24. It's difficult to pay for his/her health needs				L	
and services.	1	2	3	4	5

(Given et al., 1992)

25. Do you hire a foreign labor to help you take care of him/her? 1.  $\Box$ No, 2.  $\Box$  Yes

26. If nurses can totally take care of patients, do you think family caregivers need to spend a long time staying in the hospital? 1.  $\Box$ No 2.  $\Box$  Yes, because

These questions were designed to find out the knowledge of family caregivers about caregiving that could be a reference for nurses to provide family caregivers and patients with a good discharge plan. Please remember that there are no right or wrong answers. According to what you know about the condition of the care receiver, please choose one answer that best describes your situation.

How well do you know him/her?	Completely	Not	Partly	Most	Completely
	Not	Understand	Understand	Understand	understand
	Understand				
1. Factors that influence care receiver's	1	2	3	4	5
physical condition (e.g. pressure sore)					
2. Care receiver's safety problems (ex. fall or	1	2	3	4	5
choke)					
3. Factors that influence of care receiver's	1	2	3	4	5
emotional state (ex. happy, sad, angry, or joy)					
4. Care receiver's cognitive ability (ex.	1	2	3	4	5
judgments of time, place, and person)	i .				
5. Care receiver's personality	1	2	3	4	5
6. Care receiver's communication ability	1	2	3	4	5
7. Care receiver's comfort needs.	1	2	3	4	5

(Shyu, 2000)

Thank you very much!

- 1. Please put this completed questionnaire in the original envelope.
- 2. Do Not put your name on the questionnaire and return it to a big box in Nurse Station.
- 3. Please write your name, room number, address, and phone number on the small card and put it in another box in Nurse Station. You will get a thank you gift soon.

# APPENDIX G

## DATA COLLECTION TOOL (CHINESE VISION)

### 填寫這份問卷表示我至少18歲並代表願意參加此次研究的同意書

編號:

### 照顧者基本資料:

請回答下列有關您的問題.(選一個號碼並打勾在方格中)

1. 性別: 1. □男 2. □女

- 2. 您是哪一年出生?
- 3. 您是:1. □單身(還沒有結過婚) 2. □離婚 3. □分居 4. □喪偶 5. □已婚
- 4. 您在學校完成的最高學歷是?
  - 1. □國小和國小以下 2. □中學 2. □高中 3. □專科 4. □大學 5. □研究所
- 5. 您認爲您自己是 1. □無宗教信仰 2. □佛教 3. □猶太教 4. □信奉基督耶穌
- 5.□道教 6.□回教 7.□其他\_
- 6. 您有幾個小孩? 1. □0 2. □1-3 3. □超過 3 個
- 7. 您是被照顧者的 1. □朋友 2. □兒子 3. □女兒 4. □丈夫 5. □妻子
   6. □媳婦 7. □其他關係
- 8. 您和誰住在一起? 1. □獨居 2. □朋友 3. □父母親 4. □孩子 5. □配偶
   6. □配偶和孩子 7. □配偶,孩子和父母親 8. □配偶和父母親
- 9. 您已經做多久的照顧者?\_\_\_\_ 天 \_\_\_\_ 月 \_\_\_\_ 年

10. 您的健康狀況如何?

請選一個號碼來表示您的健康狀況

提供照顧以前

- 1.□非常不好 2.□不好 3.□普通 4.□好 5.□很好 6.□極佳 提供照顧以後
- 1.□非常不好 2.□不好 3.□普通 4.□好 5.□很好 6.□極佳
- 11. 您工作的情形如何?

提供照顧以前

1.□全職工作 2.□部份時間工作 3.□退休 4.□失業 5.□沒有在外面工作 提供照顧以後

1.□全職工作 2.□部份時間工作 3.□退休 4.□失業 5.□沒有在外面工作 您的工作時間量是否被需要擔任照顧者而受影響?

1.□沒有 2.□是

12. 您每個月的收入是多少?

