



**EFFECTIVENESS OF
THE SYMPTOM MANAGEMENT PROGRAM
ON SYMPTOM STATUS AND QUALITY OF LIFE
AMONG PERSONS WITH PNEUMOCYSTIS CARINII PNEUMONIA**

SUREEPORN THANASILP

อธิปัทนการ

จาก

บัณฑิตวิทยาลัย มหาวิทยาลัยมหิดล

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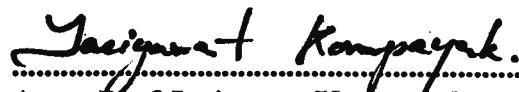
Mrs. Sureeporn Thanasilp
Candidate



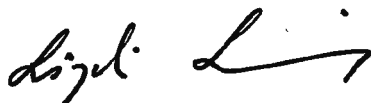
Assoc. Prof. Darunee Rujkorakarn, Ed.D.
Major-Advisor



Prof. Somchit Hanucharurnkul, Ph.D.
Co-advisor



Assoc. Prof. Jariyawat Kompayak, Dr.P.H.
Co-advisor



Prof. Liangchai Limlomwongse
Ph.D.
Dean
Faculty of Graduate Studies



Assoc. Prof. Kobkul Phanchaoenworakul,
Ph.D.
Chairman
Doctor of Nursing Science
Faculty of Nursing

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on

April 5, 2001



**Mrs. Sureeporn Thanasilp
Candidate**



**Assoc. Prof. Darunee Rujkorakarn, Ed.D.
Chairman**



**Prof. Somchit Hanucharurnkul, Ph.D.
Member**



**Mr. Chaiyos Kunanusont, MD, Ph.D.
Member**



**Prof. Liangchai Limlomwongse,
Ph.D.
Dean
Faculty of Graduate Studies
Mahidol University**



**Assoc. Prof. Jariyawat Kompayak, Dr.P.H.
Member**



**Assoc. Prof. Kobkul Phanchaoenworakul,
Ph.D.
Dean
Faculty of Nursing
Mahidol University**

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SELF-SYMPTOM MANAGEMENT ABILITY/
SYMPTOM STATUS/ QUALITY OF LIFE****SUREEPORN THANASILP: EFFECTIVENESS OF THE SYMPTOM
MANAGEMENT PROGRAM ON SYMPTOM STATUS AND QUALITY OF LIFE
AMONG PERSONS WITH PNEUMOCYSTIS CARINII PNEUMONIA.
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This experimental research aimed to test the effectiveness of a Symptom Management Program for persons with Pneumocystis Carinii Pneumonia (PCP). The program was a patient-centered continuing program based on the symptom management model and the self-management concept. The sample included 40 men and women at Nakhon Pathom Hospital who were afflicted with PCP and were randomly assigned to an experimental group and a control group. The experimental group received the four-phase symptom management program together with routine care while the control group received only routine care. The subjects' symptom status and quality of life were measured by the symptom status questionnaire and quality of life questionnaire before and one-month after the intervention. The SPSS/PC for window program was used to analyze the data.

The findings revealed that the mean score on symptom status of the experimental group at the posttest phase was significantly lower than at the pretest phase (p -value <0.01) and the mean score on quality of life at the posttest phase was significantly higher than at the pretest phase (p -value <0.01). While the mean score on symptom status of the control group at the posttest phase was not significantly different from the pretest phase (p -value >0.05), the mean score on quality of life at the posttest phase was significantly lower than at the pretest phase (p -value <0.01). The posttest mean score on symptom status of the experimental group was significantly lower than that of the control group (p <0.01) while the posttest mean score on quality of life of the experimental group was significantly higher than that of the control group (p <0.01).

This study suggests that a Symptom Management Program could decrease the symptom status and improve the quality of life among persons with PCP. This program can be implemented within the nursing practice specifically at self-care management centers and by nurse specialists in chronic illness and HIV/AIDS.

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สุรีพร ธนศิลป์: ประสิทธิผลของโปรแกรมการจัดการกับอาการ ต่ออาการและคุณภาพชีวิตของผู้ป่วยปอดอักเสบจากเชื้อนิวโมซิสติส คารินิไอ (EFFECTIVENESS OF THE SYMPTOM MANAGEMENT PROGRAM ON SYMPTOM STATUS AND QUALITY OF LIFE AMONG PERSONS WITH PNEUMOCYSTIS CARINII PNEUMONIA) คณะกรรมการควบคุมวิทยานิพนธ์: ดร.ณิ รุจกรกานต์, Ed.D. สมจิต หนูเจริญกุล, Ph.D. จริยาวัตร คมพักษณ์, Dr.P.H. 128 หน้า ISBN 974-665-623-6

การวิจัยเชิงทดลองครั้งนี้มีวัตถุประสงค์ เพื่อประเมินผลของโปรแกรมการจัดการกับอาการต่ออาการและคุณภาพชีวิตของผู้ป่วยปอดอักเสบจากเชื้อนิวโมซิสติส คารินิไอ โดยโปรแกรมได้พัฒนาขึ้นภายใต้โมเดลการจัดการกับอาการและแนวทางการจัดการด้วยตนเอง เป็นโปรแกรมที่เน้นผู้ป่วยเป็นศูนย์กลาง และให้การพยาบาลอย่างต่อเนื่องจากโรงพยาบาลสู่บ้าน กลุ่มตัวอย่างเป็นผู้ป่วยปอดอักเสบจากเชื้อนิวโมซิสติส คารินิไอ ทั้งชายและหญิง จากโรงพยาบาลนครปฐม จำนวน 40 ราย ซึ่งได้รับการสุ่มแบบง่ายเพื่อเข้ากลุ่มทดลองและกลุ่มควบคุม กลุ่มละ 20 ราย กลุ่มทดลองได้รับการพยาบาลตามปกติ ร่วมกับโปรแกรมการจัดการกับอาการที่ประกอบด้วย 4 ระยะ ส่วนกลุ่มควบคุมได้รับการพยาบาลตามปกติ ทำการวัดประสิทธิผลของโปรแกรมด้วยแบบวัดอาการและแบบวัดคุณภาพชีวิตก่อนเข้าร่วมโครงการ และภายหลังเข้าร่วมโครงการ เป็นเวลาหนึ่งเดือน ทำการวิเคราะห์ข้อมูลด้วยโปรแกรม SPSS/PC

ผลการศึกษาพบว่า กลุ่มทดลองมีคะแนนของอาการภายหลังเข้าโครงการต่ำกว่าก่อนเข้าโครงการ และมีคะแนนของคุณภาพชีวิตภายหลังเข้าโครงการสูงกว่าก่อนเข้าโครงการอย่างมีนัยสำคัญทางสถิติที่ระดับ 0.01 ส่วนกลุ่มควบคุมมีคะแนนของอาการภายหลังเข้าโครงการสูงกว่าก่อนเข้าโครงการอย่างไม่มีนัยสำคัญทางสถิติ และมีคะแนนของคุณภาพชีวิตภายหลังเข้าร่วมโครงการสูงกว่าก่อนเข้าโครงการอย่างมีนัยสำคัญทางสถิติที่ระดับ 0.01 กลุ่มทดลองมีคะแนนของอาการภายหลังเข้าโครงการต่ำกว่ากลุ่มควบคุม และมีคะแนนของคุณภาพชีวิตภายหลังเข้าโครงการสูงกว่ากลุ่มควบคุมอย่างมีนัยสำคัญทางสถิติที่ระดับ 0.01 นั่นคือ โปรแกรมการจัดการกับอาการสามารถลดความรุนแรงของอาการปอดอักเสบ และเพิ่มคุณภาพชีวิตของผู้ป่วยปอดอักเสบจากเชื้อนิวโมซิสติส คารินิไอ การนำโปรแกรมนี้นี้ไปใช้ในการปฏิบัติการพยาบาลนั้นควรคำนึงถึงการจัดตั้งศูนย์การดูแลตนเอง และการพัฒนาศักยภาพของพยาบาลให้มีความชำนาญในการดูแลผู้ป่วยเรื้อรังและผู้ติดเชื้อเอชไอวี/เอดส์

CONTENTS

	Page
ACKNOWLEDGEMENT	iii
ABSTRACT	iv
LIST OF TABLES	
LIST OF FIGURES	
 CHAPTER I INTRODUCTION	 1
-Background and Significance of the Study	1
-Research Questions	6
-Purpose of the Study	6
-Theoretical Framework	7
-Hypotheses	17
-Scope of the Study	17
-Definition of Terms	17
 CHAPTER II LITERATURE REVIEW	 20
-AIDS and PCP Knowledge	20
-The symptom experiences of person with PCP during hospitalization	25
-Quality of Life of persons with PCP	30
-The strategies to develop symptom status and quality of life among persons with PCP	36
-The exiting strategies	36
-The Symptom Management Program	37
-Summary	44
 CHAPTER III METHODOLOGY	 45
-Research Design	45
-Population and Sample	45
-Setting	48
-Instrumentation	48
-Interventions	48
-Instruments	53
-Preparation of the research assistant	56
-Data Collection	56
-Protection of the Rights of Human Subjects	60
-Data Analysis	61

CONTENTS (CONTS.)

CHAPTER IV RESEARCH RESULTS	63
-Characteristics of the samples	63
-Demographic characteristics of the samples	63
-Characteristics related to HIV infection of the samples	66
-Characteristics related to hospitalization	67
-Hypotheses testing and description of the dependent variables	68
-Comparison of the symptom status and the quality of life in the control group	68
-Comparison of the symptom status and the quality of life in the experimental group	72
-Comparison of the symptom status and the quality of life at the pretest phase	76
-Comparison of the symptom status and the quality of life at the posttest phase	78
CHAPTER V DISCUSSION	82
-Effectiveness of a Symptom Management Program	82
-Contribution to Nursing Science	88
CHAPTER VI CONCLUSION	90
-Summary of the Study	90
-Implications and Recommendation	93
-Limitation of the Study	97
BIBLIOGRAPHY	98
APPENDIX	108
Appendix A List of Experts of the questionnaire and program	108
Appendix B List of Experts of the videotape	109
Appendix C Manual of PCP Symptom Management Program	110
Appendix D Self-Symptom Management Manual Booklet for PCP	112
Appendix E Script of videotape on PCP Symptom Management	113
Appendix F Health Profile Questionnaire	114
Appendix G PCP- Symptom Status Questionnaire	115
Appendix H PCP- quality of life Questionnaire	116
Appendix I Self-assessment of symptom management form	117
Appendix J The Kolmogorov-Smirnov Z test	119
Appendix K Analysis by ANCOVA f-test	120
Appendix L Researcher information sheet for the control group	125
Appendix M Researcher information sheet for the experimental group	126
Appendix N Informed consent form	127
BIOLOGY	128

LIST OF TABLES

		Page
Table 1	Summaries of data collection for samples in the study	48
Table 2	The summarization of the intervention process	52
Table 3	Demographic characteristics of the samples	65
Table 4	Characteristics related to HIV infection of the samples	67
Table 5	Characteristics related to hospitalization of the samples	68
Table 6	Comparison of the pretest and the posttest mean scores on the symptom status of the control group	69
Table 7	Comparison of the pretest and the posttest mean scores on the quality of life of the control group	71
Table 8	Comparison of the pretest and the posttest mean scores on the symptom status of the experimental group	73
Table 9	Comparison of the pretest and the posttest mean scores on the quality of life of the experimental group	75
Table 10	Comparison of the pretest mean scores on the symptom status of the control group and the experimental group	76
Table 11	Comparison of the pretest mean scores on the quality of life of the control group and the experimental group	77
Table 12	Comparison of the posttest mean scores on the symptom status of the control group and the experimental group	78
Table 13	Comparison of the posttest mean scores on the quality of life of the control group and the experimental group	81
Table 14	A comparison of the posttest dimension mean scores on the physical/general well-being dimension (d1) of quality of life of the control group and the experimental group by ANCOVA F-test	120
Table 15	A comparison of the posttest dimension mean scores on the Life-satisfaction dimension (d2) of quality of life of the control group and the experimental group by ANCOVA F-test	121
Table 16	A comparison of the posttest item mean scores on unfeeling of loneliness (i1) of quality of life of the control group and the experimental group by ANCOVA F-test	121
Table 17	A comparison of the posttest item mean scores on getting enough rest (i2) of quality of life of the control group and the experimental group by ANCOVA F-test	122
Table 18	A comparison of the posttest item mean scores on functional ability in daily living (i3) of quality of life of the control group and the experimental group by ANCOVA F-test	122
Table 19	A comparison of the posttest item mean scores on life satisfaction (i4) of quality of life of the control group and the experimental group by ANCOVA F-test	123
Table 20	A comparison of the posttest item mean scores on strong will (i5) of quality of life of the control group and the experimental group by ANCOVA F-test	123
Table 21	A comparison of the posttest item mean scores on health satisfaction (i6) of quality of life of the control group and the experimental group by ANCOVA F-test	124

LIST OF FIGURES

	Page
Figure 1 -Conceptual Model of Symptom Management	7
Figure 2 -The process of a Symptom Management Program	13
Figure 3 -Hierarchy of Middle-range Theoretical Deduction	16



CHAPTER I

INTRODUCTION

Background and Significance of the Study

All persons with HIV infection will affect with the opportunistic infections because AIDS is a chronic disease, which the symptoms from its' opportunistic infection mostly has detrimental affect to the quality of life of AIDS patients (Ganz, et al., 1993; Holzemer, 1998; Watchel, et al., 1992). The statistics from Department of Communicable Disease Control, Thailand (2000) indicated that the respiratory problem was the major problem in AIDS patients, which infected from the opportunistic organism and PCP was the second opportunistic infection that found in those patients. PCP symptoms are mostly interrupted the quality of life because of its symptoms of dyspnea or coughing. In order to promote the quality of life of PCP patients, the improvement of the patients' self-management ability to control those symptoms will be considered. Promoting the quality of life of PCP patient is an important and compulsory issue that nursing staff must seriously take into consideration since it is the ultimate outcome in maintaining health status (Anderson & Burckhardt, 1999: 298). Developing the nursing intervention program that could effectively control symptom status and improve the quality of live among persons with PCP would be utmost benefit to uplift the quality of care.

Recording from WHO found that at the end of 1998, a cumulative total of 33.4 million people worldwide were estimated to live with HIV/AIDS, which around 13.9-

17.1 of them died and in 1998 only, approximately 2.5 million people died of HIV/AIDS worldwide (UNAIDS, 1998). In Thailand, since the first AIDS patient was diagnosed in 1984 until November 30th 1999, a cumulative 131,396 AIDS patients. The average age of these patients is between 25 – 29 years old and there are more male than female. Number of children infected with HIV is also escalating (Department of Communicable Disease Control, 2000). This evidence strongly indicates that the spreading of HIV/AIDS is universal no matter what gender, religion, age, race or economic status of the patient is. As AIDS is a critical problem, which all countries should seriously work together to control, educate and prevent the spreading of it to improve the quality of life for all people and the patients with HIV/AIDS and their families in particular.

AIDS is a chronic and ultimately fatal disease, that threatens every infected individual, their families, and society. It starts affecting them in an anxious way from the first moment, when they discovered the results of the HIV infected blood test result, as well as, throughout their illness until the last stage of AIDS disease. They immediately start feeling anxiety and fear of death and discriminate from the society. When the opportunistic infection such as *Pneumocystis Carinii* Pneumonia (PCP), Tuberculosis, Cryptococcal Meningitis occurred, their perception of quality of life getting worse. The five opportunistic infections that mostly found among the Thai AIDS patients were 27.1% of Tuberculosis inside and outside the lungs, 19.1% of PCP, 16.9% of Cryptococcal Meningitis, 5.4% of esophageal Candidiasis and trachea or lung Candidiasis and 3.7 % of Pneumonia from Bacteria infection more than once in a year (Department of Communicable Disease Control, 2000).

Therefore, studying the persons with PCP is very important and significant even though this disease was the second opportunistic infection that found in AIDS. Because its symptom of dyspnea or coughing will affect the quality of life as well as PCP disease can be treated and prevented with antibiotic drugs (Carmichael, 1997: 563; Moe & Hardy, 1994: 333). If these symptoms can not be treated the ventilation support will be required, then the quality of life will decrease. The extra treatments will cause higher cost and more health personnel needs as well as the number of the sudden death will be increased.

Thanasilp, S (1999) conducted a study to identify the problems and needs of hospitalized adult AIDS patients with PCP. The findings revealed that at the acute phase, distress from dyspnea was the critical problem that needed intensive care. Once this respiratory symptom has been controlled, other symptoms such as fatigue, weakness as well as loss of appetite also needed further care. Although, these symptoms were the symptoms of PCP but most of the patients perceived them as an advancing AIDS disease and believed that they were at the dying phase. Therefore, these patients had low self-efficacy, no self-management skills, and needed correct information and guideline to improve their self-efficacy and change their misperception about the symptom. They did not disclose of HIV blood test result to others. At the recovery phase when the patients were in the discharge plan from hospital they were worried about their illnesses, had less confidence to manage symptoms that might be reoccurred at home because lacking of knowledge. The study suggested the need of effective nursing care to improve their abilities for self-managing symptoms either in the hospital or at home.

Symptom management is a way to control symptom and its experience (Larson, et al., 1994: 274). One of the major responsibilities of Thai nurse is to help and care for patients in order to relieve their symptoms and prevent the progression of the disease (Thai Nursing Council, 1985: 11). Therefore, symptom management is one of the many roles of the Thai nurse's responsibilities. The success symptom management strategies depend on the collaboration among the health personnel and the patients or their families (Larson, et al., 1994: 273).

Conventionally, the hospital system did not mention for improving the strategies on helping the patients to care for themselves (Nantachaipan, P. 1996; Thanasilp, S. 1999). Likewise, data gleaned from various studies revealed that 66 % of hypertensive patients (Chukumnerd, 1999) and 74 % of ulcer patients (Inthisang, 1999) perceived themselves as a passive actor and reported that they were treated as subordinate in the health care service. These studies reflected that there were insufficient care to promote the patient's self- efficacy, sense of control, and sense of mastery, which were the antecedent of the effective self-management process. The patients did not have adequate knowledge or skill to manage symptoms by themselves during hospitalization or at home. So, low self-efficacy, invaluable of self, passiveness, and lacks of ability to control the change in their lives were likely to be perceived. These factors accelerated the severity of the symptoms, which in turn affected the quality of life (Miller, 1992: 4, 54, 399).

Nantachaipan, P (1996) indicated that the community-based nursing with case management strategy could lower symptom severity and improve self-care ability and quality of life of HIV/AIDS patients. Likewise, Rujkorakarn, D, et al (1998) found that

the empowerment-based nursing encouraged the AIDS patients to manage their illness at home and increased the quality of life of the patient and their families. Apart from that, it was also found that the educative and supportive nursing strategy in self-care could decrease the self-care deficit and increase the quality of life among HIV/AIDS patients at the out patient department (Wattradul, D. 1994). This strategy could also influence the self-care behavior and life satisfaction in HIV/AIDS patients before discharged from the hospital (Ratanasombat, S. 1997). These studies suggested that the community-based case management, empowerment process, and educative-supportive nursing care could improve the self-care ability and the quality of life of the patients. Therefore, the holistic and continuing care, social support, and patient-centered perspectives are essential factors in providing effective nursing intervention to improve the patient's self-management ability and quality of life. In response to that requisite, the nursing intervention program to improve the quality of life by enhancing the patient's self-symptom management abilities to control or reduce the symptom status should be constructed.

A Symptom Management Program (SMP), based on the Symptom Management Model and self-management concepts, is designed to improve self-symptom management ability of persons with PCP. It is expected that persons with PCP who receive this program with routine care can decrease the symptom status and increase the quality of life more than those who receive only routine care. Therefore, the effectiveness of the program will be tested before its actual application on the PCP patients in the nursing practice. The effectiveness of the program will improve the quality of nursing care.

Research Questions

This study attempts to answer the following questions:

1. What are the differences in the symptom status and the quality of life of persons with PCP between before and after receiving a Symptom Management Program ?
2. What are the differences in the symptom status and the quality of life between persons with PCP who receive routine care with a Symptom Management Program and those who receive only routine care ?

