DEVELOPMENT OF HOME BASED PALLIATIVE CARE MODEL FOR PEOPLE LIVING WITH END STAGE RENAL DISEASE

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DEVELOPMENT OF HOME BASED PALLIATIVE CARE MODEL FOR PEOPLE LIVING WITH END STAGE RENAL DISEASE

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ABSTRACT

The purpose of this embedded mixed methods study was to develop a home based palliative care, evaluate model and meditation healing exercise SKT6 among 194 people living with ESRD (74 for quantitative study and 120 for qualitative study). Situation analysis, focus group, interviewing, physical symptom assessment in ESAS, and uncertainty in illness were used in both study. Quasi experimental study was used to quantitative data collection in biochemical substance of the blood result.

Results found that there were 4 steps of a home based palliative care model: developing relationships, understanding, mindfulness, and acceptance. People living with ESRD and families had a great suffering experienced and identified aspects of uncertainty of illness on their lives that supported the uncertainty in illness constructs. The score of Mishel uncertainty was increased from 29 to 86. The physical assessment in ESAS instrument was range from 0 to 61, $\bar{X}$ 21.59, SD 16.68. The QoL in dialysis was 6.71 to 27.97, $\bar{X}$ 19.38, SD 4.24 One hundred percent of people living with ESRD practiced meditation healing exercise. After intervention, people living with ESRD and families showed high satisfaction on the home based palliative care model. Satisfaction was increased from 38.05 to 62.93, well-being from 5.60 to 7.85, the psychological and spiritual wellbeing from 21.17 to 28.54, and total quality of life from 18.44 to 23.65. SKT6 meditation healing exercise affected on quality of life, Blood urea nitrogen (BUN), and creatinine level significantly. There were relationship between QoL and Sodium, Chloride, BUN($r= -.40$, $-.45$, $p< .05$) and there were relationship between BUN and physical symptom($r= .52$, $P< .05$)

KEY WORDS: PALLIATIVE CARE/ END STAGE RENAL DISEASE/ SKT6/
UNCERTAINTY IN ILLNESS/ QUALITY OF LIFE.

254 pages

การพัฒนารูปแบบการพยาบาลแบบประคับประคองที่บ้านสำหรับผู้ที่มีภาวะไตวายเรื้อรังระยะสุดท้าย
DEVELOPMENT OF HOME BASED PALLIATIVE CARE MODEL FOR PEOPLE LIVING WITH END STAGE RENAL DISEASE

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บทคัดย่อ

การศึกษาวิจัยแบบผสมผสานเชิงฝังในขยายความครั้งนี้มีวัตถุประสงค์เพื่อพัฒนารูปแบบการพยาบาลประคับประคองที่บ้านและประเมินผลรูปแบบในผู้ที่มีภาวะไตวายเรื้อรังระยะสุดท้าย จำนวน 194 คน แบ่งเป็นผู้ร่วมวิจัยเชิงปริมาณ 74 คน และเชิงคุณภาพ 120 คน โดยการวิเคราะห์สถานการณ์ การสัมภาษณ์ การสนทนากลุ่ม และประเมินผลสมาธิเพื่อการเยียวยา SKT6 ต่อการมีคุณภาพชีวิต ความผาสุกด้านจิตวิญญาณ ประเมินความสัมพันธ์ระหว่างอาการทางกายโดยใช้แบบประเมิน ESAS และ ความรู้สึกไม่แน่นอนในความเจ็บป่วย ส่วนการเก็บข้อมูลเชิงปริมาณโดยวิธีกึ่งทดลองในการเปลี่ยนแปลงทางชีวเคมีของผลเลือด