- 1. □ Below N\$ 10,000 2. □ N\$10,000-19,999 3. □ N\$20,000-29,999
- 4. □ N\$ 30,000-39,999 5. □ N\$ 40,000-49,999 6. □ N\$50,000-59,999
- 7. □ N\$ 60,000-69,999 8. □ N\$ Above N\$ 70,000

病人基本資料:

- 1. 被照顧者性別: 1. □男 2. □女
- 2. 被照顧者是哪一年出生?
- 3. 被照顧者的婚姻狀況:
- 1.□單身 (還沒有結過婚) 2.□離婚 3.□分居 4.□喪偶 5.□已婚
- 4. 被照顧者在學校完成的最高學歷是?
- 1.□國小和國小以下 2.□中學 3.□高中 4.□專科 5.□大學 6.□研究所
- 5. 被照顧者的診斷是? 1. □肺癌 2. □肝癌 3. □大腸直腸癌 4. □乳癌
   5. □子宮頸癌 6. □骨癌 7. □胃癌 8. □其他
- 6. 這次病人住院接受什麼治療? (您可以選擇超過一項)
- 1.□手術 2.□放射線治療 3.□化學治療
- 7. 這次病人住院出現什麼症狀和副作用?(您可以選擇超過一項)
  1. □疼痛 2. □疲倦 3. □食慾減退 4. □體重減輕 5. □□惡心嘔吐 6. □味覺改變
  7. □ □臭 8. □ □腔炎 9. □ □乾易渴 10. □掉很多頭髮 11. □血球數下降
  12. □ 皮膚改變(例如:皮膚癢)13. □ 手腳有麻木感或針刺感
  14. □注意力不集中 15. □呼吸問題
- 8. 被照顧者住院其間最佳活動度: 1. □躺在床上 2. □能坐起, 但需要協助 3. □能坐起不需要協助 4. □能行走, 但需要協助 5. □能行走不需要協助

### 被照顧者日常活動的依賴程度

請選擇每一項目中被照顧者日常活動所需要的協助(將號碼圈起來)

	不需要協助	需要一些	需要許多	完全依賴
		協助	協助	
上下床	1	2	3	4
上廁所	1	2	3	4
穿脫衣服	1	2	3	4
進食	1	2	3	4
行走	1	2	3	4

Katz, Ford, Moskowitz, Jackson, & Jaffe, (1963)

下列問題是有關您對您自己生活中的平安舒適感覺如何

請記住沒有對或錯的答案

圈選一個號碼,它最能描述您現在對每一個 問題的同意或不同意	極不同意	有些	一點點	一點點	有些同意	極同意
1.我往往被別人強烈的意見所影響	1	不同意 2	不同意 3	同意 4	5	6
2.我對自己的意見有信心,即使這意見和一般 多數人意見相反	1	2	3	4	5	6
3.我評價我自己是以我認為重要的事, 而不是別人認為重要的事	1	2	3	4	5	6
4.一般而言,我覺得自己可以掌握我生活的 情形	1	2	3	4	5	6
5.每天生活的需求常常使我沮喪	1	2	3	4	5	6
6.我對於我每日生活中的許多責任處理得 相當好	1	2	3	4	5	6
7.認爲有新的經驗來刺激你思考有關你自 已和這個世界是重要的	1	2	3	4	5	6
8.對我而言,生活已經是一個持續學習,改變 和成長的過程	1	2	3	4	5	6
9.我早就放棄嚐試做大的改進或改變	1	2	3	4	5	6
10.對我而言,維持親密關係是有困難和感 到有挫折的	1	2	3	4	5	6
11.人們形容我是樂於施予的人,願意分享 我的時間給別人	1	2	3	4	5	6
12.我和別人還沒有許多溫暖和信賴的關係	1	2	3	4	5	6
13.我生活過一天算一天,並沒有真的想過將 來的事	1	2	3	4	5	6
14.有些人生活迷失方向沒有目標,但是我和他 們不一樣	1	2	3	4	5	6
15.我有時感覺好像我已經做完生命中所有 該做的事	1	2	3	4	5	6
16.當我看自己生命的故事,我很高興事情的 轉變	1	2	3	4	5	6
17.我喜歡我大部份的人格特質	1	2	3	4	5	6
18.在許多方面,我對自己生活的表現感到 失望	1	2	3	4	5	6