Purposes of the Study

This study aims to evaluate the intervention effectiveness of the Symptom Management Program on the symptom status and quality of life in persons with PCP. In particular, the study is undertaken:

1. To study the effectiveness of a Symptom Management Program on the symptom status and the quality of life in persons with PCP before and after receiving the program.
2. To study the effectiveness of the Symptom Management Program on the symptom status and the quality of life among persons with PCP who receive (the experimental group) and not receive (the control group) the program.

Theoretical Framework

The Symptom Management Model and the self-management concept were used as a conceptual framework in this study. The Symptom Management Model was developed by The University of California, San Francisco School of Nursing Symptom Management Faculty Group (Larson, et al., 1994: 273-275). A primary concern of this model is how to manage symptoms, which cause the most distress. It focuses on effective symptom management by encompassing the symptom experience, symptom management strategies, and symptom outcomes. These three dimensions are interrelated and each dimension has reciprocal correlation (Figure 1).

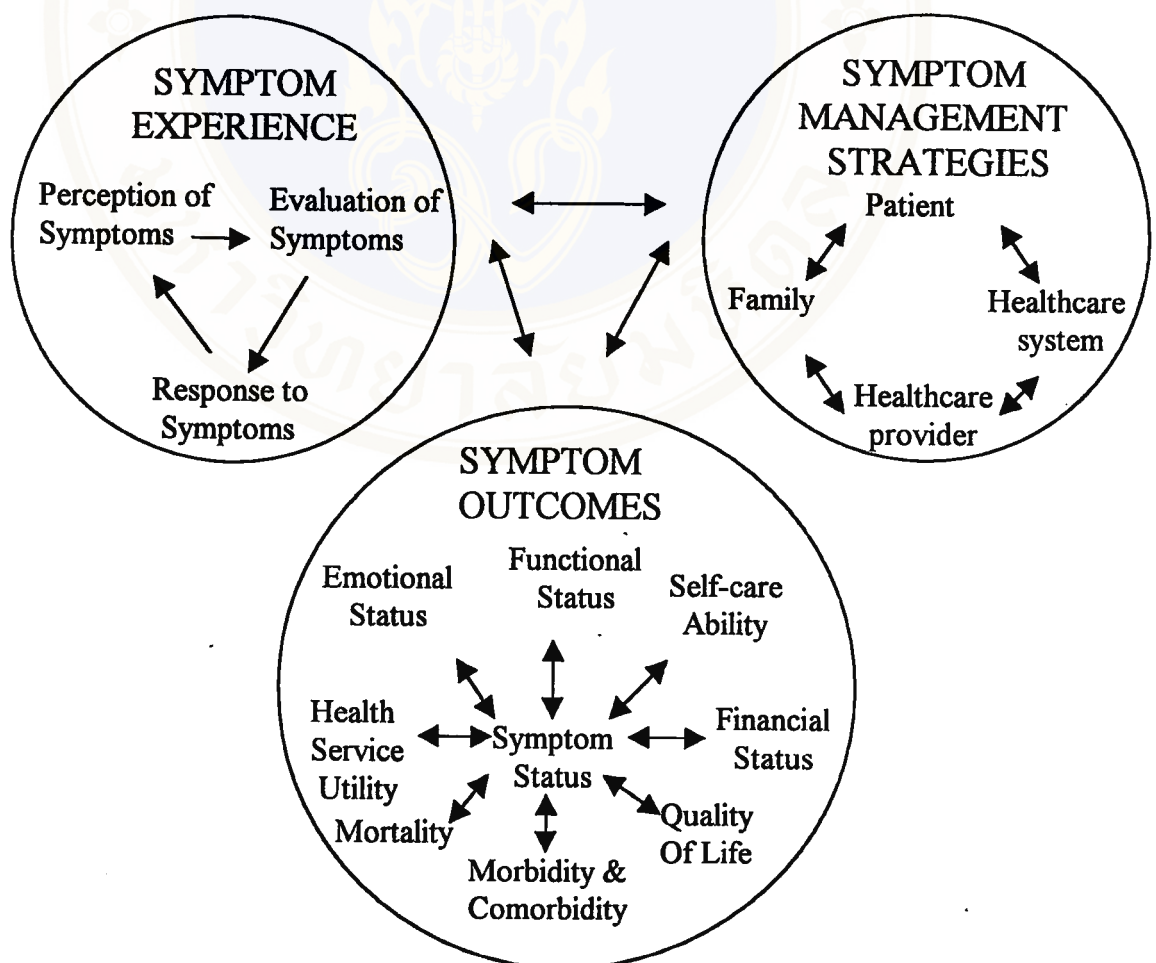


Figure 1: Conceptual Model of Symptom Management (Larson, et al., 1994: 274)

The symptom experience is dynamic, involving the interaction of the patient's perception, evaluation, and response to a symptom. Due to its multidimensional and personal manifestation of illness, injury, treatment, and experiences, understanding the interaction of the components of the symptom experience is essential for effective symptom management. Even when a disease is effectively treated, symptoms may often remain a continuing concern. If the patients have the opportunity to explore these symptom experiences, learn about their disease, and participate in symptom management, they often develop their own symptom management strategies such as increasing or decreasing their medication; which then may cause other symptom experiences.

The goal of symptom management strategies is to avert or delay a negative outcome and control the symptom experience through biomedical, professional, and self-care strategies. The process is comprised of four dynamic activities that begin with an assessment of the patient's perspective of symptom experience and is followed by identification of the focus for intervention. Once the symptoms have been determined, the implementation of intervention, and evaluation of the management process and outcomes will be applied. These activities require changes in strategies over time or in response to a patient's acceptance of the strategies, as well as a cooperative interaction among patients, their family, and health personnel. Such a relationship is one in which the work of the provider complements that of the patient, or the patient and family, encouraging and assisting efforts to prevent or manage the symptoms.

This last element is the effects or outcomes derived from the symptom experience, which are comprised of ten multidimensional indicators. These include:

symptom status, self-care ability, financial status, morbidity and comorbidity, mortality, quality of life, health service utilization, emotional status, and functional status. Figure 1 shows that symptom status is central, and the other indicators are related. Quality of life for people experiencing symptoms is often variable. If a symptom is a minor problem for a patient, or the symptom is of short duration, the quality of life might be unaffected. However, when a symptom is extremely problematic or prolonged, quality of life becomes a major concern. Lough, et al (1987 cited in Larson, et al., 1994: 275) found that for patients who had undergone a heart transplant, the quality of life was inversely related to the number of symptoms experienced and the perceived distress from those symptoms.

In conclusion, the Symptom Management Model is centered on patients and holistic nursing, so patients must be responsible for themselves or self-caring. Patients' symptom management abilities are thus very important but this model did not show the details. The researcher would like to develop and test the prescriptive theory of the promotion of patient's self-symptom management on symptom status and quality of life. This theory requires a self-management concept as a guide to strategy for patients to perform symptom management behaviors.

Based on Bandura's (1986) social learning theory, the self-management concept is defined as a total process that facilitates the persons to control themselves. It refers to the performance of preventive or therapeutic health care activities, often in collaboration with health care professionals. New behaviors would be performed not only because by a new information but also because of patient's encouragement to engage voluntarily in self-care activities (Tobin, et al., 1986: 29).

Given the relevant theoretical perspective derived from the social learning theory, four principle goals were incorporated in the development of a self-management strategy (Tobin, et al., 1986: 36). These were 1) coping-skills are taught, 2) self-efficacy is enhanced, 3) social supports are promoted, and 4) relevant physiological variables are monitored. In self-management education, five basic coping-skills should be taught in order to prepare patients. These are self-monitoring, self-instruction, self-induced stimulation change, self- induce response change, and decision-making (Tobin, et al., 1986: 36-38).

Tobin, et al (1986: 39-45) suggested the clinical applications of self-management might involve the client selection; selection of goals; and facilitating compliance. The process of promoting patients' self- management behavior required knowledge, and motivation (Gemain, 1988:74) and also self-efficacy (Bartolomew, et al., 1993: 1524). Effective self-management process also needed patients to have a sense of power and control (Coates & Boore, 1995:630) and awareness of mutual goal setting between the patient and the nurse (Tobin, et al., 1986).

The concept of self-management is most applicable and is considered most useful in improving self-symptom management behaviors in patients because of the following reasons:

1. It reflected the belief in human responsibility.
2. It reflected the aim of holistic care for patients.
3. It reflected the aim to ultimately change the client's quality of life.
4. It reflected the collaboration between the patient and the nurse.

The researcher developed the Symptom Management Program (SMP) that was derived from the Symptom Management Model. The major concepts of this program were symptom experience, symptom management strategies, and symptom outcomes that were specifically used in persons with PCP. The symptom management strategies incorporated the interaction of nurses and persons with PCP. The nurse should improve the patient's abilities to manage his/her symptoms. In order to develop self-care strategies in the symptom management dimension, the self-management concept was used to extend the strategies.

PCP is an opportunistic disease from the *Pneumocystis Carinii* organism, which is mostly found in AIDS patient. Additionally, AIDS is a chronic and ultimately fatal disease that threatens every infected individual who start to feel anxiety and fear of death as well as rejection by society at the beginning of the disease. When the symptoms of PCP occur, the quality of life is worsened. Some patients think that those symptoms are symptoms of AIDS, which has no effective cure. In fact, they had an opportunistic illness, which occurred when their immunities are decreased. Those symptoms could be treated with higher doses of antibiotics but required a longer recovery time than usual (Hirunrat, W. & Hachvanit, M. 1996: 257). This misperception and the perceived incurable of PCP lead to decreased self-awareness and misunderstanding of therapeutic management. Thus, feeling of hopelessness and depression will be occurred (Miller, 1992: 57-61).

Physical responses found in PCP patients are shortness of breath, dyspnea or respiratory distress, nonproductive cough, fever, and loss of appetite (Masur, 1984: 54; Ministry of Public Health Thailand, 1997: 68; Thanasilp, S. 1999). Among the above-

mentioned symptoms, the most disturbing to the patients' health is dyspnea (Holzemer, et al., 1995: 28; Thanasilp, S. 1999). Loss of appetite is encountered while undergoing this traumatic symptom together with the misconception that PCP is an untreatable disease deepen patients' worry (Holzemer, et al., 1995: 29). These aggravate the situation so that not only their physical welfare but also their mental well being is deteriorated (Greenberg, 1996: 250).

In order to increase the patient's symptom-management behaviors, the design of a Symptom Management Program was personalized to persons with PCP. This program was based on the particular circumstances of each individual who had different problems and limitations in self-management by interaction among the patient and the nurse. In this program, the family was not permitted to have direct interaction and only participated as a supporter because some patients had not disclosed HIV blood test result with their families. So only the family member who was permitted by the patient could interact in the program. Through cooperation, sharing information, and working together, the patient and the nurse would analyze the situation, set mutual goals, and attempt to find appropriate solutions to solve the problems. The nurse might respect the patients' perspective of the illness and accordingly follow their decision-making. In this sense, the nurse played the role of encouragement and assistance to the patient's efforts. To maximize the effective outcomes, the patient would still receive continuous nursing intervention after discharge.

This program is composed of four phases to manage PCP symptom. These are 1) The Problem Assessment and Needs Identification Phase 2) The Preparation for Symptom Management Phase, 3) The Practice for Symptom Management Phase, and

4) The Evaluation for Symptom Management Phase. These are dynamic processes and details of these processes are shown in Figure 2.

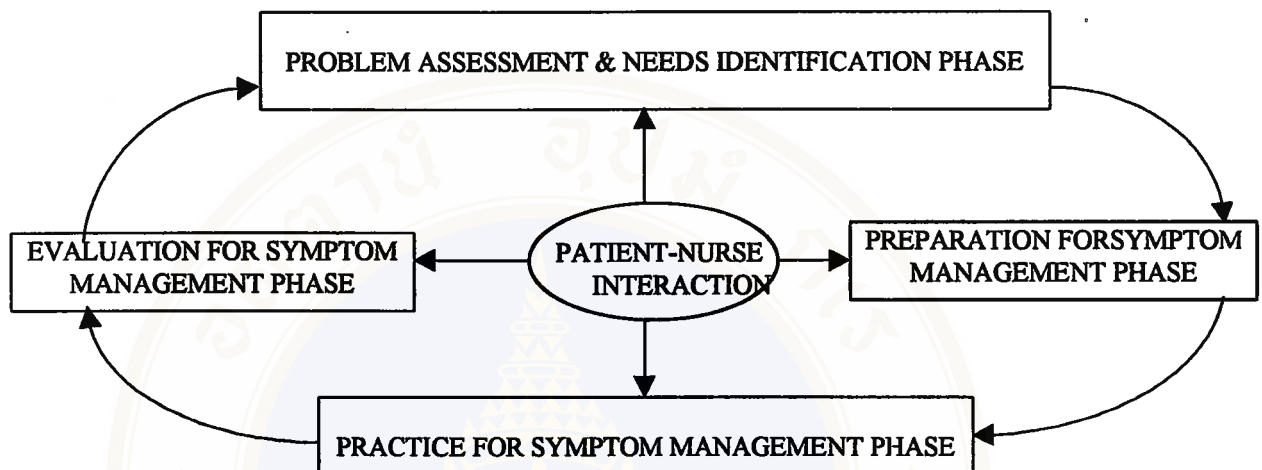


Figure 2 The Processes of a Symptom Management Program

The first phase of the program began with assessing and identifying the symptoms. This phase was an important step for the nurse to understand the patients' condition. The nurse assessed the patients' symptom experience, symptom perception, evaluation, and response, symptom knowledge, symptom management skill, symptom status and quality of life. Observation and interactive interviews were used to extract comprehensive information from the samples. During the interview, the samples were encouraged to take the leading role, as this would facilitate the free flow of the needed information. At this point, participation in the nursing care would lead to an increase in the samples' perceived self-control. This indicated that the concept of self-efficacy in Tolbin, et al (1986) was enhanced.

After the patient could clearly identify the problem, and establish the goal to solve the problem, the nurse would proceed to the preparation phase. This second step involved enhancing the patient's knowledge and skill through the disease and symptom management education. Education would be immediately intervened to correct the patient's perception. Then the training program was designed to develop patients' ability to observe and analyze any abnormal symptom by themselves and to enable them to make a decision. As a learning process, the skill development-training program involved demonstration, action and reaction that should increase the patient's abilities to effectively relieve their symptoms as well as to control the symptoms. Symptom relief and control skills for the PCP patients that need to be learned were those of deep breathing exercise, diaphragmatic breathing, pursed-lips breathing, effective coughing, taking a tepid sponge, stress management, and drug allergy observation. Learning these practices was essential in building up self-symptom management abilities in PCP patient. This step indicated that the concept of coping-skill in Tolbin, et al (1986) had been taught. The patients needed environmental supports in order to facilitate the symptom management practice. These supports included family support, appropriate environmental support or system resource support. The researcher would tell the patient and the family about the importance of family support and try to facilitate them to work together in caring activities that helped patients to cope with the illness. The researcher did not disclose the patient's blood test results. This reflected the concept of social support as described by Tolbin, et al (1986).

The practice for symptom management phase, the third step, meant the self-symptom management process had begun. The patients should set goals to achieve

desirable outcomes before they were required to continuously performing the monitoring of PCP symptom relief and control. Self-monitoring activities included the daily observation and recording of the pulse rate, the respiratory rate, symptom status, and self-symptom management abilities. Effective self-monitoring would be manifested if the patients were able to continuously perform those activities that had been taught in the second phase. This reflected that the concept of the relevant physiological variables formulated by Tolbin, et al (1986) was monitored. In this phase the researcher should continue the nursing care by using the distance care while the patients lived at home.

The final step was the evaluation for symptom management phase that comprised of a process evaluation and an outcome evaluation. Thus patients could evaluate daily their symptom status and the self-symptom management behaviors at home by using the assessment form for self-monitoring. Then they would discuss the situation with the researcher by telephone and also face-to-face meeting. If the desirable outcome could not be achieved, then the whole process would be analyzed. The problematic process that was an obstacle for each patient would be identified and corrected. If the evaluation were positive, the patient would be reinforced to continue the self-symptom management behaviors.

After the patients participated in this program, they should be able to perform new symptom management abilities. The expected abilities included PCP symptom relief and symptom control. Then, they would perceive their positive self-efficacy and they would be able to select appropriate skills to be used in a particular situation. The expected outcomes in this program were the manifestation by patient of better

symptom status and a better quality of life. The method to deduce the empirical data from the theoretical concept in this study is summarized in Figure 3.

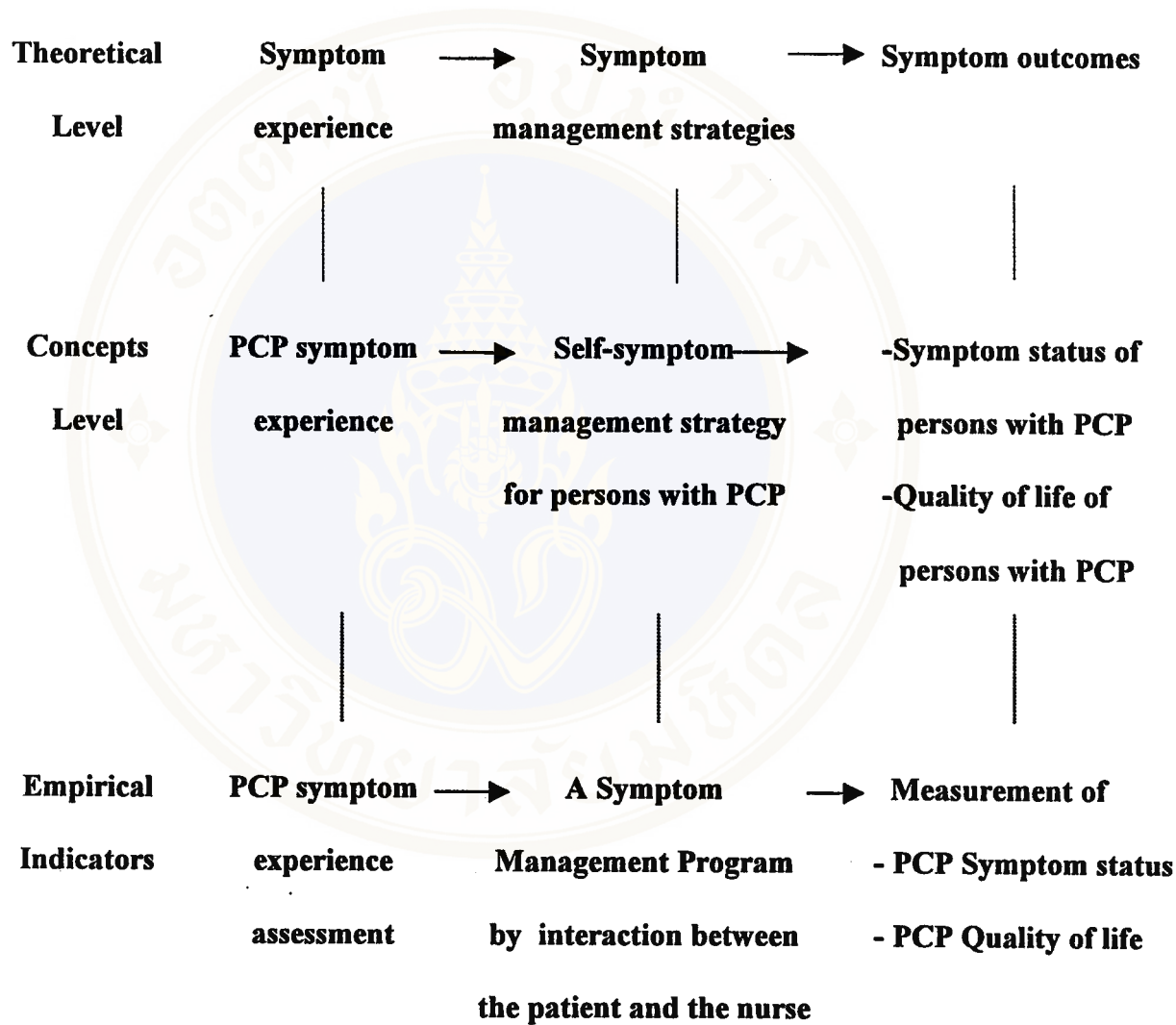


Figure 3 Hierarchy of Middle-Range Theoretical Deduction (Fawcett, 1993: 23)

Hypotheses

The research hypotheses are as followed:

1. The posttest mean score of symptom status is lower than the pretest mean score in the experimental group.
2. The posttest mean score of quality of life is higher than the pretest mean score in the experimental group.
3. The posttest mean score of symptom status of the experimental group is lower than that of the control group.
4. The posttest mean score of quality of life of the experimental group is higher than that of the control group.

Scope of the Study

The study is essentially an experimental research aims to evaluate the effectiveness of a Symptom Management Program on the symptom status and the quality of life among persons with PCP who are treated during June–October, 2000 at Nakhon Pathom Hospital, Nakhon Pathom, Thailand.

Definition of Terms

Symptom status refers to the patients' perception of changes in a physical functions that were caused by PCP disease. Assessing the symptom status was achieved through the PCP Symptom Status Questionnaire that was developed by the researcher. This questionnaire was concerned not only with physiological complaints of persons with PCP such as shortness of breath, dyspnea on exertion and/or at rest,

nonproductive coughs for a long time, fever, fatigue, and difficulties in eating but also the symptoms of the side effects from drug treatments: nausea or vomiting and rash or itching after drug intake. The response to each item in the questionnaire was scored on a four-point scale from 0 to 3. Higher mean scores indicated lowered manifestation of the symptom.

Quality of life refers to the perception of well being, satisfaction, and happiness in a patient's life. It incorporated multidimensional aspects of physical, psycho-spiritual, and societal factors that comprised five dimensional aspects: 1) Physical/general well-being; 2) Social interaction; 3) Emotional/psychological well-being; 4) Self attitude; and 5) Life satisfaction. The quality of life was assessed from the PCP quality of life questionnaire that was modified from Nantachaipan, P (1996). These dimensions are defined as follow:

1. **Physical/general well-being** refers to the perception of happiness or general well-being that is involved in aspects of eating, recreation and sleeping, activity, voiding and elimination, and functional ability.
2. **Social interaction** refers to the perception of satisfaction in social functions and roles, the relationship with others in society, and social support.
3. **Emotional/psychological well-being** refers to the patients' feelings about their illness or their life since they were infected with HIV and PCP.
4. **Self- Attitude** refers to the perception or feeling about themselves that were their self-worth, their abilities and their bodily image.
5. **Life satisfaction** refers to the feeling of pleasure in a patient's life after

he/she received the blood test result of affliction with HIV organism.

This was measured by a linear analogue scale that was 100 millimeters long with values ranging from 0-100 points for each item. The meaning of the score was the higher the score the higher the quality of life.

The Symptom Management Program refers to the promotion of the patients' self-symptom management program that was holistic and continued nursing intervention. This program was a dynamic and changeable process with interaction between the nurse and the patient. It was comprised of four phases, which were 1) The Problem Assessment and Needs Identification Phase 2) The Preparation for Symptom Management Phase, 3) The Practice for Symptom Management Phase, and 4) The Evaluation for Symptom Management Phase.

Routine care refers to the usual care that focused on the provision of medication and information about the disease of AIDS that was conducted by the nurse, physician and other health care providers at the medical ward and at the out-patient department. It also included mental care that was the pretest and posttest counseling of AIDS. The staff nurse also gave patients information concerning follow up treatment in order to maintain continuous treatment.

CHAPTER II

LITERATURE REVIEW

In order to study the effectiveness of a Symptom Management Program on symptom status and quality of life among persons with PCP, the review of theories and the literature was organized in four sections. The first one was AIDS and PCP knowledge. The second section was the symptom experiences of persons with PCP during hospitalization. The third section was the quality of life of persons with PCP. The last section detailed strategies to develop knowledge on symptom status and quality of life among persons with PCP, which included the review of exiting strategies and the Symptom Management Program.

AIDS and PCP Knowledge

The human immuno-deficiency virus (HIV) causes the acquired immuno-deficiency syndrome (AIDS). It leads to the destruction and/or functional impairment of cells of the immune system, notably CD4+ T cells. HIV progressively destroys the body's ability to fight infection, so, opportunistic infections occur easily, such as Pneumocystis Carinii Pneumonia (PCP), AIDS Dementia, wasting syndrome with diarrhea, and certain cancers, such as Kaposi's Sarcoma (KS) (Center of Disease Control, 1989; Ministry of Public Health, 1988; Thongcharoen, P. 1988). A person with HIV infection exhibits a progressive pathogenic process. It begins with primary infection, continuing with a chronic phase that is usually asymptomatic, and leads to

progressively severe symptoms or profound immuno-deficiency. Then, opportunistic infections and cancers occur, which causes severe and acute illness and can rapidly lead to death. Therefore, if the distinct stages of HIV are separated it will be beneficial for patients' care especially in giving education for health promotion. It may also the certainty benefits of diagnosis that includes the benefits of studying the pathology, the disease process and experimental uses of medicines and vaccines.

In Thailand, the Epidemics Bureau together with the AIDS Bureau have collaborated with academics from medical institutions and have divided AIDS disease into 3 periods as follow: (Weekly Epidemiological Surveillance Report Supplement, 1993)

1. The Asymptomatic HIV phase is the period of HIV infection without an expression of the symptoms but is discovered only by the presence of HIV antibody in the blood.

2. The Symptomatic HIV phase is the period of HIV infection with the expression of symptoms and presence of HIV antibody in the blood. The symptoms are caused by low immunity and include the following: Candidiasis or fungi infection in the mouth or hairy leukoplakia, herpes simplex, malfunction of the center nervous system, chronic diarrhea or chronic fever or fatigue for more than a month, body weight reduction of more than 10% of the normal weight, chronic skin rash persisting for more than a month, anemia, leukopenia and plastocytopenia, chronic cough for more than 2 months, lymph node extra-groin enlargement in at least 2 areas for more than a month.

3. The AIDS phase is the period of HIV infection with opportunistic occurrence of at least one of 25 defined diseases. It may also be a status where CD-4 is lower than 200 cells per cubic millimeter, which occurs at least twice.

This indicates that the AIDS period is a period of the acute infection beginning with an immediate infection, and continuing with implied chronic illness and which is followed by acute symptoms due to the reduction of the bodies immunity system and infection with opportunistic organism and cancer (Fact Sheet, 1998). In Thailand, there are many new cases of AIDS, which were discovered while they were newly hospitalized patients with opportunistic illness. From the statistics of the hospitalized patients at the medical ward of Nakhon Pathom Hospital it was discovered that there were 40-50% of patients were new cases of AIDS patients per month (Nakhon Pathom Hospital, 1999).

During the phase of AIDS, patients would face various illness or chronic diseases that occurred from the fungi, virus, bacteria or protozoa in different systems of their body. The main infection is found in the respiratory system, which is mostly caused by *Pneumocystis Carinii* organism (Thongcharoen, 1988). From the National Statistics published in 1999, it was found that PCP was the second most common opportunistic disease of people living with HIV/AIDS (Department of Communicable Disease Control, 2000). PCP was found as early as 1980, and at that time the rate of occurrence was very high and its recurrence rate was more than 60 % of recovered patients. After starting on a PCP prophylactic regimen, the rate of additional recovery increased. In controversy, AIDS patients who had not received the PCP prophylactic regimen and new cases were still exposed to *Pneumocystis Carinii* infection

(Carmichael, 1997: 563; Moe & Hardy, 1994: 333). In Thailand, in 1998 alone, there was a 22% increase in new cases of AIDS (Department of Communicable Disease Control, 2000). During the collection patient statistics at Nakhon Pathom Hospital from October 1999 to March 2000, 232 AIDS patients were found and 60 cases of them had PCP (Nakhon Pathom Hospital, 2000).

Pneumocystis Carinii organism mostly causes pneumonia that is seen in AIDS patients. This organism is a protozoa or fungi that can be found on land or in animal feces and does not cause illness in normal people except for those with low immunity such as the elderly or AIDS patients (Hirunrat, V & Hachvanit, M, 1996: 253; Moe & Hardy, 1994: 335).

The diagnosis of this disease in practice has mainly used clinical symptoms. The typical complaints presented by AIDS patients with PCP are: a nonproductive cough for a long time, shortness of breath, dyspnea on exertion and/or at rest, fever, fatigue, or respiratory distress that occurred in severe cases (Holzemer, et al., 1995: 280; Masur, 1984: 54; Ministry of Public Health, 1997: 86; Moe & Hardy, 1994: 336; Wachter, et al., 1992). These symptoms can be grouped into aspects of respiratory problems and aspect of non-respiratory problems as done in the study of Janson-Bjerklier, et al (1992: 114-121). It was found that 201 hospitalized AIDS patients with PCP had in total 601 problems, which could divided into 61 items that involved the dyspnea and 83 items related to other symptoms of respiratory problems and the rest were problems that were not related to symptoms of respiratory problems.

In addition, the diagnosis could be used together with the result of a chest x-ray that indicated bilateral interstitial infiltration or it might have a normal result.

Laboratory testing has improved as well with the sputum gram-stain, and AFB or sputum cultures for identification of other infections. If the disease cannot be detected in the consideration process, then the broncho-alveolar lavage (BAL) would be used (Ministry of Public Health, 1997: 85-88). Although the BAL method will give an almost 100% correct result of the disease it is not much used in practice because of the high expenses (Hirunrat, W. & Hachvanit, M. 1996: 255).

PCP can be cured by doses of trimethoprim-sulfate thioxazole (TMP-SMX) for 14-21 days. However, patients would get significant side effects or allergies from that drug easier than normal patients because of their decreased immunity. Those symptoms included rash, fever, leukopenia, thrombocytopenia, hyponatremia, hyperkalemia, elevated hepatic transaminases, and renal insufficiency. If these symptoms happened, other drugs such as dapasone-trimethoprim or clindamycin plus primaquin or pentamidine isethionate would be considered for use instead of TMP-SMX but these drugs also have the strong side effects (Hirunrat, W. & Hachvanit, M. 1996: 257; Ministry of Public Health, 1997: 87).

Therefore, AIDS patients who begin to have acute symptoms and can not take care of themselves at home, they need to be treated in hospital. The patients either responded to the illness or managed the symptoms differently while being care for in the hospital and while staying at home.

The symptom experiences of persons with PCP during Hospitalization

The symptom experiences that occurred to persons with PCP can be explained by using the Symptom Management Model (Larson, et al., 1994).

Symptom experience is dynamics that involves the interaction of symptom perception, symptom evaluation and symptom response as follows:

1. Symptom perception is how individual notices a change from the way the patient usually felt or behaved (Larson, et al., 1994: 273). The perception occurred through the cognitive process, and patient had understanding and had problem solving ability through the use of old experiences (Quinn, 1995: 324).

When the symptoms of opportunistic infection such as PCP occurred, some patients would think that those symptoms were AIDS, for which there was no effective cure. In the fact, they had opportunistic illnesses, which occurred when their immunity systems were decreased. Those symptoms could be treated with antibiotics in high but they take more time than usual (Hirunrat, W. & Hachvanit, M. 1996: 257). When they had a misperception of this knowledge, they had no self-awareness and they would perceive that the symptom could not be controlled. Then the hopelessness and depression would be occurred (Miller, 1992: 57-61).

The perception of symptom management is the ability for patients to relieve and control the symptom and care of themselves based on the patient's perspective. Entering hospital for treatment let the patients know that doctors and nurses were responsible for managing their symptoms and the hospital system did not focus on helping patients care for themselves (Nantachaipan, P. 1996: 131). That was why patients did not have freedom to chose the kind of treatment they wanted and they felt

of no value confused and depressed. Consequently, they would perceive no control of the situation or of symptoms, that indicated powerlessness, which is an ineffective response (Miller, 1992: 4,3,6). The study of Powell-Cope (1996:26) found that AIDS patients with PCP who had powerlessness would only passively change their behaviors. Likewise the study of Corless, et al (1994: 7-8) found that 128 hospitalized AIDS patients had high possibilities to become powerless, 37.5% exhibited powerlessness, 29.2% depression, and 19.5% loss of body image. If the powerlessness had not been correctly helped, helplessness would have also been occurred (Miller, 1992: 10,62).

The other important element that affects the symptom perception is the social stigma. There is no support from society because it is socially undesirable disease that would make the patient keep it secret and be afraid to ask for help. Therefore, they lacked supporting resources to control the symptom to encourage them to have quality of life. The study of Ounprasertpong, L (1997) revealed that social stigma had a negative effect on the role adaptation of HIV/AIDS patients. While Nantachaipan, P (1996) defined role adaptation as a component in the social interaction dimension of the quality of life. Also, several studies found that social support had a positive correlation to quality of life (Friedland, et al., 1996; Noimuanvai, P. 1993).

2. Symptom evaluation is the judgment people made about their symptoms, such as symptom severity, cause, treatability, and the effects of symptoms.

The misperception of their symptoms cause patients to think that this symptom was AIDS and that no drug could cure it and that they were in the dying phase. Therefore, the patients did not have the will to be strong and thus would become more anxious.

3. Symptom response is the feelings, thoughts, or behaviors that are secondary to actual or potential health problems. A person's response to a symptom or a symptom cluster includes physiological, psychological, and behavioral components.

Physical responses of persons with PCP were involved to the functional abilities especially in the acute stage. The patient would sleep silently on the bed, not move the body, not eat and reduce drinking, which could be caused by either the body or the mind. Thanasilp, S (1999) conducted a study to identify the problems and needs of hospitalized adult AIDS patients with PCP. The findings revealed that at the acute phase, distress from dyspnea was the critical problem that needed intensive care. Once this respiratory symptom has been controlled, other symptoms such as fatigue, weakness as well as loss of appetite also needed further care. Although, these symptoms were the symptom of PCP but most of the patients perceived them as an advancing AIDS disease and believe that they were at the dying phase. Therefore, these patients had low self-efficacy, no self-management skills, and needed correct information and guideline to improve their self-efficacy and change their misperception about the symptom. They did not disclose of HIV blood test result to others. At the recovery phase when the patient was in the discharge plan from hospital they were worried about their illnesses, had less confidence to manage symptoms that might be reoccurred at home because lacking of knowledge. This showed that the problems occurred from a lack of information, along with a system that was not helping them to realize the importance of self-management.

Hospitalized AIDS patients with PCP received mainly physical care, and a little mental care (Thanasilp, S. 1999). They mostly had insufficient nursing care to

promote self-care by themselves (Chukumnerd, 1999; Inthisang, 1999; Nantachaipan, P. 1996; Thanasilp, S. 1999). This was because nurses did not focus on helping patients to manage their symptom by themselves, so their symptom management skills were ignored and not developed. Consequently, they perceived dependence and could not control symptoms.

The patients' psychological status would have increased pressured from the effects of the physical symptoms and this would also affect the physical status, so there was reciprocal effects (Greenberg, 1996: 250). The patients would be more anxious because of interruption of the respiratory system and an incorrect AIDS knowledge that caused them to think that their symptoms were severe. They could feel a fear of death because the illness was not treated with any medicine. The patient would be hopeless and depend on others. So, it would cause them to perceive low self-esteem, and they had no energy to face the disease. These results showed that the patients had a status of powerlessness (Miller, 1992:12; Wallerstein & Bernstein, 1988 cited on Gibson, 1991: 355). Powerlessness included passivity, less ability to learn, feeling more dependent and less independence, having inefficient communication, and negative self-control and self worth (Miller, 1992: 399).

The patients who did not accept the HIV blood test result would not disclosed themselves and were afraid for others to be known about it. Especially, when the illness was apparent, it would make them afraid that the secret would be disclosed. For the others who were able to accept the result, they were carried away with harsh words or an expression of society, which considered them offensive (Rujkorakarn, et al., 1998). They were not anxious about the blood test result disclosure. Then they could

live in society as normal and be supported by society. They were able to have the will to fight the disease and actively care for themselves according to the advice and directions given to them (Sangchat, B in P Boonmongkol, et al (Eds)., 1999: 88).

The social responses to this group of patients were always to conceal and to separate them from the society but the acute symptom might make them afraid of the disclosure of the blood test result. Then they might be rejected by society. Therefore, they would be more stressed and it always showed that the patients in this phase were not interested in the environment, or the things that the nurses performed for them and they did not talk.

The ability to go back to work is the hope of most of the patients. It might be the original work that they had to respond to the family or self, or simple tasks that they wanted to do in order to reduce the stress. Most studies showed that AIDS patients had less income and they mainly wanted economic support as well as regain skills diminished by the symptoms.

Misperception of the symptoms, perception of low self-efficacy and self-control to manage symptoms, and lack of self-management skills, made patients get more worried about the disease. So their symptoms would worsen and their functional ability would be decreased. Those caused a decrease in their perception of life satisfaction, well being, and happiness in life while they got PCP or the quality of their life was decreased.

Quality of Life of persons with PCP

Definition of Quality of life

Quality of life refers to the perception of well being, satisfaction, and happiness in a patient's life (Dalkey & Rourke, 1973: 40 cited in Hanucharurnkul, 1998: 34; Padilla & Grant, 1985; Goodinson, 1989; Ferrans & Powers, 1992: 32). It incorporates multidimensional aspects of physical, psycho-spiritual, and societal factors (Bunch, 1998; Ferrans & Powers, 1992; Murdaugh, 1998; Nantachaipan, 1996; Padilla & Grant, 1985; Schag et al cited in O'Leary, 1998: 434; Wilson, et al., 1997; Zahn, 1992). To measure these interrelated dimensions, a holistic measurement should be considered.

The Symptom Management Model emphasizes that the more extremely problematic or prolonged the symptoms become, the more the quality of life of the patient became a major concern. Maintenance of patients' functional status to a level where they could function independently was a desirable outcome. In persons with PCP whose most major acute and critical symptom was a respiratory problem, chronic breathing difficulty affects a patient's quality of life. The results of Janson-Bjerklie, et al (1986) revealed that patient with obstructive, restrictive, or vascular pulmonary disease perceived dyspnea as greatest negative affect to quality of life.

Factors related to quality of life

Quality of life is affected by many factors both internal and external as follow:

1. Internal factors comprise the stage of the disease, the symptom status, self-care deficit or hardness.

- 1.1 Stage of disease: data on this aspect is controversial. Lubeck & Fries

(1992); Regsdale & Morrow (1990) and Schag, et al (1992) found that AIDS patients had a lower quality of life than the asymptomatic patients. In addition, Ragsdale & Morrow (1990) found that AIDS patients and symptomatic patients did not have a difference in quality of life. This indicated that the stage of disease was related to the quality of life. On the contrary, Nokes, et al (1994 cited in Mellors, et al., 1997) found that the stage of AIDS disease did not relate to the quality of life.

1.2 Symptom status: symptom status is the best predictor of the quality of life, and symptom suffering related to the physical dimension and psychological dimension of the quality of life (Lovejoy et al, 1991; Wachtel et al, 1992; Wu, 1993). This was congruent to the studies of Ganz, et al (1993); Holzemer, et al (1998); and Wachtel, et al (1992) concluded that symptom status was negatively related to the quality of life in HIV/AIDS patients. On the contrary, AIDS patients with PCP who had different symptoms did not have differences in functional ability, pain feeling, or fatigue (Janson-Bjerklie, et al., 1992: 114-121). Therefore, the differences of the symptoms of PCP patients did not affect the physiological dimension of the quality of life.

1.3 Self-care deficit: The study of Noimuenwai, P (1993) found that self-care deficit was negatively related to the quality of life in AIDS/HIV patients.

1.4 Hardiness: Perception of hardiness was positively related to the quality of life in AIDS/HIV patients (Krutkaew, W. 1997).

2. Social support is an important external factor. From several studies it can be concluded that social support is positive related to the quality of life (Friedland, et al., 1996; Noimeunwai, P. 1993).

Quality of life measurement

It is difficult to define the meaning of the quality of life and its measurement because of cultural, moral, religious and the individual beliefs. Those factors have influenced to the person's perception then it can involve its definition and its outcome (Zahn, 1992:796). Therefore, these issues must be carefully considered whenever the quality of life measurements that had been built or developed from Western culture are used to measure the people in the East.