圈選一個號碼, 它最能描述您現在 對每一個 問題的同意或不同意	極不同意	有些不同意	有些同意 有些不同意	有些同意	極同意
1.我覺得照顧他是一種榮幸	1	2	3	4	5
2.家人將照顧他(她)的責任丟給我	1	2	3	4	5
3.我的財力資源足夠支付照顧他所需的費用	1	2	3	4	5
4.我的活動都以照顧他爲中心圍繞著	1	2	3	4	5
5.自從照顧他以後,我似乎總覺得疲倦	1	2	3	4	5
6. 我很難從家人得到幫助來照顧他(她)	1	2	3	4	5
7.我怨恨必須去照顧他	1	2	3	4	5
8.我必須中斷手邊正在進行的工作(去照顧他)	1	2	3	4	5
9.我真的想要去照顧他	1	2	3	4	5
10.自從照顧他,我的健康情形越來越差	1	2	3	4	5
11.自從照顧他,我減少拜訪家人和朋友	1	2	3	4	5
12.我無論如何照顧他,都不足以回報他	1	2	3	4	5
13.我和家人同心協力來照顧他(她)	1	2	3	4	5
14.自從照顧他,我已經從我的時間進度 表刪去一些事情	1	2	3	4	5
15.我有足夠的體力來照顧他	1	2	3	4	5
16.自從照顧他(她).我覺得家人疏遠我	1	2	3	4	5
17.照顧他使我感覺愉快	1	2	3	4	5
18.續性的中斷造成很難找到時間休息	1	2	3	4	5
19.我有足夠的健康去照顧他	1	2	3	4	5
20.對我而言,照顧他是重要的事	1	2	3	4	5
21.照顧他使家庭經濟緊縮	1	2	3	4	5
22. 我的兄弟, 姊妹都不管, 只我一個人單獨照顧他	1	2	3	4	5
23.我喜歡去照顧他	1	2	3	4	5
24.支付他的健康需要與服務費用是有困難的	1	2	3	4	5

(Given et al., 1992)

25. 您是否有請外藉勞工來幫您照顧他? 1.□沒有 2.□有

26. 如果護士可以完全地照顧病人,您認為家庭照顧者需要花一段長時間待在醫院嗎?

1.□不需要 2.□需要,因爲

# 請記住沒有對或錯的答案,

依照您對被照顧者了解的情形,請圈選一個答案最接近您的情況

您對他的了解如何	完全不瞭解	不瞭解	普通	瞭解	十分瞭解
影響被照顧者身體狀況的原因 (例如:壓瘡)	1	2	3	4	5
導致被照顧者安全問題的因素 (例如:跌倒或哽住窒息)	1	2	3	4	5
影響被照顧者情緒狀況的的因素	1	2	3	4	5
(例如:高興,難過,生氣,或快樂) 被照顧者的認知功能	1	2	3	4	5
(例如: 判斷時間, 地點, 及人) 被照顧者的個性脾氣	1	2	3	4	5
被照顧者的溝通的能力 被照顧者的舒適需要	1	2	3	44	5 5

(Shyu, 2000)

非常感謝您!

1.請將完成的問卷放回原來的信封袋內

2.不要寫您的名字在問卷上並且將它放入護理站的大盒子內.

3.請寫您的姓名,床號,地址,及電話號碼在小卡片上,並且將它放進護理站另外一個盒子.

您將會很快得到一份感謝禮物!

## APPENDIX H

-

## PERMISSION LETTER TO CONDUCT THE STUDY

#### **AFFILIATION LETTER**

Yeh, Pi-Ming School of Nursing

Milwankee, WI Date of Transmittal 11/15/02

#### Professor Jia-Yuh Chen

Taichung 40203, Taiwan R.O C

#### Dear Professor Chen,

The University of Wisconsin-Milwaukee (UWM) and school of nursing wish to express their appreciation to you and your organization for allowing Pi-Ming Yeh, doctoral student, to perform scholarly research in your organization on your premises.

In accordance with Wis. Stat. § 146.82(2)(a) 6., UWM assures that the information disclosed will be used only for the purpose for which it is provided to the researcher as an unpaid student investigator. The following are the researcher's reason for investigating the primary family caregivers: To explore the factors that influence family caregiver burden. The information will not be released to a person not connected with the study.