One argument about the measurement is whether it should be subjective or objective. Some academic though considers quality of life is the individuals' experiences and perception. Hence, the evaluation should be determined from personal activities (Cooley, 1998:153; Sutcliffe & Holmes, 1991: 493; Benner, 1985: 1). Moreover, the measurement of the relationship or the physical environment should be done by others (Draper, 1992: 966) but Zahn (1992: 795); McCall's (1975, cited in Meeberg, 1993: 34) and Campbell (1975) suggested that the quality of life should be assessed from both objective and subjective measurements. That was because the individual's perception had an effect on the personal background, social status, culture, environment and age (Zahn, 1992: 796) but it was hard to interpret the result because of differences in scales or scores. Changing the score from raw scores to the standard scores might reduce those problems but they might not be able to communicate or respond to the facts. Therefore, Campbell (1975) suggested that the objective data affected the subjective data. Likewise, the researcher agrees with the stated thought because the researcher believes that perception is more important than what really happen (Dracup & Ruffin, 1989 cited in Miller, 1992:264) and believes in the



individuality of the person. Therefore, implying the meaning of incidents should be the judgement of that person.

Who should be assessed while measuring the quality of patient's life: the patient, the caretaker or the professionals such as the doctor or the nurse? Pearlman & Uhlmann (1988) showed that the relationship between assessing quality of life by the health personnel and by the patient was at a low level ($r = 0.15-0.31$). It was a serious view that had several arguments from academia. Zahn (1992) summarized from many studies that patients should be asked about quality of life. However, in the case of the mentally disabled or those unable to communicate, the family members or professionals who take care of them should be assessed the quality of life (Montazeri, et al., 1996a: 165).

Holzemer & Wilson (1995) collected questionnaires to assess the quality of life of HIV/AIDS patients from twelve studies. Fourteen different questionnaires were found to be used, of which 3 were objective measurements and 11 were subjective measurements. Eight of the questionnaires had been used more than 2 times before and 6 of them had been used only once. All of those measurements were modified from questionnaires that were used with other patients.

Various quality of life questionnaires were used for HIV patients from other countries. Most of them are modified from other patients' measurements to fit HIV/AIDS patients, such as the HOPES and the MOS-HIV. The living with HIV questionnaire of Holzemer et al, (1998) was developed from gathering information from AIDS patients to syntheses the items, which were more suitable for AIDS patients. However, this assessment form did not focus on the physical problems that

affect the quality of life of patients so it has limitations of usage with hospitalized HIV/AIDS patients.

Likewise, the quality of life measurements that have been used for Thais living with HIV/AIDS are as follow:

1. Padilla and Grant's Quality of Life Index, (1985) which was transformed and adjusted to Thai culture by Hanucharunkul (1988) and this measurement was developed to use with cancer patients. It had 19 questions with the dimensions of physical, psychological, social, body image, and diagnostic and treatment reactions. It has a linear analogue scale that had a length of 100 mm. The higher scores mean higher quality of life. This was used with the group of HIV/AIDS patients in the study of Noimeunwai, P (1993). In the study of Wattradul, D (1994), she developed this measurement by adding 10 more questions.

2. Cantril's Quality of Life questionnaire (1965) measured satisfaction and happiness in life. It had scores as staircase rungs ranging from 0-10 points. The higher scores mean a higher quality of life. This measurement was used in Chowsilpa's study (1997).

3. Ferrell et al's Quality of Life questionnaire (1995) which was translated and modified for Thai culture by Krutkaew and Tapinta (1996) measured the perception of physical, mental, social and spiritual contentment with a total of 41 questions. The questionnaire results were displayed as linear scores ranging from 0-10 points. This measurement was used by Krutkaew, W (1997).

4. Quality of Life questionnaire was developed by Nantachaipan, P (1996) by

using the framework from a literature review, previous related research and a pilot study. It comprised of 5 dimensions: 1) physical/general well-being 2) social interaction 3) emotional/psychological well-being 4) self-attitude and 5) life satisfaction dimension. The 24 questions were in a linear analogue scale with a length of 100 mm, scoring from 0 to 100 points. A higher score meant a higher perception of quality of life.

All studies that used these measurements to collect data from samples in their studies were considered them as an interval scale. Most of the quality of life measurements that were used among HIV patients in Thailand had been modified from other countrys and also were developed for other diseases. Only one of them developed items from HIV/AIDS patients based data. Therefore it was considered to be more suitable to use with AIDS patients in Thailand than the others. However, the context of the study and the severity of the symptom status need to be considered while using this measurement. Therefore, the researcher tested it with 60 HIV/AIDS out-patient of Nakhon Pathom Hospital. The results revealed that it had a high reliability ($\alpha=0.88$). Each item was able to explain variables of quality of life of more than 53%. However, a few items such as the item related to social rejection, usefulness in society and sexual activity still needed improvement because of their lower relation to the whole items ($r=0.2$). Especially the item related to usefulness in society was not valid because most patients did not have those experiences because they had not formed a group to do benefits. Moreover, the item related to social rejection was invalid. Therefore, those two items should be eliminated when the questionnaire was

used with the advanced AIDS patients who were treated in hospital and had social stigmatization (Thanasilp, S. 1998).

Strategies to develop symptom status and quality of life among persons with PCP

1) The exiting strategies to develop quality of life

There are several strategies to improve symptom status and quality of life in AIDS patients. Most of them focus on the effectiveness of medicines. Other studies used a combination of strategies in one study to find the individual effect of them. Those strategies are summarized as follows: 1) Anti-virus drug used; 2) Self-help group strategy; 3) The combinations of self-management, problem-solving and stress management strategies; 4) Group teaching and training about stress management, communication, exercise, and methods to increase self efficacy; 5) Educative and supportive method; 6) Cognitive behaviors strategy; and 7) Empowerment based on community and individual strategy (Eller, 1999; Nantachaipan, P. 1996; Ratanasombut, S. 1997; Rujkorakarn, D., et al., 1997; Wattradul, D. 1994; Wu, et al., 1990).

These strategies reflected that the important factors that affected symptom status and quality of life involved both biophysiological factors and the interaction between the patient and the professional or the family support. Most of them focus on improving self-care ability, which was important for this group of patients, but few studies have proven the strategy especially in self-symptom management by a scientific method. In addition, the continuing nursing care strategy for AIDS patients who did not disclose their HIV blood test result to other was not widely studied.

2) The Symptom Management Program

The framework of this study was developed by a deductive approach technique that derived from the Symptom Management Model. The University of California, San Francisco (Larson, et al., 1994) developed this model which was a middle-range theory comprised of three dimensions: symptom experience, management strategies, and outcomes. These dimensions were interrelated and provided the nursing perspective and framework on how the symptoms should be managed effectively. The model mainly identified the principal strategies for symptom management that were interaction from the patient, family, the health personnel, and the health care system because it is believed that symptom management and resulting outcomes are the responsibilities of the patient and the family. However, it did not explain the appropriate practical aspects of each strategy due to the limited nature of the middle-range theory. The concept of self-management in chronic illnesses was investigated by modifying the self-care strategy.

Self management concept: self-management is a critical activity required in nursing intervention process that is aimed to ultimately change client morbidity, mortality, and quality of life (Tobin, et al., 1986: 49). The self-management concept derived its theoretical base from social learning and cognitive and psycho-physiological theory (Nakagawa-Kogan & Bertus, 1984: 7). This treatment required a combination of biological, psychological, and social intervention techniques, with a goal of maximal functioning of the regulatory process (Kanfer & Goldstien, 1975).

Basic skills that are required in self management education are as following:

1. **Self-monitoring:** refers to a patient's observation and recording of factors that influence the health problem. It might involve any or all of the four processes, behavioral; environmental-social; cognitive and physiological processes that impact health and self-care.

2. **Self-instruction:** refers to information that the patients provide themselves to direct, increase, maintain, or decrease certain aspects of their responses.

3. **Self-induced stimulation change:** refers to any attempt to change environmental conditions that can impact on some aspect of a patient's illness.

4. **Self-induced responses change:** refers to changeable behaviors, which reinforce or punish a patient's responses that affect his/her health. Relaxation is an example of this skill that provides a means of controlling physiological processes that precipitate symptoms.

5. **Decision-making:** refers to problems in every day life. It is an important aspect of self-management process.

Self symptom-management ability is patients' behaviors for dealing with symptoms; for examples: increased use of and practice of relaxation, stress management in patients' with tension headache; increase use of decision making and problem solving in asthmatic patients proper diet using blood sugar self assessment in diabetic patients and use of thermal biofeedback in patients with Reynaud's disease (Tobin, et al., 1986: 40). In empowerment aspect, the results of interaction between patients and nurses depend on their mutual goal setting (Hawks, 1992: 611).

The above knowledge guided the researcher to develop a Symptom Management Program for persons with PCP by means of an interaction between the

patient and the nurse. This program was comprised of four phases: 1) Problem Assessment and Needs Identification Phase 2) Preparation for Symptom Management Phase, 3) Practice for Symptom Management Phase, and 4) Evaluation for Symptom Management Phase.

1) Problem Assessment and Needs Identification Phase.

The first phase of the program began with assessing and identifying the symptoms. This phase was an important step for the nurse to understand the patient and his condition. The nurse assessed the patients' symptom experience: symptom perception, evaluation, and response; symptom knowledge; symptom management skill; symptom status and quality of life. Observation and interactive interviews were used to extract comprehensive information from the samples. During the interview, the samples were encouraged to take the leading role, as this would facilitate the free flow of the needed information. At this point, participation in the nursing care would lead to increases in the samples' self-efficacy. Participating in the problem assessment and needs identification process made the samples understand a real individualized experience leading to effective planning and symptom management (Gibson, 1991).

2) Preparation for Symptom Management Phase.

After the patient could clearly identify the problem and establish a goal to solve the problem, the nurse would proceed to the preparation phase. This second step involves enhancing the patient's knowledge and skill through the disease and symptom management education. Education would be immediately intervened to correct patients' perception. This could have an effect on shaping their cognition which is defined as mental process improvement, that involves knowing, learning, problem-

solving, remembering, and perceiving ((Quinn, 1995: 37; Collins Cobuild English Dictionary, 1995: 304). The researcher should correct their perception by giving systematic information in order to improve the symptom and symptom management perceptions, so that patients would learn the correct knowledge and have self-awareness (Quinn, 1995:39).

After that, patients would be able to recognize their problems and perceive their symptom correctly, so they could cope with stress effectively and perceive their abilities in symptom controlling (Miller, 1982 cited in Miller, 1992:12). These were cognitive and decision-making controlling abilities (Miller, 1992:12). Dealing with these symptoms requires practice, consisting of demonstration, action and reflection to help patients gain the relieving and controlling abilities (Quinn, 1995: 137, 279). Then the training program was designed to develop patients' ability to observe and analyze any abnormal symptoms by themselves and the ability to make a decision. As a learning process, a skill development training program involves demonstration, action and reaction (Quinn, 1995: 137). This process would increase the patients' abilities to effectively relieve their symptoms as well as to control the symptoms.

This cognitive process was needed for mastery of the modeling that is widely applied to develop intellectual, social, and behavioral competencies. Complex skills that are broken down into sub skills thus modeled on videotape are easily mastered in steps and produce better learning than trying to teach everything at once. Effective modeling teaches general rules and strategies for dealing with different situations rather than only specific responses or scripted routines (Bandura, 1997: 258).

Symptom relieving and controlling skills for PCP patients who needed to be instructed were those of deep breathing exercise, diaphragmatic breathing, pursed-lips breathing, effective coughing, using a tepid sponge, stress management, and drug allergy observation. Learning these practices is essential in building up self-symptom management abilities in PCP patients. The patient need environmental supports in orders to facilitate the symptom management practice. These supports include family support, appropriated environment support or system resource support.

3) Practice for Symptom Management Phase.

The third step meant the self-symptom management process has begun. The patients should set goals to achieve desirable outcomes before they are required to continuously perform the monitoring of PCP symptom relief and control. Daily practice in symptom management facilitated the samples to relieve their symptoms.

Self-monitoring is the observation and recording of the results, which are occurred in practice sessions, in order to compare the effectiveness of the practice skills. And it would also be a positive reinforcement for patients to get valuable information about self-management. These could improve abilities of self symptom-management and maintain those abilities long term. Effective self-monitoring would be manifested if the patients were able to continuously participate in those activities in which they were trained. Redland & Stuijbergen (1993: 437) suggested that self-monitoring could sustain a desired behavior so the objective of the self-monitoring was to maintain patients' ability to care for themselves.

Self-monitoring activities included the daily observation and recording of the pulse rate, the respiratory rate, symptom status, and self-symptom management

abilities. Effective self-monitoring would be manifested if the patients were able to continuously complete those activities for which they were trained in the second phase. Then, they should have the assessment form for self-monitoring at home. Daily self-monitoring would evaluate of the symptom status and the symptom management practice. Then this form would be used to evaluate any problems or obstacles with the researcher. In addition, daily self-evaluation will enable them to observe the progression of their symptoms and management ability.

Effective practice requires environmental support that was also a helping process. It could reinforce and sustain the cognitive shaping and the skill development components that the patient could receive from their location and from people such as the family, relatives, neighbors and friends in order to facilitate, improve and maintain the durability of their self-symptom management abilities. For examples, the manual booklet reinforces the retention of the information acquired during the interaction with the researcher.

In this phase the researcher should continue the nursing care by using the distance care while they lived at home. The study of Sangchart, B (1999) suggested that distance care was an appropriate method for HIV/AIDS patients who prepared themselves for improving the self-care ability at home.

4) Evaluation for Symptom Management Phase.

The final step is the evaluation for symptom management phase that includes process evaluation and outcome evaluation. This process needs the patient's self-monitoring strategy and active participation between the patient and the researcher.

If the desirable outcome can not be achieved, the whole process would be analyzed. The problematic process that was an obstacle for each patient would be identified and corrected. If the evaluation were positive, the patient would be reinforced to continue the self-symptom management behaviors.

Therefore, the self symptom- management ability in this study was ability to relief and control symptoms that depended on patients' individual goal. These abilities include symptom relief such as decreasing of dyspnea, coughing, fever, and rash/itching and patient's compliance ability, in order to control symptom by taking medicines and checking the side effects of drugs, and to promote physical health and to follow up by attending for health to be checked. The physical health promotion included having exercise continuously, eating and sleeping well, desisting from factors that cause a worsen condition. These include, stress management, safe sex, avoidance of cigarette smoking and alcohol consumption as well as avoiding contact with pets and dirty places. In addition, they incorporated the basic skills of self management in dealing with self-monitoring, self-instruction, self-induced stimulation change, self-induced response change and decision making that will help patients accomplish better quality of life.

Therefore, patients who participated in a Symptom Management Program and achieved the program goal will have appropriate self-symptom management ability. Then, their symptom status and their quality of life will be improved.

Summary

PCP is an opportunistic infection that is mostly found in AIDS patients, which has a curative drug to treat and prevent it but most of them had a misperception of the symptoms that meant they had less perception of self-control. In addition, the patients were not being prepared for an appropriate method to improve the self-symptom management behavior in order to deal with the symptoms when they returned home. Therefore, a Symptom Management Program (SMP) was designed to be used with persons with PCP by enhancing their symptom management behaviors through the interaction between the patient and the researcher. This program was a patient-centered and holistic care with a dynamic process. After patients received the four phases of this program, they would gain the self-symptom management ability that caused a decrease in symptom status and improved the quality of life.

CHAPTER III

METHODOLOGY

In this chapter, methodological aspects, including the research design, population and sampling, the setting, instruments, data collection, protection of the rights of human subjects, and data analysis were discussed.

Research Design

This research was a pretest-posttest (before-after) experimental design (Polit & Hungler, 1995: 157-163). At the pretest phase, the samples were gathering baseline data or pretest assessment about symptom status and quality of life. For the subjects who were admitted in the in-patient medical ward, the pretest assessment occurred when they were in the hospital discharge plan period while among the subjects from the out-patient department, pretest assessment was performed right after the subjects agreed to participate in this study. The posttest evaluation about symptom status and quality of life was conducted one-month after the pretest assessment.

Population and Sample

Population of the Study

The population in this study was HIV infected persons who were first diagnosed with *Pneumocystis Carinii* Pneumonia (PCP) at Nakhon Pathom Hospital.

Samples of the study

1. Sample size

The sample size of each group, the control and the experimental group was 20. The total sample size in this study was 40 persons who were diagnosed with PCP.

2. Sampling procedures

The purposive sampling method was used to obtain qualified samples in this study. The following steps were used to recruit the samples:

2.1 HIV patients' health records from medical wards and the out-patient department at Nakhon Pathom hospital were reviewed to identify the samples having the following inclusion criteria.

The inclusion criterias:

- 1) Not being in an acute phase (with a respiratory rate lower than 25 per minute, not using of oxygen therapy, and not having cyanosis),
- 2) Not being treated with an anti-HIV drug,
- 3) Not having other complicating diseases such as tuberculosis, pneumothorax, cryptococcus meningitis, diarrhea, diabetes mellitus or pregnancy,
- 4) Male or female aged 15 years and above,
- 5) Literate in the Thai language,
- 6) Being conscious,
- 7) Willing to collaborate and participate in this program.

2.2 Once each qualified subject had been identified, he/she would be randomly assigned to either the control or experimental group by using the sealed-envelop with

no replacement technique. The researcher would draw a ballot out of the forty that were mixed together in a box. Of the forty ballots, 20 of them were marked with the letter "C" for the control group and another 20 ballots had the letter "E" for the experimental group. Any ballot that was drawn would be assigned to that subject and was not replaced in the box. Then the researcher approached the subject and presented information about this project in order to seek their approval to participate in the study. Once the prospective subject agreed to participate in this study, he/she would have to sign a consent form.

2.3 Due to the severity of the disease, an above average drop out of rate of subjects was likely to occur. For the initial data collection, total 58 PCP patients were approached to participate in the study, but eighteen patients were unable to participate throughout the whole process of the study. There were three reasons for this dropout: 1) eleven patients developed complications such as tuberculosis or diabetes mellitus or pneumothorax or cryptococcal meningitis or pregnancy; 2) four patients were failed to maintain follow up after discharge from the hospital; and 3) three patients died. The final sample therefore, consisted of 40 patients, 20 of them were in the control group who obtained only routine care while the other 20 were in the experimental group who obtained routine care in addition to the Symptom Management Program. 75% of each group were recruited from the in-patient department and 25% were recruited from the outpatient department. Details of the data collection are presented in Table 1.

Table 1 Summary of number of samples in the study, at the pretest and posttest phase.

Step	Control group	Experimental group	Total
Pretest	32	26	58
Off case	12	6	18
Complication	6	5	11
Loss follow up	4	0	4
Dead	2	1	3
Posttest	20	20	40
IPD	15	15	30
OPD	5	5	10

Setting

This study was conducted in medical wards of the in-patient department and at the outpatient department of Nakhon Pathom Hospital. There were 30 samples from the in-patient department and 10 samples from the outpatient department who were assigned equally to each group, the control and experimental group.

Instrumentation

1. Interventions:

1.1 A Symptom Management Program

1.1.1. Incubation of the Program

Intervention in this study, a Symptom Management Program, was focused on the patient ability to handle the symptoms. The researcher developed this program based on the symptom management model and self-management concept. The development process of the program comprised of 4 phases:

1) Needs assessment phase.

This first phase focused on the need assessment from 15 hospitalized PCP patient (Thanasilp, S.1999). The finding was found that the PCP

patients had misperception of the symptom, low self-efficacy and self-control to manage symptom, no self-management skills, and did not disclose of HIV blood test result to others. These factors increased psychological problems such as depression and low self-esteem of the PCP patients. This information was the essential baseline data that facilitate the effective development of the program.

2) Program developmental phase

The data acquired from the needs assessment phase was used to plan a Symptom Management Program. This plan was flexible and allowed for the individual implementation. The details of the program were in the Manual of PCP Symptom Management Program (see Appendix C). After this manual was validated, the self-symptoms management information from the program manual was conversed into a script for the video production (the details of this script was presented in the Appendix E). The intervention comprised of two sets of instruments: two manual booklets and two sets of videotapes.

2.1) Self-Symptom Management Manual Booklet for persons with PCP. The booklet developed by the researcher was used as the manual for the samples in the experimental group. It contained information about pneumonia and how to self-management pneumonia symptom.

2.2) Manual of PCP Symptom Management Program for the nurse. The researcher developed this manual to give the nurse an information on how to promote the PCP patient's self-symptom management. The conceptual framework, steps of the self-symptom management promotion program, and substance knowledge with illustration about PCP and AIDS were included in this manual.

These two manuals were content validated by 6 experts; 2 physicians and 4 nurses' instructors to determine its appropriateness.

2.3) Videotape on PCP Symptom Management. The videotape based on the script derived from the Manual of PCP Symptom Management Program for the nurse was produced to supplement the symptom management training session. This 20 minute long videotape demonstrated the self-symptom relieving techniques for dyspnea, cough, fever, stress, drug side effects as well as the PCP disease controlling methods.

Five experts validated this videotape: two academics nurses in media, two academics in educational technology, and one academic in communication.

2.4) Videotape about the stories of persons living with HIV/AIDS. This videotape was edited from the original production of the Living film (1997). The original 30 minutes version was edited to last only 15 minutes to contain the selected pictures presenting self-care strategies that were appropriate to the samples' context.

3) Program trial phase:

The revised program manual and videotape were try-out on two PCP patients who had similar characteristics to the patient in the study. The try-out proved that the instruments were qualified to be used as the intervention in this study. Although the videotape did not mention any word of "AIDS", the researcher determine that it might not be appropriated to play this videotape in the open room as

the patients apprehended that the others might learn of their HIV infection. Thus, the training should be conducted in a private room.

4) Modification phase

The data from the third phase indicated that the appropriate setting for the training should be in a private room. Upon securing the permission from the director of the hospital, the self-care corner was installed in the out patient department of the Nakhon Pathom Hospital to facilitate the execution of the program.

1.1.2. Substance of a Symptom Management Program

The program comprised of 4 phases, which included 1) Problem Assessment and Needs Identification Phase; 2) Preparation for Symptom Management Phase; 3) Practice for Symptom Management Phase; and 4) Outcome Evaluation Phase. Three meeting sessions were conducted to complete the one-month processing of the program. Each session contained different phases designed in the program and lasted about 30, 60, and 40 minutes, respectively. The intervention process was summarized in Table 2.

1.2 Routine care

All samples in the study received the routine care that conducted by the nurse, physician and other health care providers at the medical ward and the out patient department. The routine care included the information about medication and the disease of AIDS. Mental care in the form of pretest and posttest counseling were also provided. The staff nurse also gave the information concerning the follow up to keep on the continuous treatment.

Table 2 The summarization of the intervention process.

PHASE	CONTENTS	METHOD	SESSION& TIME
Problem Assessment &Needs Identification	-Trust building -Problem solving process -Mutual goal setting	-Individual sharing -Information from questionnaire & asking -Individual counseling -Participation in process	-Session I -30 minute
Preparation for Symptom Management	-PCP & AIDS knowledge -PCP symptom management skill training -Information about the resources that effect the management	-Individual teaching with videotape & manual booklet -Individual training with videotape and the researcher -Individual counseling	- Session II -60 minute
Practice for Symptom Management	-Symptom controlling -Symptom relieving -Distance care -Self reflecting	-Daily Self monitoring -Telephone follow up -Individual counseling at the first follow up	- Session II, III - 30 minute
Evaluation for Symptom Management	-Process evaluation -Outcome evaluation	-self-assessment form -participate with the researcher	-Daily - Session III -10 minute

2. Instruments:

Four sets of questionnaires were used to facilitate the data gathering in this study. These were:

2.1 Health profile questionnaire. This questionnaire comprised of two parts: personal history and health history. The checklists of demographic and socioeconomic characteristics of the patients included age, sex, religion, marital status, education level, occupation, and income of the samples. The second part of the questionnaire contained checklists regarding information about HIV, which included length of HIV infection, history of illness after infection with HIV, and family support.

2.2 PCP Symptoms status questionnaire. The researcher developed this questionnaire, which was composed of nine items that represented PCP symptoms. There were not only physiological complaints of person with PCP, such as shortness of breath, dyspnea on exertion and/or at rest, nonproductive coughs for a long time, fever, fatigue, and loss of appetite but also the symptoms of the drug's side effects that were nausea or vomiting and rash or itching after taking medication or drugs. This questionnaire was content validated by 6 experts; 2 physicians, 3 nurse instructors and one practical nurse. The revised symptom status questionnaire comprising seven items was used to determine the communication with the fifteen hospitalized PCP patients.

The responses to the item were coded on a four-point scale, there were: 0 (no occur), 1 (mild), 2 (moderate), and 3 (severe). The severity of PCP symptoms were assessed by summarizing the total scores, so possible scores was in the range of 1 to 21. The meaning of the scores was that the higher the score the more the severity of symptoms.

2.3 PCP-Quality of life questionnaire. This questionnaire was modified from Nantachaipan's quality of life questionnaire (1996) that was developed to measure the quality of life of persons with HIV/AIDS who lived at home. It was composed of 24 items with five dimensions, which were physical/general well-being, social interaction, emotional/psychological well-being, self-attitude, and life satisfaction. The numbers of questions were 5, 5, 4, 5, 5 items, respectively. Thanasilp, S (1998) used this questionnaire with HIV/AIDS patients who were treated at an outpatient department, but found that the items relating to rejection from society and social usefulness in the social interaction dimension seldom occurred. Therefore, she suggested that those items could be deleted when used in a hospital context. During the trial study, the researcher found that the hospitalized patients could not answer those two items, so in this study the two items were deleted. The original questionnaire was initially designed for patients who resided in the community, so it might not focus on the symptom status, which was an important factor that affected the quality of life. This study focused on persons with PCP who were hospitalized patients so that the dyspnea symptom was the major concern. Therefore, two items that were related to suffering from illness and dyspnea discomfort were added in the physical/general well-being dimension to reflect the symptom concept that was specific to the quality of life of persons with PCP.

The PCP-quality of life questionnaire in this study comprised 24 items in 5 dimensions; they were the physical/general well being dimension, the social interaction dimension, the emotional/psychological well being dimension, the self-attitude dimension, and the life satisfaction dimension. The numbers of questions were

6, 4, 4, 5, 5 items, respectively. A linear analogue scale that was 100 millimeters long with values from 0 to 100 points for each item was used. The scale was scored by revising all negative items and then summarizing the responses to yield a possible total score ranging from 0–2400 points. Then the sum scores were divided by the total number of items making the full score of points 100 points so that it could be compared with the other studies. The meaning of that score was that the higher the score the higher the quality of life.

The reliability of the quality of life questionnaire was tested on 22 hospitalized AIDS patients. The Conbarch's alpha coefficient of reliability was calculated on the trial data and was 0.91. This reliability was acceptable when compared to the 0.78-0.90 reliability of the original study conducted by Nantachaipan (1996). Conbarch's alpha on the quality of life questionnaire using the 40 samples of this study was 0.84, and that of the physical/general well being dimension, social interaction dimension, emotional/psychological well being dimension, self-attitude dimension, and life satisfaction dimension were 0.85, 0.82, 0.83, 0.84, and 0.89, respectively. The alpha value was considerably high, indicating that the scale had demonstrated good internal consistency (LoBiondo-Wood & Haber, 1994).

2.4 Self-assessment of symptom management behavior form. This checklist was developed by the researcher for the subjects in the experimental group to use to monitor their daily practices while staying at home. This checklist was divided into three parts, which included 1) general symptoms controlling; 2) subjects' affective behaviors towards the symptom status; and 3) specific symptom management that the subjects used to handle a symptom when it occurred. The subjects were asked to

monitor themselves according to the checklists in this form for 4 weeks after discharged from the hospital. The researcher collected this form from the subjects every week to ensure that each subject keep track with the procedures designed in this study. No subjects fail to follow this monitoring phase.

Preparation of the research assistant

The research assistant in the study was a volunteer nurse from the Infectious Control Unit of Nakhon Pathom Hospital who helped administer the questionnaires to the samples. The due information necessary for the assistant such as the objectives, procedures, and the questionnaires used in the study was provided. To ensure the mutual understanding of the factors mentioned above the question and answer was repeated until the assistant demonstrate the correct understanding of the whole process of the Program.

Data Collection

Procedures in data collection were as follows:

1. Obtained the permission to conduct a study from the administration of Nakhon Pathom Hospital.
2. Recruited the prospected samples according to the inclusion criteria set forth in this study. Once the samples had been identified, the researcher clearly explained the details of the program including its advantages and disadvantages before asking that subject to sign the consent form if agreed to participate in the study.
3. Randomly assign the subjects into an experimental and a control group.
4. The demographic data and illness history of the samples were asked.

5. The research assistant conducted the pretest by asking the subjects to answer the PCP symptom status questionnaire and the PCP-quality of life questionnaire by explaining the method and the meaning of the scale measurements to the samples.

6. The samples in the control group and the experimental group still received nursing care as routinely conducted by the health personnel at the inpatient and outpatient department.

7. The researcher provided the interventions designed in a Symptom Management Program to the subjects in the experimental group. This program was conducted in 3 sessions.

Session I:

The first session began with establishing the rapport between each subject and the researcher to build trust and cooperation. The researcher and the subjects would discuss the symptom experience and the situation in order to arrive at the mutual understanding of the problems and the agreement on the problem solving strategies. Based on the results of the base-line data concerning the subjects' health and quality of life, the subjects would view the videotape on the lived-experience about AIDS patient to gain the correct information about AIDS and its management. After viewing the videotape the researcher discussed with the subject to confirm whether he/she had correct understanding about AIDS and how to conduct self-care activities. Before ending the first session, the researcher gave a "Self-Symptom Management Manual Booklet" to the subjects in order to read before the second meeting. It should be noted here that the first meeting was conducted when the subject was in the IPD hospital discharge program.

Session II:

The second session took place on the next day after the first session. This session intended to prepare the subject the knowledge and the skill for enhancing the self-symptom management ability by using the videotape and the booklet. After viewing the videotape, the researcher asked the subject to follow the action he/she had seen in the videotape to determine whether the subject gained the self-symptom management skill. If the subject cannot follow every steps appeared he/she would be re-trained until he/she had the appropriate skill for managing PCP symptom. Then the researcher explained the procedures that the subject could practice at home towards the booklet. Before closing the meeting, the subject would receive self-assessment of symptom management behavior form to complete every day and sent it to the researcher every week. The subject used that form to monitor the symptom management behaviors at home for 4 weeks. The subject who needed to contact the researcher before the appointment scheduled might call on the researcher in any time.

In the case of the subject from the OPD setting, the first and the second session were combined. The researcher conducted the intervention according to steps designed in the two sessions at one time on the first day that the subject agreed to participate in the study. Up to this point, the subjects from IPD and OPD settings would receive the same interventions and gained more or less similar skill designed in the Program.

Telephones follow up:

A telephone follow up was conducted in this session. For those who did not have the telephone the subjects used the public telephone to report their symptom

status and symptom management to the researcher. The researcher and the subjects exchanged the information concerning the obstacle or the problem that the subjects may not be able to manage.

Session III:

This session would occur at the second weeks after discharged when the patients came to the hospital for their follow up at the outpatient department. In this session the patients submitted the self-assessment form of their symptom management behavior that they were asked to monitor while at home. The researcher and the subject would evaluate the information gained together. Had the outcomes did not meet with the expected outcomes set forth in the study the researcher and the subject would undergo further discussion until the subject understood the process correctly. In some cases, the re-training was needed to equip the subjects with the necessary knowledge and skill.

Telephones follow up:

The phone call was again used to evaluate progress of the process of the Symptom Management Program. In the plan of this study the researcher would call each subject one time during this session. However, the subjects were allowed to call the researcher any time if they needed to.

8. When the samples came back to the hospital for the second follow up at one-month after discharged, they were asked to answer the questionnaires about the symptom status and the quality of life.

Protection of the Rights of Human Subjects

The samples in this study had been given the due information concerning this study, threat and benefit without reservation to enable them to make reasonable and sound decisions before giving their approval. The written information declared all the rights the subjects had (see Appendix L, M, and N). The subjects were clearly informed of their rights to terminate the participation at anytime with no consequences at all.

This intervention program presented no harm at all to the subjects, and did not interrupt with the routine nursing care or medical care. It would also make the effective nursing care to encourage the patients' self-symptom management behaviors. Then symptom status would be decreased and quality of life would be increased. Throughout the study process, the researcher would make attempt to avoid any possibility of discomfort, interference, or excessive response burden on the subjects. So the subjects would select the methods to communicate with the researcher during staying home. The data had been collectively analyzed and presented. Information that concerned all private subjects was treated as confidential.

In order to protect the subjects in the control of the right to receive the due cares without discrimination, each subject in this group received the same intervention provided to the experimental group after the posttest evaluation, which was a month after participated in the program.

Data Analysis

The SPSS/PC for window program was used to analyze the data. The following statistics were applied.

1. Descriptive statistics were performed to describe the demographic characteristics of the samples, HIV characteristics and hospitalization characteristic. In order to test the differences in the demographic data, HIV infection and hospitalization data between the subjects in the control and experimental groups, a chi-square test was conducted.

2. Characteristics of data to be analyzed were initially considered to match the appropriate statistical test. In this study, the discrepancy of the unit of measurement was realized. The unit of measurement of the symptom status and quality of life data could be considered either an interval scale or an ordinal scale according to the different perspectives hold from different schools of thought. To maximize its usefulness to the knowledge development, the interval scaling was assumed in collecting the data concerning the symptom status and the quality of life of the subjects. This scaling allowed the researcher to compare and collate the findings from this study to other studies.

3. Consideration of the distribution of the data was the next necessary step to be taken. If the distribution of data was normal the parametric test could be used. The result of Kolmogorov-Smirnov Test showed the normal distribution of the symptom status score and quality of life score of the total samples, the samples in the control and the experimental group at the pretest and posttest phase, parametric test was conducted to examine the differences of these variables (see Appendix J). It was found

that the distributions of the dependent variables in all groups and at both phases were normal. Therefore, parametric test such as t-test or F-test was conducted to examine the differences of the scores of those variables.

4. Paired t-test was conducted to examine the differences of the symptom status and the quality of life mean scores between pretest and posttest of the control and the experimental group.

5. As the result of the pretest symptom status score and quality of life score were not statistically differences between the control group and the experimental group, independent t- test was conducted to examine the differences of these variables. However, if there was difference of the pretest scores of both groups, analysis of covariance (ANCOVA) was considered.



CHAPTER IV

RESEARCH RESULTS

The results of the research findings were presented in two parts. The descriptive analysis of the demographic characteristics of the samples, characteristics regarding HIV infection and data regarding hospitalization of the samples were presented in the first part, followed by the results of hypotheses testing with the description of the dependent variables.

Characteristics of the Samples

1. Demographic characteristics of the samples

Most of the samples in this study were male (55%), were in the age group of 31-40 years (52.5%), married (57.5%), had children (60%), graduated from elementary school (45%), were day laborers (55%), had income of less than 5,000 bath per month (67.5%) and were able to pay for the costs incurred during hospitalization by themselves (45%).

In the control group, the majority of the subjects were also male (60%), were married (65%), had children (70%), were day laborers (70%), and had income of less than 5,000 bath per month (80%). There were the same percentages (45%) of the samples in the age group of 21-30 years and 31-41 years. Half of the subjects in the control group graduated from elementary school (50%), and slightly less than half

control group graduated from elementary school (50%), and slightly less than half paid for the costs incurred during hospitalization by the government health card (45%).

In the experimental group, 50% of the subjects were male, and had children. Most of the subjects were in the age group of 31-40 years (60%), were married (50%), graduated from elementary school (40%), were day laborers (40%), had income of less than 5,000 bath per month (55%) and paid for the costs incurred during hospitalization by themselves (50%).

Chi-square test revealed no statistically significant differences between the control and the experimental group regarding sex, age group, marital status, progeny, education, occupation, income and method of payment of hospital bills (see Table 3).

Table 3 Demographic characteristics of the samples

Characteristics	Control group	Experimental group	Total	χ^2
	Number (%)	Number (%)	Number (%)	
Sex: Female	8 (40)	10 (50)	18 (45)	0.41 ^{ns}
Male	12 (60)	10 (50)	22 (55)	
Age group				
21-30 years	9(45)	6(30)	15(37.5)	1.03 ^{ns}
31-40 years	9(45)	12(60)	21(52.5)	
>41 years	2(10)	2(10)	4(10.0)	
Marital status				
Single	4(20)	4(20)	8(20.0)	1.39 ^{ns}
Married	13(65)	10(50)	23(57.5)	
Divorced/ Separated	3(15)	6(30)	9(22.5)	
Children				
Have children	14(70)	10(50)	24(60)	1.67 ^{ns}
Do not have children	6(30)	10(50)	16(40)	
Education				
Elementary level	10(50)	8(40)	18(45.0)	1.14 ^{ns}
Secondary level	4(20)	5(25)	9(22.5)	
High school	4(20)	3(15)	7(17.5)	
Higher education	2(10)	4(20)	6(15.0)	
Occupation				
Day laborer	14(70)	8(40)	22(55.0)	5.73 ^{ns}
Merchant/farmer	1(5)	3(15)	4(10.0)	
Unemployed	5(25)	6(30)	11(27.5)	
Government employer	0(0)	3(15)	3(7.5)	
Income: < 5,000	16(80)	11(55)	27(67.5)	2.83 ^{ns}
> 5,001	4(20)	9(45)	13(32.5)	
Sources of payment				
Self	8(40)	10(50)	18(45.0)	0.97 ^{ns}
Government health card	9(45)	6(30)	15(37.5)	
Employer support	3(15)	4(20)	7(17.5)	

^{ns} not significant

2 Characteristics related to HIV infection of the samples

The majority of the samples disclosed their HIV blood test results to others (62.5%) and among those who disclosed it, 92% disclosed it to spouses or close friends. 72.5% were old cases of HIV infection, 65% knew about the blood test result for more than 6 months, and 95% received family support. All of the samples were receiving a combination of treatment with conventional therapy.

In the control group, the majority of the subjects disclosed their blood test results (60%) and among those who disclosed it, 91.67% disclosed it to a spouse or close friends. 70% were an old cases of HIV infection, 55% had known about the blood test result for more than 6 months, and 90% received family support. All of them were receiving a combination of treatment with conventional therapy.

A similar pattern of results was found among the subjects in the experimental group. The majority of the subjects had disclosed their blood test results to others (65%) and among those who disclosed it, 92.31% disclosed it to a spouse or close friends. 75% were an old case of HIV infection, and had known about the blood test result for more than 6 months (75%). All of them were received family supported and receiving a combined treatment with conventional therapy.

There were no statistically significant differences between the control and the experimental group in regard to HIV blood test results, case status, length of time of knowing the HIV blood test result, family support, and the combination of treatment with conventional therapy (see Table 4).

Table 4 Characteristics related to HIV infection of the samples

Characteristics related to HIV infection	Control group	Experimental group	Total	χ^2
	Number(%)	Number(%)	Number(%)	
Blood test result				
Not disclosed	8(40)	7(35)	15(37.5)	0.11 ^{ns}
Disclosed to:	12(60)	13(65)	25(62.5)	
Spouse; closed friend	11(91.67)	12(92.31)	23(92)	
Community	1(8.33)	1(7.69)	2(8)	
Case status				
New case of HIV	6(30)	5(25)	11(27.5)	0.13 ^{ns}
Old case of HIV	14(70)	15(75)	29(72.5)	
Length of time of knowing HIV blood test result				
<6 months	9(45)	5(25)	14(35)	1.76 ^{ns}
>6 months	11(55)	15(75)	26(65)	
Family support				
Yes	18(90)	20(100)	38(95)	2.11 ^{ns}
No	2(10)	0(0)	2(5)	
Combination of treatment with conventional therapy				
Yes	20(100)	20(100)	40(100)	0.00 ^{ns}
No	0(0)	0(0)	0(0)	

^{ns} not significant

1.3 Characteristics related to hospitalization

Seventy five percent of the samples were recruited from the in-patient department at the hospital. There were 75% of the subjects from the in-patient department and 25% of the subjects were from the out-patient department who were assigned equally to the control group and the experimental group. Twenty-five percent of the samples were readmitted to the hospital during the first one-month after discharge. 35 % of subjects in the control group were readmitted and 15 % of the subjects in the experimental group were also readmitted.

There were no statistically significant differences between the control and the experimental group with regard to department, and re- hospitalization (see Table 5).