- The student will require access to data (and other resources if listed below) necessary to conduct research for a project entitled: Factors influencing family caregiver burden at hospital in Taiwan. (UWM IRB Protocol No. 23-226)
- 2. We understand that the contact person at your organization with whom the student is to communicate with in regard to such access is Yuan, Su-Chuan, Associated Professor, Dean of Nursing Department in Chung-Shan Medical University Hospital, who may be reached at telephone number: \_\_\_\_\_\_\_ ext\_\_\_\_\_ or \_\_\_\_\_\_ ext\_\_\_\_\_ ext\_\_\_\_\_ or \_\_\_\_\_\_ ext\_\_\_\_\_ ext\_\_\_\_\_. office address: \_\_\_\_\_\_\_\_.
- The student has agreed and has been instructed to protect the confidentiality of data collected so that no subject will be individually identifiable.
- 4. The student will share a copy of a final report with your organization upon request.
- If any problems and/or concerns arise regarding this project, please notify the UWM complaint person (Jeanne M. Kreuser, JD. Human Protections Administrator, institutional Review Board, for the Protection of Human Subjects, Graduate School University of Wisconsin-Milwaukee P.O. Box 340, Milwaukee, WI 53201.
   Please sign a copy of this letter to acknowledge receipt and your understanding of the scope of
- Please sign a copy of this letter to acknowledge receipt and your understanding of the scope of the student's proposed activity. Return it to <u>Pi-Ming Yeh</u> at the address listed above. Thank you for your cooperation.

For: Sci	oard of Regents of the University of Wisconsin
By Signature (Title) Associate Dean for Research ()	(Signe
For: (Sig	
By: (rit	) (Dute) 101/14/03
(Date) $\mathcal{N}(\partial Y, \mathcal{A}, \mathcal{A})$	

## APPENDIX I

### INFORMATION SHEET

(English and Chinese Vision)

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

### Factors Influencing Family Caregiver Burden at Hospital in Taiwan

### **Information Sheet**

I am a doctoral student at the University of Wisconsin –Milwaukee in America. My major professor, Dr. Wierenga, and I are conducting a study. This research is concerned with the factors that influence the burden of family caregivers of hospitalized patients diagnosed with Cancer in the hospital in Taiwan. We would appreciate your participation in this study. Results of this study should benefit Cancer patients and their families when nurses use your experiences to help plan and give care to patients and their families in the hospital and preparing for discharge.

Your decision to participate in this study is voluntary and will not affect the care provided your relative. Submission of the completed questionnaires implies consent to participate in the study. Do not put your name on the questionnaires. Completing these questionnaires will not pose a risk for you.

Agreement to participate will involve completion of questionnaires about your perception, knowledge and tasks of caregiving, your health status, and sociodemographic data. There are a total of sixty questions that you will need about thirty minutes to complete. About ninety family caregivers of patients diagnosed with Cancer will participate in this study. All information obtained will be used for the purpose of this study. Aggregate results will be shared in professional journals, the research presentations at professional meetings, and Chung-Shan Medical University Hospital. You will not be identified, because all of the data will be analyzed to become aggregate results not personal data. When you complete this questionnaire, please put in the envelope, and put it in a big box in the nurse station and it will be stored in a locked cabinet. Please write your name, room number, address, and phone number on a small paper card and put it in a small box in the nurse station, so we can give you a thank you gift according to the small paper card.

Although we could study this question by just interviewing your doctor and office staff, we feel that the family caregiver is the best resource to find out the family caregiver burden.

Once the study is completed, we would be glad to give the results to you. In the

meantime, if you have any questions, please as us or contact:

Pi-Ming Yeh School of Nursing University of Wisconsin-Milwaukee TEL: 4

If you have any complaints about your experience as a participant in this study, please call or write:

Jeanne M. Kreuser, JD Human Protections Administrator Institutional Review Board for the Protection of Human Subjects Graduate School, University of Wisconsin-Milwaukee

Although Ms. Kreuser will ask your name, all complaints are kept in confidence.

Filling out this data collection tool indicates that I am at least 18 years old and that I am giving my informed consent to be a subject in this study.