Table 5 Characteristics related to hospitalization of the samples

Characteristics related to hospitalization	Control group	Experimental group	Total	χ^2
	Number(%)	Number(%)	Number(%)	
Department				
IPD	15(75)	15(75)	30(75)	0.00
OPD	5(25)	5(25)	10(25)	
Re-hospitalization				
No	13(65)	17(85)	30(75)	2.13
Yes	7(35)	3(15)	10(25)	
Advanced PCP	6(85.71)	3(100)	9(90)	
Drug allergy	1(14.29)	0(0)	1(10)	

^{ns} not significant

Hypotheses testing and description of the dependent variables

The comparison of the symptom status and the quality of life of the control and the experimental group and the descriptive characteristics of those variables at the pretest and the posttest phase are described below.

1. Comparison of the symptom status and the quality of life in the control group

1.1 Comparison of the symptom status between the pretest and the posttest

In general, the findings revealed that the subjects in the control group had symptom status with the total mean score of 7.20 (SD=3.98) at the pretest phase. There were 2 specific symptom statuses that had a moderate level of severity. They were coughing (mean=1.75, SD=1.02), and the dyspnea or shortness of breath (mean=1.50, SD=1.00), respectively. The symptom that had the lowest mean score of 0.20 (SD=0.41) was nausea or vomiting after drug taking.

At the posttest phase, it was found that the total mean score on symptom

status of the control group was 8.85 (SD=5.53). The findings on the individual items mean scores showed that almost all the mean scores of the specific symptoms in nearly all items had considerably increased except fatigue whose mean score remained the same. The highest mean score by item was concerned with the symptom of coughing (mean=1.85, SD=0.93) followed by the symptom of dyspnea or shortness of breath (mean=1.80, SD=1.01) and the lowest mean score by item was concerned with nausea or vomiting after drug taking (mean=0.55, SD=0.95).

Testing of the statistical differences revealed that the mean scores on symptom status of the control group at the posttest phase was not significantly different than at the pretest phase ($p\text{-value} > 0.05$). However, the mean scores on the symptom of rash or itching after drug taking of the control group at the posttest phase was significantly increase than at the pretest phase ($p\text{-value} < 0.05$) (see Table 6).

Table 6 Comparison of the pretest and the posttest mean scores on the symptom status of the control group

Symptom Status	Pretest		Posttest		t-value
	Mean	SD	Mean	SD	
1. dyspnea or shortness of breath	1.50	1.00	1.80	1.01	-1.10 ^{ns}
2. cough	1.75	1.02	1.85	0.93	-0.42 ^{ns}
3. fever	0.90	1.02	1.15	1.27	-0.87 ^{ns}
4. fatigue	1.35	1.14	1.35	1.27	0.00 ^{ns}
5. loss of appetite	1.05	1.10	1.20	1.20	-0.43 ^{ns}
6. nausea or vomiting after drug taking	0.20	0.41	0.55	0.95	-1.58 ^{ns}
7. rash / itching after drug taking	0.40	0.99	0.95	1.23	-2.07*
Total	7.20	3.98	8.85	5.53	-1.27^{ns}

^{ns} not significant, * $p < 0.05$

1.2 Comparison of the quality of life between the pretest and the posttest phase

Total mean score on quality of life of the subjects in the control group at the pretest and the posttest phases were above average (average = 50) with the mean scores of 66.31 (SD=13.20) and 57.29 (SD=16.87), respectively.

At the pretest phase the mean scores of all specific dimensions were above the average. The highest mean score of 73.35 (SD=15.58) concerned the life satisfaction dimension whereas the lowest mean score of 62.88 (SD=24.75) concerned the emotional/psychological well being dimension. However, the mean score of the emotional/psychological well being dimension at the posttest phase was the highest, and the mean score of the physical/general well-being dimension was the lowest with the mean score of 63.38 (SD=29.98) and 51.83 (SD=19.28), respectively. In addition, the lowest item of mean score was the item concerning dyspnea discomfort in the physical/general well-being dimension with the mean scores of 16.50 (SD=24.98).

In the posttest phase, almost all dimensions mean scores had considerably decrease except the emotional/psychological well being dimension whose mean score had increased. It was found that most of the items mean scores at the posttest phase were lower than at the pretest phase.

Testing of the statistical differences revealed that the posttest total mean score was significantly lower than the pretest total mean score at the level of 0.01. The posttest dimensions mean scores of 4 dimensions were statistically significantly decreased. Those dimensions concerned the physical/general well-being dimension (p-value<0.01); the self-attitude dimension (p-value<0.01); the life satisfaction dimension (p-value<0.05); and lastly, the social interaction dimension (p-value<0.05). Only the

mean score on the emotional/psychological well being dimension had not significantly different between the pretest and the posttest mean scores ($p>0.05$). The posttest mean scores of six items were significantly lower than the pretest mean score at the level of 0.01 (see Table 7).

Table 7 Comparison of the pretest and the posttest mean scores on the quality of life of the control group

Quality of Life	Pretest		Posttest		t-value
	Mean	SD	Mean	SD	
Physical/general well-being dimension	62.25	12.51	51.83	19.28	3.85**
1. Getting enough rest	81.50	21.34	54.00	36.91	3.18**
2. Elimination aspect	75.50	25.85	74.0	36.76	0.19 ^{ns}
3. Functional ability in daily life	85.50	25.23	72.50	34.92	2.80**
4. Eating enough	73.00	26.38	67.00	30.80	1.27 ^{ns}
5. Suffering from illness	41.50	35.73	23.00	32.94	1.93**
6. Dyspnea discomfort	16.50	24.98	20.50	27.04	-0.65 ^{ns}
Social interaction dimension	68.88	18.04	58.63	29.56	1.89*
1. Loneliness	60.00	37.28	55.00	41.61	0.54 ^{ns}
2. Social contact with friends and relations	59.50	43.10	60.00	41.30	-0.04 ^{ns}
3. Participation in normal social functions	80.50	29.11	51.50	43.20	2.79**
4. Caregiver support	75.50	34.26	68.00	39.42	1.05 ^{ns}
Emotional/psychological well-being dimension	62.88	24.75	63.38	29.98	-0.11^{ns}
1. Anxiety	51.50	42.61	59.50	43.95	-1.18 ^{ns}
2. The future	57.50	42.83	56.50	42.83	0.08 ^{ns}
3. Peace of mind	65.00	34.11	67.50	35.08	-0.31 ^{ns}
4. Dreams	77.50	32.26	70.00	41.42	1.05 ^{ns}
Self- Attitude dimension	64.85	19.07	52.30	18.03	3.20**
1. Family love and care	74.00	34.55	75.00	33.80	-0.12 ^{ns}
2. Body image	47.50	40.64	38.50	40.17	1.00 ^{ns}
3. Social discrimination	58.00	38.20	42.00	39.15	1.35 ^{ns}
4. Strong will	87.00	19.49	64.00	32.99	3.32**
5. Health satisfaction	57.75	34.43	42.00	30.02	1.45 ^{ns}
Life satisfaction dimension	73.35	15.58	62.90	17.15	2.32*
1. Hope	72.50	31.93	57.00	35.41	1.67 ^{ns}
2. Self-worth awareness	79.00	29.72	68.00	32.86	1.50 ^{ns}
3. Course of life	52.00	34.48	49.50	33.48	0.25 ^{ns}
4. Life satisfaction	72.50	28.07	49.00	35.38	2.65**
5. Sexual activity	90.75	23.30	91.00	23.60	-0.03 ^{ns}
Total	66.31	13.20	57.29	16.87	3.63**

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

2. Comparison of the symptom status and the quality of life in the experimental group

2.1 Comparison of the symptom status between the pretest and the posttest

In general, the findings revealed that the subjects in the experimental group had symptom status with the total mean scores of 8.05 (SD=4.52) at the pretest phase. There were 2 specific symptom statuses that had a moderate level of severity. They were dyspnea or shortness of breath. (mean=1.90, SD= 0.85), and coughing (mean=1.70, SD=0.92). The symptom that had the lowest mean scores of 0.45 (SD=0.83) was nausea or vomiting after drug taking.

At the posttest phase, the total mean score on symptom status of the experimental group was 5.10 (SD=4.13). All mean scores, by item, of the specific symptoms of the posttest phase had considerably decrease except the symptom of rash or itching, and nausea or vomiting after drug taking. The highest mean score of an item was concerned with the symptom of coughing (mean = 1.15, SD=1.04) followed by the symptom of fatigue (mean = 0.95, SD=0.94) and the lowest item mean score was concerned with fever (mean = 0.30, SD=0.57).

The total mean score on symptom status of the experimental group at the posttest phase was significantly lower than at the pretest phase ($p\text{-value}<0.01$). Additionally, the mean scores on dyspnea or shortness of breath, fever and cough at the posttest phase were statistically significant lower than the mean score of the pretest phase (see Table 8).

Table 8 Comparison of the pretest and the posttest mean scores on the symptom status of the experimental group

Symptom Status	Pretest		Posttest		t-value
	Mean	SD	Mean	SD	
1. dyspnea or shortness of breath	1.90	0.85	0.90	0.91	3.82**
2. cough	1.70	0.92	1.15	1.04	2.34*
3. fever	1.00	0.86	0.30	0.57	2.90**
4. fatigue	1.35	1.18	0.95	0.94	1.51 ^{ns}
5. loss of appetite	1.10	1.25	0.70	0.98	1.51 ^{ns}
6. nausea or vomiting after drug taking	0.45	0.83	0.55	0.94	-0.46 ^{ns}
7. rash / itching after drug taking	0.50	1.10	0.55	1.05	-0.25 ^{ns}
Total	8.05	4.52	5.10	4.13	3.26**

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

2.2 Comparison of the quality of life between the pretest and the posttest

Total mean score on quality of life of the subjects in the experimental group at the pretest and the posttest phases were above average (average = 50) with the mean scores of 60.15 (SD=16.44) and 72.77 (SD=16.03), respectively.

At the pretest phase, the mean scores of all specific dimensions were above the average. The highest mean score of 71.25 (SD=17.37) was concerned with the social interaction dimension whereas the lowest mean score of 52.08 (SD=18.53) was concerned with the physical/general well-being dimension. Similarly, the mean score of the social interaction dimension remained the highest mean score in the posttest phase at 79.00 (SD=16.92) and the mean score of the physical/general well-being dimension was the lowest with a mean score of 69.38 (SD=19.61). In addition, the lowest item of mean score was the item concerning dyspnea discomfort in the physical/general well being dimension with the mean score of 16.25 (SD=23.27).

In the posttest phases, mean scores of all dimensions were increased.

Similarly, mean scores of almost all items were higher than in the pretest phase, except for two items of mean scores, which were decreased. They were a feeling of loneliness in the social interaction dimension and body image in the self-attitude dimension.

Testing of the statistical differences revealed that the posttest total mean score was significantly higher than the pretest total mean scores at the level of 0.01. The mean scores of all posttest dimensions had significantly increase ($p < 0.01$). Two items had significantly higher mean scores ($p < 0.05$) at the posttest when compared with the pretest scores. Also 10 items had significantly higher mean scores ($p < 0.01$) at the posttest when compared with the pretest scores (see Table 9).

Table 9 Comparison of the pretest and the posttest mean scores on the quality of life of the experimental group

Quality of Life	Pretest		Posttest		t-value
	Mean	SD	Mean	SD	
Physical/general well-being dimension	52.08	18.53	69.38	19.61	-4.12**
1. Getting enough rest	63.50	34.07	80.00	20.26	-1.77*
2. Elimination aspect	64.50	37.48	82.00	28.21	-1.55 ^{ns}
3. Functional ability in daily life	67.50	32.42	85.00	26.66	-3.68**
4. Eating enough	70.50	29.11	77.50	24.68	-1.29 ^{ns}
5. Suffering from illness	30.25	35.85	39.50	39.27	-0.93 ^{ns}
6. Dyspnea discomfort	16.25	23.27	52.25	33.89	-4.04**
Social interaction dimension	71.25	17.37	79.00	16.92	-2.35*
1. Loneliness	79.50	25.85	79.00	28.64	0.06 ^{ns}
2. Social contact with friends and relations	64.00	29.81	79.00	19.71	-2.85**
3. Participation in normal social functions	69.50	34.26	76.50	24.77	-0.84 ^{ns}
4. Caregiver support	72.00	28.95	81.50	21.34	-2.45**
Emotional/psychological well-being dimension	58.38	26.76	70.06	22.81	-2.75**
1. Anxiety	51.00	38.10	63.50	33.92	-1.48 ^{ns}
2. The future	56.50	39.64	61.25	37.13	-0.60 ^{ns}
3. Peace of mind	59.00	37.96	75.50	19.59	-2.93**
4. Dreams	67.00	36.15	80.00	31.46	-2.37**
Self- Attitude dimension	61.00	21.74	71.20	18.81	-2.91**
1. Family love and care	80.00	31.12	91.00	15.18	-1.73*
2. Body image	52.00	37.36	44.00	39.12	1.21 ^{ns}
3. Social discrimination	63.00	37.99	75.50	24.38	-1.39 ^{ns}
4. Strong will	74.00	23.71	78.50	21.59	-2.02**
5. Health satisfaction	36.00	35.89	67.00	29.40	-3.50**
Life satisfaction dimension	61.50	19.01	75.60	17.53	-3.31**
1. Hope	57.50	34.62	75.00	22.12	-2.39**
2. Self-worth awareness	66.50	30.31	78.00	22.85	-1.52 ^{ns}
3. Course of life	47.50	32.26	74.50	21.64	-4.19**
4. Life satisfaction	51.50	28.34	56.00	34.40	-0.53 ^{ns}
5. Sexual activity	84.50	27.24	94.50	9.99	-1.51 ^{ns}
Total	60.15	16.44	72.77	16.03	-5.12**

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

3. Comparison of the symptom status and the quality of life at the pretest phase

3.1 Comparison of the symptom status of the control and the experimental group at the pretest phase

The statistical testing of the mean scores on symptom status of the control group and the experimental group at the pretest phase revealed no significantly differences at the level of 0.05 (see Table 10).

Table 10 Comparison of the pretest mean scores on the symptom status between the control group and the experimental group

Symptom Status	Control group		Experimental group		t-value
	Mean	SD	Mean	SD	
1. dyspnea or shortness of breath	1.50	1.00	1.90	0.85	-1.36 ^{ns}
2. cough	1.75	1.02	1.70	0.92	0.16 ^{ns}
3. fever	0.90	1.02	1.00	0.86	-0.34 ^{ns}
4. fatigue	1.35	1.14	1.35	1.18	0.00 ^{ns}
5. loss of appetite	1.05	1.10	1.10	1.25	-0.13 ^{ns}
6. nausea or vomiting after drug taking	0.20	0.41	0.45	0.83	-1.21 ^{ns}
7. rash / itching after drug taking	0.40	0.99	0.50	1.10	-0.30 ^{ns}
Total	7.20	3.98	8.05	4.52	-0.63^{ns}

^{ns} not significant

3.2 Comparison of the quality of life of the control and the experimental group at the pretest phase

There were no statistically significant differences between the total mean score on quality of life of the control group and the experimental group at the pretest phase (p-value >0.05). However, there were two dimensions; the physical well-being dimension, and the life satisfaction dimension, whose mean scores were statistically different at the pretest phase at the level of 0.05. Regarding specific items, it was found that the mean scores of six items of the control group and the experimental group at the

pretest phase were statistically different at the level of 0.05. They were: getting enough rest, functional ability in daily life, a feeling of loneliness, strong will, health satisfaction and life satisfaction (see Table 11).

Table 11 Comparison of the pretest mean scores on the quality of life of the control group and the experimental group

Quality of Life	Control group		Experimental group		t-value
	Mean	SD	Mean	SD	
Physical/general well-being dimension	62.25	12.51	52.08	18.53	2.03*
1. Getting enough rest	81.50	21.34	63.50	34.07	2.00*
2. Elimination aspect	75.50	25.85	64.50	37.48	1.08 ^{ns}
3. Functional ability in daily life	85.50	25.23	67.50	32.42	1.96*
4. Eating enough	73.00	26.38	70.50	29.11	0.29 ^{ns}
5. Suffering from illness	41.50	35.73	30.25	35.85	0.99 ^{ns}
6. Dyspnea discomfort	16.50	24.98	16.25	23.27	0.03 ^{ns}
Social interaction dimension	68.88	8.04	71.25	17.37	-0.42^{ns}
1. Loneliness	60.00	37.28	79.50	25.85	-1.92*
2. Social contact with friends and relations	59.50	43.10	64.00	29.81	-0.38 ^{ns}
3. Participation in normal social functions	80.50	29.11	69.50	34.26	1.09 ^{ns}
4. Caregiver support	75.50	34.26	72.00	28.95	0.35 ^{ns}
Emotional/psychological well-being dimension	62.88	24.75	58.38	26.76	0.55^{ns}
1. Anxiety	51.50	42.61	51.00	38.10	0.40 ^{ns}
2. The future	57.50	42.83	56.50	39.64	0.80 ^{ns}
3. Peace of mind	65.00	34.11	59.00	37.96	0.53 ^{ns}
4. Dreams	77.50	32.26	67.00	36.15	0.97 ^{ns}
Self- Attitude dimension	64.85	19.07	61.00	21.74	0.60^{ns}
1. Family love and care	74.00	34.55	80.00	31.12	-0.58 ^{ns}
2. Body image	47.50	40.64	52.00	37.36	-0.37 ^{ns}
3. Social discrimination	58.00	38.20	63.00	37.99	-0.42 ^{ns}
4. Strong will	87.00	19.49	74.00	23.71	1.89*
5. Health satisfaction	57.75	34.43	36.00	35.89	1.96*
Life satisfaction dimension	73.35	15.58	61.50	19.01	2.16*
1. Hope	72.50	31.93	57.50	34.62	1.42 ^{ns}
2. Self-worth awareness	79.00	29.72	66.50	30.31	1.32 ^{ns}
3. Course of life	52.00	34.48	47.50	32.26	0.42 ^{ns}
4. Life satisfaction	72.50	28.07	51.50	28.34	2.35*
5. Sexual activity	90.75	23.30	84.50	27.24	0.78 ^{ns}
Total	66.31	13.20	60.15	16.44	1.31^{ns}

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

4. Comparison of the symptom status and the quality of life at the posttest phase

4.1 Comparison of the symptom status of the control and the experimental group at the posttest phase

It was found that the mean score on symptom status at the posttest phase of the control group was 8.85 (SD=5.53), while that of the experimental group was 5.10 (SD=4.13). The posttest total mean score on symptom status of the experimental group was significantly lower than that of the control group (p -value<0.01). There were three items of symptom status of the experimental group that mean scores were significantly lower than that of the control group at the levels of 0.05 and 0.01. They were coughing (p -value <0.05), dyspnea or shortness of breath, and fever (p -value<0.01) (see Table 12).

Table12 Comparison of the posttest mean scores on the symptom status of the control and the experimental group

Symptom status	Control group		Experimental group		t-value
	Mean	SD	Mean	SD	
1. dyspnea or shortness of breath	1.80	1.01	0.90	0.91	2.97**
2. cough	1.85	0.93	1.15	1.04	2.24*
3. fever	1.15	1.27	0.30	0.57	2.73**
4. fatigue	1.35	1.27	0.95	0.94	1.13 ^{ns}
5. loss of appetite	1.20	1.20	0.70	0.98	1.45 ^{ns}
6. nausea or vomiting after drug taking	0.55	0.95	0.55	0.95	0.00 ^{ns}
7. rash / itching after drug taking	0.95	1.23	0.55	1.05	1.10 ^{ns}
Total	8.85	5.53	5.10	4.13	2.43**

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

4.2 Comparison of the quality of life of the control and the experimental group at the posttest phase

The total mean score on quality of life at the posttest phase of the control group was 57.29 (SD=16.87), while that of the experimental group was 72.77 (SD=16.03). The total mean scores on quality of life of the experimental group was statistically significantly higher than that of the control group (p -value <0.01).

To test the statistical differences of the mean scores by dimension and the mean scores by item in each dimension, the t-test and analysis of co-variance f-test were used. It was found that all mean scores of dimension, except the emotional/psychological well-being dimension of both groups had statistical differences at the significant levels of 0.05 and 0.01. The result of t-test analysis on the social interaction dimension (p -value<0.05) and self-attitude dimension (p -value<0.01) revealed that the dimensional mean scores of the experimental group were significantly higher than those of the control group. The result of the analysis of co-variance f-test on the physical/general well being dimension (p -value<0.01) and life satisfaction dimension (p -value<0.01) revealed that the dimensional mean scores of the experimental group were significantly higher than those of the control group. Details of the ANCOVA F-test are presented in Appendix K in Table 14 and Table 15, respectively.

Regarding the item analysis of individual items, the analysis of co-variance f-test was applied to the six items where the mean score of the control group and the experimental group were statistically significantly different at the pretest phase. The t-test was used to analyze the other items that did not have significant differences. The

result of the t-test analysis of 18 items where their pretest mean scores were not statistically significantly different revealed that in 7 items the mean scores of the experimental group were significantly higher than the mean scores of the control group at the level of 0.05 and 0.01. The result of the analysis of co-variance F-test on mean scores of individual items revealed that in six items the mean scores of the experimental group were statistically higher than those of the control group at the significant level of 0.01(see Table 13). Details of the ANCOVA F-test are presented in Appendix K in Table 16, 17, 18, 19, 20, and 21.

Table 13 Comparison of the posttest mean scores on the quality of life of the control group and the experimental group

Quality of Life	Control group		Experimental group		t-value
	Mean	SD	Mean	SD	
Physical/general well-being dimension	48.42^a	16.78	71.32^a	16.97	240.71^{b**}
1. Getting enough rest	46.68 ^a	36.91	70.67 ^a	20.26	46.54 ^{b**}
2. Elimination aspect	74.00	36.76	82.00	28.21	-0.77 ^{ns}
3. Functional ability in daily life	66.45 ^a	34.92	87.59 ^a	26.66	237.18 ^{b**}
4. Eating enough	67.00	30.80	77.50	24.68	-1.19 ^{ns}
5. Suffering from illness	23.00	32.94	39.50	39.27	-1.44 ^{ns}
6. Dyspnea discomfort	20.50	27.04	52.25	33.89	-3.28 ^{**}
Social interaction dimension	58.63	29.56	79.00	16.92	-2.68[*]
1. Loneliness	56.28 ^a	41.61	64.03 ^a	28.64	65.62 ^{b**}
2. Social contact with friends and relations	60.00	41.30	79.00	19.71	-1.86 [*]
3. Participation in normal social functions	51.50	43.20	76.50	24.77	-2.25 [*]
4. Caregiver support	68.00	39.42	81.50	21.34	-1.35 ^{ns}
Emotional/psychological well-being dimension	63.38	29.98	70.06	22.81	-0.79^{ns}
1. Anxiety	59.50	43.95	63.50	33.92	-0.32 ^{ns}
2. The future	56.50	42.83	61.25	37.13	-0.38 ^{ns}
3. Peace of mind	67.50	35.08	75.50	19.59	-0.89 ^{ns}
4. Dreams	70.00	41.42	80.00	31.46	-0.86 ^{ns}
Self- Attitude dimension	52.30	18.03	71.20	18.81	-3.24^{**}
1. Family love and care	75.00	33.80	91.00	15.18	-1.93 [*]
2. Body image	38.50	40.17	44.00	39.12	-0.44 ^{ns}
3. Social discrimination	42.00	39.15	75.50	24.38	-3.25 ^{**}
4. Strong will	58.98 ^a	32.99	83.71 ^a	21.59	208.83 ^{b**}
5. Health satisfaction	24.09 ^a	30.02	50.04 ^a	29.40	19.83 ^{b**}
Life satisfaction dimension	56.20^a	21.68	78.37^a	21.12	232.90^{b**}
1. Hope	57.00	35.41	75.00	22.12	-1.93 [*]
2. Self-worth awareness	68.00	32.86	78.00	22.85	-1.12 ^{ns}
3. Course of life	49.50	33.48	74.50	21.64	-2.81 ^{**}
4. Life satisfaction	38.98 ^a	35.38	56.92 ^a	34.40	38.39 ^{b**}
5. Sexual activity	91.00	23.60	94.50	9.99	-0.63 ^{ns}
Total	57.29	16.87	72.77	16.03	-2.97^{**}

^a = adjusted mean score from the mean score at the pretreatment period of each item

^b = f-value from the analysis of covariance

^{ns} not significant, * = $p < 0.05$, ** = $p < 0.01$

CHAPTER V

DISCUSSION

The purpose of this study was to evaluate the effectiveness of a Symptom Management Program on symptom status and quality of life among persons with PCP. Results of the study and lesson learned from this study were discussed in 2 parts: 1) the effectiveness of a Symptom Management Program, and 2) the contribution to nursing science.

Effectiveness of a Symptom Management Program

This Symptom Management Program was developed from the Symptom Management Model (Larson, et al., 1994) and the Self-management concept (Tolbin, et al., 1986) as a framework to facilitate the self symptom management of the PCP patients. The program was designed to empower the patient to gain the ability to control the PCP symptoms especially dyspnea and coughing, which were the most serious problems. The salient findings from the results of the program were as follow.

1. The patient-based nursing intervention of the program did facilitate the empowerment process in accordance with the individual problems and needs which increase the patient's self-ability.

The patient-based approach used in this program provided the nursing care that evolved around the context of each patient, which was different from the routine cares currently provided in most clinics. This care was mostly disease-oriented and

emphasized the collective symptoms of the diseases while individual problems were neglected. On the contrary, the individual problems and needs of patients who received the program were recognized from the patient's perspective and ability. Assessment of problems, needs, ability to manage the symptom and setting of the self-management goal were mutually conducted between the patient and the nurse. Through this mutual process the patient was empowered and able to efficiently care for his/her symptom. The self-ability gained from participating in this Program should be sustained when returning home.

2. The knowledge concerning self-care management from the actual experience of AIDS patient depicted in the video, and the self-symptom management for the PCP patients provided the correct perception of the PCP symptoms and increased the patient's self-symptom management ability.

Innovative approaches provided in the program emphasized the pattern and consistency of the learning process through the instructional media and manual. Each patient correctly perceived the PCP symptom as curable and preventable from the simulation provided in the videotape. The videotape allowed the patient to review the demonstration and repeat it as many times as needed. The acquired knowledge and self-ability increased the patient's self-confidence and will to fraternally live with the disease while at home. Miller (1992: 399) insisted that gaining self-ability empowered a person to be active, have more learning ability, feel less dependent and more independent, be able to efficiently communicate, and have positive self control and self worth"

3. The Self-symptom Management Program increased the self-monitoring ability of the patients.

Daily monitoring of the symptom status could sustain a desired behavior, and thus inspire and encourage the subjects to continue practicing self-symptom management behaviors.

4. Telephone follow up is needed to effectively continuity of care and support at home.

A Self-symptom Management Program provides continuity care and support from the hospital to patient's home via the telephone. This proved to be an effective continuous distant care method especially for the patients who disclosed HIV blood test results. The mutual evaluation of the symptoms between nurses and patients facilitated instant control of the PCP according to its actual problems and needs, and proved to be an effective intervention. This process was a positive reinforcement from the nurse that increased the self-symptom management motivation of the patient.

In accordance with the foregoing four advantages, the patient-centered framework of the program to improve the self-symptom management ability of the PCP patient was substantiated. When the physical sickness was subdued, the quality of life was likely to increase.

A comparison between the severity of the symptoms and the perceived quality of life at one month after discharge of the experimental and the control group revealed that the severity of the symptoms of the control group was increasing and the perceived quality of life decreasing. This implied that the routine care provided might be insufficient to reduce the symptoms and increase the quality of life of the patients. The

data from follow-up records revealed that some patients turned to herbal medicine instead of using modern medicine. This practice was different from the practice of those in the experimental group. The program provided continuous interaction between the patient and the nurse and led to sustainable care. The finding from AIDS Division (1997 in W, Poolcharoen, et al (Eds.), 1999: 652) revealed that home visits provided to AIDS patients could improve the quality of life of the patients after participating in the program.

The findings from this study are congruent with Larson, et al (1994: 274) who stated “ The purpose of the symptom management strategy is to control the symptom status and quality of life, which are components of the symptom outcomes”. Besides, this Model could be applied to manage other chronic diseases such as hypertension (Chukumnerd, P. 1999) asthma (Duangjai, P. 1999) and peptic ulcers (Inthisang, S. 1999). The findings from these three studies were congruent to the findings in this study in that the patients with hypertension, asthma, and peptic ulcer who participated in the collaborative symptom management between the patient and nurse while at home could control and decrease their life disturbance, and increase their satisfaction and perception of health.

It can be concluded that increasing the patient's quality of life should take into consideration the ability to reduce the severity of the symptom. The findings in this study supported the findings of Watchel, et al (1992); Ganz, et al (1993) and Holzemer, et al (1998) where there were the negative relationships between symptoms and the quality of life of the AIDS patient. The findings suggested the importance of the symptom status to the perceived quality of life of the patients.

However, a Symptom Management Program could not reduce the loneliness of the experimental group due to the individual orientation based of the program, and the most patients who participated in the program did not want others to know about their symptoms. The non-disclosure of HIV blood test result prevented the patient from seeking comforting from the others. A similar reason accounted for the non-involvement of the family in this program. Although, the researcher concerned that the self-help group had a positive impact to the social interaction dimension of quality of life but this activity could not be included in the intervention because of patients' non-disclosure. The finding of loneliness was controversy to the study of Nantachaipan (1996) in that the community-based nursing intervention, which included home visits and family support, could reduce the loneliness of the AIDS patients after participating in the self-care program.

Nevertheless, the findings in the present study revealed that the experimental group had a lesser degree of loneliness than those in the control group. This may be due to the fact that the patients in the experimental group had the researcher whom they could turn to if they need for companionship or information had arisen. Telephoning was proven to be an effective distant care method in this study. Sangchat (1997) suggested that this strategy worked better for the AIDS patient who did not want to disclose themselves to the public. In addition, follow-up care provided by the researcher might establish the rapport and the secure feeling that they still have someone who care for them. This feeling had never happened among the control group. This affiliation helped to retain the number of the subjects in the experimental group at the one-month follow up compared to the 16.5% dropouts that occurred in

the control group. Likewise, this program enabled the patients to keep track of their treatment.

Although a Symptom Management Program did increase the perceived quality of life of PCP patients, this increase was not in optimal level as had been expected. There were various factors that influenced the quality of life of the patient such as of the state of the symptom: social support, disclosure of the blood result, and availability of the self-help group that could provide support for each member. The fact that this study was conducted among patients in the AIDS stage, which usually had the lowest quality of life and individual care provision, explained the failure to increase the optimum quality of life among the subjects. The use of family support was limited, as many patients did not want to disclose their diagnosis to the family. Being afflicted with AIDS disease was considered a fatal and communicable disease that was not well accepted in society. People in society still have a negative attitude towards AIDS patients. Unlike the AIDS patient, the patient with cancer received more empathy and social support from others. If family and social support could be incorporated into the program, the quality of life of the AIDS patients could be improved to the optimal level.

In summary, the Symptom Management Program does decrease the symptom status and improve the quality of life among the persons with PCP.

Contribution to Nursing Science

The Symptom Management Program for persons with PCP provided in this study generates a prescriptive theory, which is essential in nursing practice. The proven hypotheses ascertain the effectiveness of intervention provided in the program to improve the symptom status and the quality of life of persons with PCP. In addition, steps of promoting self-symptom management ability designed in the manual program were useful for nursing intervention.

Moreover, this research study can be considered as testing or modifying the Symptom Management Model. In order to deduce theory, three dimensions in the Model of Symptom Management were modified and operative. First, the symptom experience dimension was defined in the symptom perception, symptom evaluation, and symptom response in the context of PCP patients. Symptom management strategy to relieve the PCP symptoms was modified by incorporating the self-management concept of Tolbin, et al (1986). Finally, the symptom outcomes had been equated with the symptom status, and the quality of life in this study.

This study developed the hypotheses under the deductive system to test the proposition posited in the Symptom Management Model (Larson, et al., 1994: 274) that “the symptom management strategies is aim to avert or delay a negative outcome and control the symptom experience through biomedical, professional, and self-care strategies”. The results of the study revealed that persons with PCP who received a Symptom Management Program could relieve the symptom status and improve the quality of life. Therefore, the model was tested in the specific situation of PCP patient.

The program in this study developed four strategies for the nurse to improve the patient's self-symptom management activities. These strategies are 1) enhancing the self-ability, 2) providing the symptom management knowledge and training, 3) using the self-monitoring to sustain self-symptom management activities, and 4) using the distance care to provide continuity of care and support. These strategies required further study to strengthen their substances in the nursing concept.

This empirically substantiated the Symptom Management Model. The findings suggested that the self-symptom management strategy could be applied to other opportunistic disease in AIDS, which lead to respiratory problems such as tuberculosis, or pneumonia, or bronchitis.

In summary, in the area of adult nursing science, the self-symptom management is an essential concept that nurse should be acquired to facilitate the patients' self-symptom management ability. Promoting better symptom status and quality of life is the important role and responsibility of a professional nurse.

CHAPTER VI

CONCLUSION

The conclusion of this study is presented in three parts as follows: 1) summary of the study, 2) implications and recommendation, and 3) limitation of the study.

Summary of the Study

This experimental research aimed to test the effectiveness of a Symptom Management Program among persons with PCP. The specific objectives of the study are;

1. To examine the differences in the symptom status and the quality of life of persons with PCP before and after receiving a Symptom Management Program.
2. To examine the differences in the symptom status and the quality of life between persons with PCP who received a Symptom Management Program in addition to routine care with those who received only routine care.

The sample included 40 men and women at Nakhon Pathom Hospital who were afflicted with PCP and were randomly assigned to an experimental group and a control group. The number of each group were 20, in order to 15 persons of each group were recruited from in-patient department and 5 persons were from out patient department.

The control group received only routine care while the experimental group received routine nursing care with a Symptom Management Program. A Symptom

were comprised of four phases included: 1) problem assessment and needs identification, 2) preparation for symptom management, 3) practice for symptom management, and 4) evaluation for symptom management phase. These phases, which covered three sessions, were applied throughout the experiment group within one month in each subject by the researcher.

Four sets of questionnaires were used to collect the data. They were 1) Health profile questionnaire, 2) Symptom status questionnaire, 3) Quality of life questionnaire, and 4) Self-symptom management behavior assessment form. Six experts validated the questionnaires and manual booklets. The five experts validated the videotape on PCP Symptom Management. Cronbach's alpha on the total quality of life questionnaire using 40 samples in this study was 0.84 and its reliability of the physical / general well-being dimension, social interaction dimension, emotional / psychological well-being dimension, self-attitude dimension, and life satisfaction dimension were 0.85, 0.82, 0.83, 0.84, and 0.89, respectively.

Data collection consisted of two phases: pre and posttest at one month. In pretest phase, the research assistant interviewed all samples using two questionnaires of symptom status and quality of life. In the posttest phase, all samples answered those two questionnaires by themselves.

Descriptive statistic was used to analyze demographic data. The chi-square testing and t-test were used to test the differences of the all variables in two groups and t-test was applied to test the research hypotheses.

The findings could be summarized into two parts:

1. Characteristics of the samples:

Most of the samples in this study were male (55%), were in the age group of 31–40 years (52.5%), married (57.5%), had children (60%), graduated from elementary school (45%), were day laborers (55%), had income of less than 5,000 bath per month (67.5%) and were able to pay for the costs incurred during hospitalization by themselves (45%). The majority of the samples disclosed their HIV blood test results to others (62.5%) and among those who disclosed it, 92% disclosed it to spouses or close friends. 72.5% were old cases of HIV infection, 65% knew about the blood test result for more than 6 months, and 95% received family support. All of the samples were receiving a combination of treatment with conventional therapy.

2. Results of the hypotheses testing: the results supported the hypotheses as follows:

2.1 The mean score on symptom status of the experimental group at the posttest phase (mean = 5.10, SD = 4.13) was significantly lower than at the pretest phase (mean = 8.05, SD = 4.52) (t -value = -3.26, p -value < 0.01).

2.2 The mean score on quality of life of the experimental group at the posttest phase (mean = 72.77, SD = 16.03) was significantly higher than at the pretest phase (mean = 60.15, SD = 16.44) (t -value = 5.12, p -value < 0.01).

2.3 The mean score on symptom status of the control group at the posttest phase (mean = 8.85, SD = 5.53) was not significantly different from the pretest phase (mean = 7.20, SD = 3.98) (t -value = 1.27, p -value > 0.05).



2.4 The mean score on quality of life of the control group at the posttest phase (mean = 57.29, SD = 16.87) was significantly lower than at the pretest phase (mean = 66.31, SD = 13.20) (t-value = -3.63, p-value<0.01).

2.5 The posttest mean score on symptom status of the experimental group (mean = 5.10, SD = 4.13) was significantly lower than that of the control group (mean = 8.85, SD = 5.53) (t-value = -2.43, p-value<0.01).

2.6 The posttest mean score of quality of life of the experimental group (mean = 72.77, SD = 16.03) was significantly higher than that of the control group (mean = 57.29, SD = 16.87) (t-value = 2.97, p-value<0.01).

It was concluded that the Symptom Management Program could decrease the symptom status and improve the quality of life among persons with PCP.

Implication and Recommendations

1. Implication and Application of Research Findings

Four aspects: 1) the program, 2) the nursing system, 3) the patient, and 4) the setting context must be considered if the program is to be implemented in nursing practice.

1.1 The Program: This nursing intervention, a Symptom Management Program, provides a holistic and patient-based continuous care to promote the patient's self-symptom management ability. Effective use of the program depends on the nurse's understanding of its contents and technology as follow.

1.1.1 Contents: The target group for this program is the PCP patient whose major problematic symptom is the respiratory system. The patient-based

perspective of this program emphasizes on the dynamic process of intervention. Strategies to be used, thus would depend upon specific problems and needs of individual patient.

1.1.2 Technology: Two sets of manual and videotape used to improve the self-symptom management ability of persons with PCP maximized the effectiveness of the Program.

1) The Manual of PCP Symptom Management Program for the nurse and the Self-Symptom Management Manual for persons with PCP provide the new strategic intervention that have been proven for their effectiveness. The easy-to-use and handy nurse's manual provides the steps to improve self-symptom management supplemented by the comprehensive information on the PCP and PCP symptom management. The self-symptom management manual was carefully designed to encourage the patient to freely study and follow. It also contains the comprehensive information that the PCP patients should ever need.

2) The videotape on PCP Symptom Management is the nursing media that facilitate the patients' training in order to improve their self-symptom management skills. It provides informative and consistency demonstration that the viewer can easily follow and use. In addition, the videotape on experiences of AIDS patients provides information about abilities that AIDS patients act to self-care themselves in the real situation. These videotapes are the useful media that extend nurse ability and allow nurse to effectively deliver care to patient.

1.2 Nursing system: The nursing system, which is the nursing context and the professional nurse, must be taken into consideration while implementing this program.

1.2.1 The Self-care Management Center for patients with chronic illness and HIV/AIDS must be established in the hospital to improve quality of nursing care. The cares provided should concentrate on developing the patients' self-symptom management ability that can increase their quality of life.

1.2.2 The professional nurse should be extensively trained to increase their expertise to be a Nurse Specialist in delivery care of chronic illness and HIV/AIDS in particular. Expertise of the nurse is a key factor to maintain the effectiveness and sustainability of the Program.

1.3 Patients: Patients' co-ordination is also an essential factor in this program. Preparation of the patients entails providing information concerning the advantages and disadvantages of the program to the patients. Willingness to participate in the program is the best motivation for the patients to responsive do the symptom management ability by themselves at home. Quality of the practices cannot be achieved if the patients cannot discipline themselves to act accordingly as designed. The patients' human rights must be honored. Patients' information and records must be treated as highly confidence and by no means should be publicized to humiliate its owner. Bringing-in the family supports in some cases must be handle with great care and consideration for its negative effect that may or may not occur.

1.4 Setting context: This program was developed and tested with persons with PCP who only disclosed their blood test results to their couples or closed friends

but not to family or society. In addition, it was conducted in the setting that no self-help group of HIV/AIDS patients is available. Individualized patient-based nursing intervention is cost and time consuming despite its effectiveness of care provided. Group care needs fewer resources but could not be implemented in the patients who did not disclose themselves to society. Privacy should be emphasized while delivering cares either to group or individual. It is utmost important to conduct this Program in private room to honor the patients' rights to keep their secrets from those who do not deserve the rights to know.

2. Recommendation to Further Research

2.1 The symptom management program that can be appropriately applied in the patients with different symptoms besides the respiratory symptoms that mostly occur in the PCP patients such as the symptom of fatigue, loss of appetite, etc should be created. Since the program provided the patients only the surface knowledge to deal with those symptoms and left only ample time for practicing, therefore, further study should include more detail about these symptoms and as well as allow enough time for practices to improve the quality of life of the patients to be in the optimal level.