This research project has been approved by the University of Wisconsin-Milwaukee Institutional Review Board for the Protection of Human Subjects for a one year period.

### 影響台灣癌症住院病人家庭照顧者負荷之因素 說明介紹單

我是美國威斯康辛州立大學米爾瓦基分校的博士班學生,我的主要指導教授渥潤根 (Wierenga) 博士和我一起進行這研究.

這研究是有關影響台灣癌症住院病人家庭照顧者負荷之因素.我們非常感謝您參與這研究. 研究的結果將有益於癌症病人及其家屬當護理人員應用您的經驗,將有助於他們計劃提供 住院病患和家屬服務,以及出院的準備.

您決定參與這研究是出於自願的並且不會影響對您親人所提供的照顧. 交回填寫好的問卷表示同意參與這研究.請不要寫您的名字在問卷上. 完成這份問卷不會對您造成任何危險.

同意參與將包括完成以下問卷有關您的感覺,提供照顧的知識與項目,您的健康情形,以及

個人基本資料總共有六十個問題,您大約需要三十分鐘來完成. 大約有九十位癌症病人的家庭照顧者將會參與這研究.所有得到的資料將用於本研究目的. 整體性的結果將分享與專業期刊,專業會議的研究報告,以及中山醫學大學附設醫院.

因為所有 資料將被分析成為整體性的結果而不是個人的資料,所以您將不會被辨識出來. 當您完成這份問卷,請放入信封袋內並 投進護理站大盒子中,然後它會被存放在

上鎖的櫃子中.

另外一張小卡片上請寫上您的姓名,床號,地址,和電話號碼,後放進護理站小盒子中,根據 這張小卡片我們可以送您一份感謝的禮物.

一旦研究完成,我們樂意將結果告訴您.同時,如果您有任何問題請與我們連絡:

**Pi-Ming Yeh** School of Nursing

TEL:

University of Wisconsin-Milwaukee

如果您有任何抱怨有關您參與這次的研究,請打電話或寫信給:

Jeanne M. Kreuser, JD Human Protections Administrator Institutional Review Board for the Protection of Human Subjects Graduate School University of Wisconsin-Milwaukee

雖然, 庫瑟(Kreuser)女士將會問您的姓名,但是,所有的抱怨都會被保密. 這研究已經被美國威斯康辛州立大學米爾瓦基校區人權保護審查委員會審核通過,維持一 年有效期間.

### APPENDIX J

## INSTITUTIONAL REVIEW BOARD (IRB)

# FOR THE PROTECTION OF HUMAN SUBJECTS

University of Wisconsin-Milwaukee

Graduate School, Office of Research Services & Administration Institutional Review Board for the Protection of Human Subjects

Room 140, Mitchell Hall

MEMORANDUM

Date: January 14, 2003

To: Mary Wierenga Professor, Nursing-Health Restoration CUN 695

Pi-Ming Yeh

Milwaukee, WI 53211

From: Jeanne M. Kreuser, Human Protections Administrator Institutional Review Board for the Protection of Human Subjects

#### Re: Protocol #03-026

Title: Factors Influencing Family Caregiver Burden at Hospital in Taiwan

1 would like to acknowledge receipt of the materials requested by the Institutional Review Board (IRB) in granting approval of your protocol. As final materials fulfilling the conditions for exemption were received by the IRB Office on January 14, 2003 your protocol is approved as exempt.

You do not need to have further review of this protocol. However, it is the policy of the University of Wisconsin-Milwaukee that, if necessary to your research protocol, you must have your signed affiliation letters filed with the Institutional Review Board (IRB) Office before you may begin your research. Signed affiliation letters from the agencies with whom you are doing research are only necessary if you are doing your research at an organization other than UWM, where you are not employed and where you do not have a contractual relationship.

If you have questions or if your plans for human subject involvement change substantially from those approved by the IRB, please contact me at the IRB Office for via email at arrange for a review of the new procedures.

Thank you for your cooperation and best wishes for a successful project.

cc: Protocol File

Carol H. Ott - Assistant Professor, Foundations of Nursing

## APPENDIX K

## PERMISSION TO USE MEASUREMENT TOOLS

Reproduced with permission of the copyright owner. Further reproduction prohibited without permission.

INSTITUTE ON AGING University of West chaste Ma	dis a	2245 Medical Science Centra 1300 University Avenue Madicos, Wisconsin 53706-1332 Ph 608-262-1518 Fas: 608-263-6211 Web: www.sec.wisc.redwiging Komail.aging@ssc.wisc.edu	
	January 3, 2003		
Pi-Ming Yeh			
Dear Pi-Ming Yeh			
You have my permission to includissertation. Please send me cop	ide the Ryff Scales of Psysies of any findings you ge	chological Well-Being in your nerate with the measures	
l wish you well in successfully e			
	Sincerely,		******
	Carol D. Ryff, Ph.D. Director, Institute on Professor of Psycholo	Aging	
			*****

 CHANG GUNG UNIVERSITY
Yee Ing Lobis Shya, RN, PhD PROFESSOR & CHAIR CHANG GLING UNIVERSITY SCHOOL OF INJERSING 259 WEN HUA 157 ROAD KWELGHAR TAO-YUAN 333, TAIWAN, ROC 588 3-325-3016 est 5025
FAN 1806 3 328-8200 EMAL: yearsy@mail.cgu.ed:: 14 Junuary 6, 2003
Dear Ms. Yeh:
This letter is in response to your request to use the Femily Caregiving Factors Inventory (FCFI) in your doctoral dissertation. I am pleased with your interest in FCFI.
You may use the FCF1 in your dissertation study. I would like to emphasize that the FCF1 is for your use only and may not be disseminated for general use.
I wish you luck in your studies and will be interested in the results. Please feel free to contact me if I can be of further assistance.
Sipcerrit
Vea-Ing Louis Shyu, RN, PhD Professor and Chair School of Nursing,
Chang Gung University

-

148

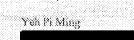
	1	3555	~		
1		****	÷	$\sim$	
/3	Ø.	3886	<u>، ۶</u>	۰.	S.
	22	K.		122ê	÷.
181	₩.	8	Ś.,	8	÷,
	X		iii)	28	ÿ .
	1	17,55	÷	1	

# Family Care Study Michigan State University

College of Nursing + College of Hermon Medicine + Department of Family Practice \$427 W. Fin Hall + East Canong, MI 46873 [\$17] 353-CHE + [\$17] 353-8815 (Sol + (SKI) 353-0306 (fail free)



#### February 4, 2003



#### Dear Yes Pi Ming,

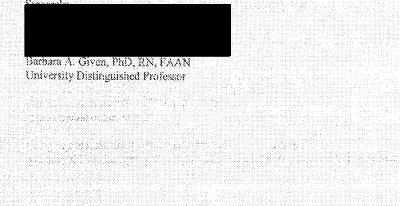
We are happy to provide for you the Caregiver Reaction Assessment (CRA) from the Panily Care Research Program at Michigan State University.

### It is available online at: http://www.healthteam.msu.edu/ferp/tooluse.htm.

From here, you may view it online or print off a hard copy.

Should you have any additional comments and/or questions, please do not hesitate to let us know.

Thank you very much and have a great day.



Learning how families care

ыж) ы ын Афиналык өскка/карын Одронинка інаныкы

## VITA

Name	Pi-Ming Yeh
Home Address	
Telephone/Fax	Home: (
Work Address	School of Nursing University of Chung-Shan Medical University , Taiwan R.O.C. 402

# Formal Education

B. S.	School of Nursing Taipei Medical University, Taiwan	19821986
M.N.	Institute of Medicine in Chung-Shan Medical University, Taiwan	19931996
Ph.D.	College of Nursing University of Wisconsin-Milwaukee, U.S.A.	1999 2003

## **Professional Experience**

Date	Position	Employing Agency & Address	Nature of Experience
1986 1989	Registered Nurse	Taipei Veterans General Hospital, Taipei, Taiwan.	Clinic
1989 1996	Teaching Assistant	Chung-Shan Medical University, Taichung, Taiwan.	Teaching, Research, Clinic
1996-1999	Lecturer	Chung-Shan Medical University, Taichung, Taiwan.	Teaching, Research, Clinic
Feb2000 Aug 2000		Professor Mary Wierenga Nursing Research Center in UWM, U.S.A.	Research
8/31/00 May 16, 2003	Project Assistant	Center for Nursing Research in UWM, U.S.A.	Assisting work with faculty on their research

### **Community Service Experience:**

When I was an undergraduate student (in1984 summer), I participated a government sponsored program that provided basic health care and health preventive screening in the mountainous areas in Taiwan. After half a month's training, we traveled among the aboriginal tribes to serve native people for one month. This experience has taught me to better understand the importance of cooperation, helping, and caring for other people, especially those in need. I also saw very beautiful high-mountain landscape and I will keep the memory forever.