2.2 This finding indicated that the program could improve the quality of life among persons with PCP but the sustainability of the level of quality of life had not been proven in the present study. Therefore, longitudinal study is needed to establish sustainable interventions.

2.3 During the data-gathering period, it was observe that cares provided to the dying patients were not appropriate due to the inability of the nurse or the caregiver. Care for the dying patient is sensitive and needs special attention. Unable to

provide appropriate care to the dying patients suggested that there is a need to educate and re-train the nurse in this special ward. This is an important issue in nursing as little research deals with the end of life intervention. Buddhism view of death and dying could be of great use to guide the future research.

Limitation of the study

The quality of life would be best summarized when the comprehensive data gained during the long period of time were analyzed. The quality of life derived from this study which was conducted within only a month would be too limited and could reflect only the state phenomenon not the trait phenomenon of the quality of life. Reference to this finding must be done with careful consideration.

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APPENDIX A

List of experts:

- Symptom status of PCP questionnaire,
 - Self Symptom Management Manual Booklet for persons with PCP
 - Manual of PCP Symptom Management Program
-

รายนามผู้ทรงคุณวุฒิ เกี่ยวกับแบบประเมินอาการ เนื้อหาโรคปอดอักเสบจากเชื้อราฟิซีที และ
โปรแกรมการจัดการกับอาการปอดอักเสบ

1. รศ. นพ. เกียรติ รักรุ่งธรรม
คณะแพทยศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย
2. ผศ. ดร. กรองกาญจน์ สังคาส
คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล
3. ดร. พิกุล นันทชัยพันธ์
คณะพยาบาลศาสตร์ มหาวิทยาลัยเชียงใหม่
4. รศ. ดร. พวงเพ็ญ ชูณหปราณ
คณะพยาบาลศาสตร์ จุฬาลงกรณ์มหาวิทยาลัย
5. นางสาว วาณี คัมมาตย์
หัวหน้าหอผู้ป่วยอายุรกรรมชาย โรงพยาบาลรามาริบดี
6. พญ. อรพินท์ คำขาว
แพทย์ผู้รับผิดชอบผู้ป่วยเอชไอวี ประจำคลินิกตามนัด โรงพยาบาลศูนย์
นครปฐม

APPENDIX B

List of experts:

Videotape on PCP Symptom Management

รายนามผู้ทรงคุณวุฒิ ด้านสื่อวิดีโอ

1. ผศ. ดร. กรองกาญจน์ สังกาศ
คณะพยาบาลศาสตร์ มหาวิทยาลัยมหิดล
2. ดร. จันทิมา เขียวแก้ว
คณะนิเทศศาสตร์ มหาวิทยาลัยหอการค้า
3. ผศ. ดร. ภารดี นานาสีลปี
คณะพยาบาลศาสตร์ มหาวิทยาลัยขอนแก่น
4. ดร. รัตนาภรณ์ ประวิติวัชร
คณะมนุษยศาสตร์ มหาวิทยาลัยหอการค้า
5. ดร. สุเทพ หุ่นสวัสดิ์
ผู้อำนวยการวิทยาลัยเทคนิคอุทัยธานี

APPENDIX C

Manual of PCP Symptom Management Program

Contents

ปัญหา

ปรัชญา

โปรแกรมการจัดการกับอาการ

Phase I Needs Assessment and Problem Identification Phase

หลักการ

วัตถุประสงค์

กิจกรรม

การประเมินผล

ระยะเวลา

Phase II Preparation for Symptom Management Phase

หลักการ

วัตถุประสงค์

กิจกรรม

การประเมินผล

ระยะเวลา

Phase III Practice for Symptom Management Phase

หลักการ

วัตถุประสงค์

กิจกรรม

การประเมินผล

ระยะเวลา

Phase IV Evaluation Phase

หลักการ

วัตถุประสงค์

กิจกรรม

การประเมินผล

ระยะเวลา

รายละเอียดเนื้อหาเกี่ยวกับปอดอักเสบและการจัดการ -เอกสารชุด ก-เอกสารชุด ฉ

เอกสารชุด ก

1.ความสัมพันธ์กาย-จิต

เอกสารชุด ข(ข้อ1-4)

2.ความรู้เกี่ยวกับโรคปอดอักเสบและเอดส์

เอกสารชุด ข (ข้อ5-13)

3.ความรู้เกี่ยวกับการจัดการกับอาการปอดอักเสบ

เอกสารชุด ข (ข้อ14)

4.ทักษะในการสังเกต วิเคราะห์และแก้ไขอาการผิดปกติ

เอกสารชุด ค-ฉ

5.ทักษะในการจัดการกับอาการเฉพาะ 8 ทักษะ

APPENDIX D

Self-Symptom Management Manual Booklet for persons with PCP

ประกอบด้วยเนื้อหาเกี่ยวกับ

- ความรู้เรื่องปอดอักเสบ
- การดูแลตนเองในการจัดการกับอาการปอดอักเสบ

APPENDIX E

Script of videotape on PCP Symptom Management

ภาพ ที่	ภาพ	เสียง
1	-ภาพวิว	เสียงเพลงที่เร้าใจ
2	-Caption 1 :หัวข้อเรื่อง “การจัดการกับ อาการปอดอักเสบด้วยตนเอง” (-background เป็นภาพวิว แสงให้นาน 15 วินาที)	“การจัดการกับอาการปอดอักเสบด้วยตนเอง”
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.		
.		
.		
.		
.		
.		
.		
100	ภาพดอกไม้	เสียงเพลงเบาๆ
101	-Caption 18..... ผลิตโดย ผ.ศ. สุวีพร ธนศิลป์	

APPENDIX F

HEALTH PROFILE QUESTIONNAIRE (HP-Q)

ผู้ป่วยหมายเลข.....

1) ประวัติส่วนบุคคล

ชื่อ.....นามสกุล.....HN.....
สถานที่ที่ติดต่อได้สะดวก บ้านเลขที่..... ถนน.....ตำบล.....
อำเภอ..... จังหวัด..... โทรศัพท์.....

อายุ (ปี) ☐ 15-20 ☐ 21-30 ☐ 31-40 ☐ 41-50 ☐ 51-60 ☐ > 61
เพศ ☐ หญิง ☐ ชาย

สำหรับผู้วิจัย

2) ประวัติการเจ็บป่วยและการรักษาภายหลังการติดเชื้อ

การเจ็บป่วยในอดีต.....
.....
.....

*****ตัวอย่างในกลุ่มควบคุมตามเฉพาะหน้า 1 และ หน้า 2 เท่านั้น

3) การรับรู้เกี่ยวกับอาการและการจัดการกับอาการ.....

4)สรุปปัญหาก่อนกลับบ้าน.....

5) การติดตามผู้ป่วยขณะมาตรวจตามนัดที่คลินิกผู้ป่วยนอกและขณะอยู่บ้าน

APPENDIX G

PCP-Symptom Status Questionnaire (PCP-SS-Q)

ให้ท่านทำเครื่องหมาย ✓ ในช่องที่ท่านรับรู้ถึงความรุนแรงของอาการที่เกิดขึ้นกับท่าน

ในขณะนี้ท่านมีอาการใดบ้าง และอาการดังกล่าวมีความรุนแรงมากน้อยเพียงใด

อาการ	ไม่มี	มี		
		ความรุนแรง		
		น้อย	ปานกลาง	มาก
1. หายใจเหนื่อยหอบ/ไม่อึด				
.				
.				
.				
.				
.				
7. ผื่น/คัน ภายหลังรับประทานยา				

APPENDIX H

PCP-quality of life questionnaire

แบบวัดคุณภาพชีวิตของผู้ที่มีปอดอักเสบ

1. ท่านมีความรู้สึกโดดเดี่ยวอย่างไร ที่พึ่งพา มากน้อยเพียงใด?

0 10 20 30 40 50 60 70 80 90 100

|-----|

ไม่รู้สึกเช่นนั้นเลย รู้สึกมากที่สุด

2. ท่านมีความวิตกกังวลเกี่ยวกับตนเอง มากน้อยเพียงใด?

0 10 20 30 40 50 60 70 80 90 100

ไม่มีความวิตกกังวลเลย วิตกกังวลมากที่สุด

.....

.....

.....

.....

24. ท่านมีความพึงพอใจในสุขภาพของท่านขณะนี้มากน้อยเพียงใด?

0 10 20 30 40 50 60 70 80 90 100

ไม่พึงพอใจเลย พึงพอใจมากที่สุด

APPENDIX I

Self-assessment of symptom management form

ประกอบด้วย 3 ส่วน

ส่วนที่ 1 แบบวัดพฤติกรรมการควบคุมอาการโดยทั่วไป

ข้อความ	วันที่.....						วันที่.....	
	ทำ	ไม่ทำ	ทำ	ไม่ทำ	ทำ	ไม่ทำ	ทำ	ไม่ทำ
1.ฉันตรวจนับการหายใจ								
2.ฉันจับชีพจร								
.....								
.....								
.....								
6. ฉันรับประทานยาอย่างต่อเนื่องและสม่ำเสมอ								

ส่วนที่ 2 แบบวัดความรู้สึของผู้ป่วยเกี่ยวกับอาการของโรค

ข้อความ	วันที่.....		วันที่.....		วันที่.....		วันที่.....	
	มี	ไม่มี	มี	ไม่มี	มี	ไม่มี	มี	ไม่มี
1.ฉันมีอาการหายใจหอบเหนื่อย								
2.ฉันมีอาการไอ								
.....								
.....								
.....								
.....								
7.ฉันคลื่นไส้ อาเจียน มากขึ้น								

ส่วนที่ 3 แบบวัดพฤติกรรมการลดอาการ เฉพาะอาการที่เกิดขึ้นจริง

การจัดการ	วันที่		วันที่.....		วันที่.....	
	ทำ	ไม่ทำ	ทำ	ไม่ทำ	ทำ	ไม่ทำ
เมื่อนั้นเกิดอาการหายใจเหนื่อยหอบ						
1.ฉันเตือนตัวเองให้ทำจิตใจให้สงบเชือกเส้น						
.....						
.....						
เมื่อก่อนอาการไอ						
1.ฉันจิบน้ำอุ่น ๆ หรืออมขอม เพื่อให้หายไอ						
.....						
เมื่อก่อนอาการไข้						
1.ฉันจะทานยาลดไข้ 2 เม็ด						
.....						
.....						
เมื่อก่อนอาการแพ้ยา						
1.ฉันจะหยุดยาทันที						
.....						

เมื่อตอบถึงวันที่..... โปรดนำติดตัวมาโรงพยาบาลเพื่อส่งคืนด้วยคะ

ขอบคุณมากคะ

APPENDIX J

The Kolmogorov-Smirnov Z test

The distribution of symptom status variable which at the pretreatment period and at the one-month after discharge period of the whole group (Kolmogorov-Smirnov $Z = 0.76$, $p = 0.61$; Kolmogorov-Smirnov $Z = 0.94$, $p = 0.34$), the control group (Kolmogorov-Smirnov $Z = 0.55$, $p = 0.93$; Kolmogorov-Smirnov $Z = 0.62$, $p = 0.83$) and the experimental group (Kolmogorov-Smirnov $Z = 0.54$, $p = 0.93$; Kolmogorov-Smirnov $Z = 0.92$, $p = 0.37$) were normal. So these variables could be analyzed by the parametric test such as the t-test or the f-test.

APPENDIX K

Analysis by ANCOVA F-test

2 dimensions and 6 items posttest mean scores of quality of life of the control and experimental group that had statistically significant differences of the pretest mean score were analyzed by ANCOVA F-test. There were

Table 14 A comparison of the posttest dimension mean scores on the physical/general well-being dimension (d1) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * pred1	152,337.31 ^A	76,168.66	2	240.71**
Error	12,024.50	316.43	38	
Total	164,361.81		40	

(A = R Squared of the model = 0.92; pred1= pretest mean score of d1 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	51.83	48.42 ^a
Experimental group	69.38	71.32 ^a

(^a = evaluated at covariates appeared in the model: pred1 = 57.17)

Table15 A comparison of the posttest dimension mean scores on the life satisfaction dimension (d2) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * pred2	189,407.91 ^A	94,703.95	2	232.90**
Error	15,452.09	406.63	38	
Total	204,860.00		40	

(A = R Squared of the model = 0.92; pred2 = pretest mean score of d2 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	62.90	56.20 ^a
Experimental group	75.60	78.37 ^a

(^a = evaluated at covariates appeared in the model: pred2 = 67.43)

Table16 A comparison of the posttest item mean scores on unfeeling of loneliness (i1) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei1	181,302.99 ^A	90,651.50	2	65.62**
Error	52,497.01	1,381.50	38	
Total	233,800.00		40	

(A = R Squared of the model = 0.78; prei1= pretest mean score of i1 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	55.00	56.28 ^a
Experimental group	79.00	64.03 ^a

(^a = evaluated at covariates appeared in the model: prei1= 69.75)

Table17 A comparison of the posttest item mean scores on getting enough rest (i2) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei2	156,217.48 ^A	78,108.74	2	46.54**
Error	63,782.52	1,678.49	38	
Total	220,000.00		40	

(A = R Squared of the model = 0.70; prei2 = pretest mean score of i2 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	54.00	46.68 ^a
Experimental group	80.00	70.67 ^a

(^a = evaluated at covariates appeared in the model: prei2 = 72.50)

Table18 A comparison of the posttest mean scores on functional ability in daily life (i3) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei3	265,066.16 ^A	132,533.08	2	237.18**
Error	21,233.84	558.79	38	
Total	286,300.00		40	

(A = R Squared of the model = 0.92; prei3 = pretest mean score of i3 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	72.50	66.45 ^a
Experimental group	85.00	87.59 ^a

(^a = evaluated at covariates appeared in the model: prei3 = 76.50)

Table19 A comparison of the posttest mean scores on life satisfaction (i4) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei4	105,021.68 ^A	52,510.84	2	38.39**
Error	51,978.32	1,367.85	38	
Total	157,000.00		40	

(A = R Squared of the model = 0.65; prei4 = pretest mean score of i4 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	49.00	38.98 ^a
Experimental group	56.00	56.92 ^a

(^a = evaluated at covariates appeared in the model: prei4 = 62.00)

Table20 A comparison of the posttest item mean scores on strong will (i5) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei5	215,126.86 ^A	107,563.43	2	208.83**
Error	19,573.14	515.08	38	
Total	234,700.00		40	

(A = R Squared of the model = 0.91; prei5 = pretest mean score of i5 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	64.00	58.98 ^a
Experimental group	78.50	83.72 ^a

(^a = evaluated at covariates appeared in the model: prei5 = 80.50)

Table 21 A comparison of the posttest item mean scores on health satisfaction (i6) of quality of life of the control group and the experimental group by ANCOVA F-test

Source	Sum of squares	Mean square	df	F
Group * prei6	80,990.28 ^A	40,495.14	2	19.83**
Error	77,609.72	2,042.36	38	
Total	158,600.00		40	

((A = R Squared of the model = 0.49; prei6 = pretest mean score of i6 as an covariance)

	Mean score before adjusted	Adjusted mean score
Control group	42.00	24.09 ^a
Experimental group	67.00	50.04 ^a

(^a = evaluated at covariates appeared in the model: prei6 = 46.88)

APPENDIX L

RESEARCH INFORMATION SHEET FOR THE CONTROL GROUP

My name is Sureeporn Thanasilp, a nurse who is pursuing a doctoral degree of Nursing at the Faculty of Nursing, Mahidol University. I am conducting a study on “Effectiveness of the Symptom Management Program on the symptom status and the quality of life among person with Pneumocystis Carinii Pneumonia”. This study is aimed to help the patient to relief the symptom and improve the quality of life. It is therefore expected that the results of this study will contribute to improve the quality of health care for the person with PCP.

You are a person who could participate in this study and if you wish to volunteer, I will interview you twice during the one-month period of the study. During the interview, I will ask and record your personal life, symptom status, and quality of life.

During your participation in this study you may decline to answer any questions or withdraw from the study at anytime and that will have no influence on your receiving service or any medical treatment. All your information will be treated as strictly confidential. There will be no individual identities used in any reports or publications resulting from this study.

If you have any questions or suggestions or can not participate in this study you can directly contact me by phone number 01-3080046 or 034-214172. If you agree to join this program, please sign your name on the consent form. Please remember to keep our appointment.

Thank you for your kind cooperation

(Mrs. Sureeporn Thanasilp)

APPENDIX M

RESEARCH INFORMATION SHEET FOR THE EXPERIMENTAL GROUP

My name is Sureeporn Thanasilp, a nurse who is pursuing a doctoral degree of Nursing at the Faculty of Nursing, Mahidol University. I am conducting a study on "Effectiveness of a Symptom Management Program on the symptom status and the quality of life among persons with Pneumocystis Carinii Pneumonia". This study is aimed to help the patient to relief the symptom and improve the quality of life. It is therefore expected that the results of this study will contribute to improve the quality of health care for the person with PCP.

You are a person who could participate in this study and if you wish to volunteer, I will initiate the following procedures:

1. You will be interviewed, twice during the one-month period of the study. I will ask and record about your personal life, your symptom experience, symptom status, and quality of life.
2. I will meet you 2 times during your hospitalization. The first visit begins on the first day after you sign the consent form. The second visit continues with the day after the first meeting. You will get my advice concerning the PCP knowledge by using the videotape and the manual booklet to develop your symptom management skills.
3. After your discharge from the hospital, I will contact you with the telephone for two in the one-month study for evaluate the process of the program.
4. At the follow up period at the two weeks after discharge, I will meet you at the outpatient department for any advice that you want.

During your participation in this study you may decline to answer any questions or withdraw from the study at anytime without any effect on your receiving service or any medical treatment. All your information will be treated as strictly confidential. There will be no individual identities used in any reports or publications resulting from this study.

If you have any questions or suggestions or can not participate in this study you can directly contact me by phone number 01-3080046 or 034-214172. If you agree to join this program, please sign your name on the consent form. Please remember to keep our appointment.

Thank you for your kind cooperation

(Mrs. Sureeporn Thanasilp)

APPENDIX N**INFORMED CONSENT FORM**

Title Effectiveness of the Symptom Management Program on symptom status and quality of life among person with Pneumocystis Carinii Pneumonia
Researcher Ms. Sureeporn Thanasilp
 D.N.S. candidate, Faculty of Nursing, Mahidol University.
Patient Name age.....
Patient Consent

I, _____, was informed about the details of the research entitled “Effectiveness of a Symptom Management Program on the symptom status and the quality of life among person with Pneumocystis Carinii Pneumonia” and was assured that no parts of my personal information and the research result shall be individually revealed to the public. If any problems or issues arise, I can discuss them with the researcher. I reserve the right to withdraw from this project anytime without any effects on any medical services and treatments that were rightfully due to me. I am willing to participate in this project, and hereby endorse my signature.

Given by _____ (Consented)

_____ (Witness)

_____ (Witness)

Date _____

Researcher's Note

I had given the detailed information of the research entitled “Effectiveness of the Symptom Management Program on the symptom status and the quality of life among person with Pneumocystis Carinii Pneumonia” to the patient. She / He has been given the opportunity to ask questions and was satisfied with the due answers.

Signature _____ (Researcher)

Date _____



BIOGRAPHY

NAME	Mrs. Sureeporn Thanasilp
DATE OF BIRTH	15 July 1960
PLACE OF BIRTH	Trang, Thailand
INSTITUTIONS ATTENDED	Prince of Songkla University, 1979-1983: Bachelor of Science (Nurse&Midwifery) Mahidol University, 1986-1988: Master of Science (Nursing) Mahidol University, 1996-2001: Doctor of Nursing Science
RESEARCH GRANT	Doctoral Collaborative Program, Ministry of University Affairs, Thailand Faculty of Graduate Studies, Mahidol University in the Academic Year 2000
POSITION & OFFICES	1983-1984 Nursing Staff, Medical Nursing Unit, Bangkok Hospital. 1984-1995 Nurse Instructor, Department of Medical Nursing, Faculty of Nursing, Prince of Songkla University. 1995-present Assistant Prof. Adult Nursing, Faculty of Nursing, Chulalongkorn University.