### **Teaching Experience:**

From 1989 to 1999, I was a teaching assistant and then a lecture in Chung-Shan Medical & Dental University, Taichung, Taiwan. My responsibilities included medical and surgical nursing, physical examinations, basic nursing, and clinical advising for the Medical & Surgical Units, Surgical Intensive Care Unit, and the Operation Room. Most patients were older adults and chronically ill patients.

### **Honors and Awards:**

2003	A member of Sigma Theta Tau International Eta Nu Chapter #0406963
2001-2002	Milton and Joan Morris Graduate Scholarship in UWM, U.S.A.
1999-2000	Inez G. Hinsvark Doctoral Fellowship in UWM, U.S.A.
1999	Honors for Serving ten years in Chung-Shan Medical University, School
	of Nursing in Taichung, Taiwan.
1999	Distinguished Teacher in college education, from Government Education
	Department, Taiwan.

### **Major Research Interests:**

- 1. Factors that influence family caregiver burden.
- 2. What kind of health education family caregivers have been taught before discharged?
- 3. How do the family caregivers cope with caregiving tasks?
- 4. What kind of help do the family caregivers need?
- 5. How can the health care system help family caregivers to relieve their burden?

### **Major Interested Courses:**

Medical & Surgical Nursing, Long Term Care, Chronic illness care, Nursing Research,

Nursing Phenomena, Family Development Over Life Span, and Family Theory.

### **Publications:**

- Kuo, B. J., Yeh, P. M., Yuan, S. J., Yeh, S. H., et al. (1998). Nursing Care of Clinical Symptom. Taiwan: Fayfar Publishing Co., Ltd. Taipei, Taiwan.
- Hsu, Y. H., Li, S. Y., Chiou, H. Y., Yeh, P. M., Liou, J. C., Hsueh, Y. M., Chang, S. H., & Chen, C. J. (1997). Spontaneous and induced sister chromatid exchanges and delayed cell proliferation in peripheral lymphocytes of Bowen's disease patients and matched controls of arseniasis-hyperendemic villages in Taiwan. *Mutation Research*, 386: 241-251.
- Yeh, P. M. (1995). Chromosomal Studies of Skin Cancer Patients in Areas Where High-Arsenic Well Water Was Used for Drinking. Taiwan: Master's Thesis.
- Yeh, P. M. (1993). A Study on the Factors Involved in Nurses in a Teaching Hospital to Teach Breast Self-examination. *Chung Shan Medical Journal*, 4(1): 13-21.

### **Presentation:**

- Yeh, P. M., Wierenga, M. E., & Yuan, S. C. (2002). A pilot study of factors that influence family caregiver burden in a Taiwanese hospital. Presented at the UWM Undergraduate Student Research Day, Milwaukee, WI, U.S.A.
- Yeh, P. M. (2001). Issues in health care delivery systems in Taiwan. Center for Nursing Research and Evaluation Brown Bag Presentation and Discussion, in UWM School of Nursing, Milwaukee, WI, U.S.A.
- Wierenga, M. E., Yeh, P. M., & Kelber, S. T. (2001). *The factors that affect health status in type II Diabetes Mellitus*. Presented at Building bridges to research based practice and enhancing care outcomes, Milwaukee, Wisconsin, U.S.A.
- Wierenga, M. E., Yeh, P. M., & Kelber, S. T. (2001). *The factors that affect health status in type II Diabetes Mellitus*. Presented at the UWM Undergraduate Student Research Day, Milwaukee, WI, U.S.A.

#### **Major Department: Nursing**

Signed

6/20/03 Major Professor