ผลการศึกษาพบว่าการพัฒนารูปแบบการพยาบาลแบบประคับประคองที่บ้านมี 4 ระยะคือ การทำให้อุ่นใจ เข้าใจ ทำใจ และปลงใจ ผู้ที่มีภาวะไตวายเรื้อรังระยะสุดท้ายและครอบครัวมีประสบการณ์ชีวิตที่ทุกข์ทรมานจากอาการทางกาย จิตใจอารมณ์ และจิตวิญญาณ ภาวะเครียดทางเศรษฐกิจ และมีคะแนนความรู้สึกไม่แน่นอนในความเจ็บป่วยอยู่ ระหว่าง 29-86 การประเมินอาการทางกายจากคะแนนของ ESAS score อยู่ระหว่าง 0-61 , $\overline{X}$ 21.59 , SD 16.68 มีคะแนนคุณภาพชีวิตจากการรักษาด้วยการล้างไต อยู่ระหว่าง 6.71-27.97 , $\overline{X}$ 19.38, SD 4.24 ผู้ป่วยมีการปฏิบัติสมาธิเพื่อการเยียวยา SKT6 100% และมีผลต่อคุณภาพชีวิตโดยการใช้สมาธิเพื่อการเยียวยามีความพึงพอใจเพิ่มขึ้นในกระบวนการพยาบาลประคับประคองจาก 38.05 เป็น 62.93 ความผาสุกทั่วไปจาก 5.60 เป็น 7.85 ความผาสุกด้านจิตวิญญาณจาก 21.17 เป็น 28.54 และคุณภาพชีวิตโดยรวมจาก 18.44 เป็น 23.65 ส่วนผลต่อการเปลี่ยนแปลงทางชีวเคมีพบว่าระดับค่า Blood urea nitrogen(BUN) และ Creatinine มีการลดลงอย่างมีนัยสำคัญ มีความสัมพันธ์ระหว่างคุณภาพชีวิตกับผลของ โซเดียม คลอไรด์และ BUN ($r = -.40$, $-.45$, $p<.05$) และมีความสัมพันธ์ของBUN กับอาการทางกาย($r= .52$, $P<.05$).

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CHAPTER I

INTRODUCTION

1.1 Background and significance of the problems

Chronic illness has a profound impact on one's life and creates a lot of grief in response to the losses it imposes such as in chronic kidney disease. At present, chronic kidney disease (CKD) is a worldwide public health crisis. There is no cure for chronic renal failure that can lead to end stage renal disease (ESRD). ESRD is the reduction in, or absence of, kidney function and leads to a host of maladaptive changes including fluid retention, anemia, disturbances of bone and mineral metabolism, dyslipidemia, and protein energy malnutrition**.** These disturbances can cause pain, pruritus, anemia, bone loss, and increased fracture risk, and can contribute to hypertension and cardiovascular disease (Chertow, &Lowrie, 2000). Despite ongoing technological advances, patients with end-stage renal disease (ESRD) have a mortality rate of approximately 23% per year, and comorbid cardiovascular, cerebrovascular, and peripheral vascular disorders often make life on dialysis an ordeal (David, Lewis,& Michael ,2003). The burden of ESRD in developing countries is significant as there may be no social security system or health insurance scheme in place; the burden is often borne solely by the people living with ESRD and family in many developing countries (Gilbertson et al., 2005). There is a large variety of potential life interruptions and psychological changes one will go through when dealing with this illness.

ESRD Trends

In developed countries, such as the United States, the point prevalent counts of reported ESRD has increase from 533,753 in 2008 to 584,079 in 2010 (United State renal data system ,2011). The prevalence counts are expected to increase in the U.S. by 44 to 85% from 2000 to 2015. These data are congruent with the reported ESRD prevalence of 81% in 2010. One of the major causes for this dramatic projected increase is the concurrent increasing prevalence of obesity and associated diabetes mellitus in over 40% of U.S. people living with ESRD (Elsayem et al., 2004). Due to advances in treatment in the United States, people living with ESRD can manage his/her disease with hemodialysis or peritoneal dialysis in the home or outpatient clinic setting. The majority receive care management services which have been shown to improve the sense of well-being and improve treatment outcomes for people living with ESRD(Delanaye, Cavalier, & Krzesinski, 2009). Similarly, in the U.K. and other developed countries such as Canada, the prevalence of ESRD has increased over the past several decades. U.K. Renal Registry data reveal that the percentage of incident patients over the age of 75 has risen from 18% to 23% from 1998 to 2004. Over the past decade, the number of Canadians over the age of 65 with ESRD has more than doubled (Robinson, 2005). Although developed countries have made progress in the treatment for ESRD, many still suffer from the consequences of ESRD. Many studies in palliative care for ESRD focus on advanced care directives, hospice care and bereavement services. These studies reveal a lack of standardized community practice guidelines for palliative care in the community (Robinson, & Stacy, 2010).

In developing countries such as India and Pakistan, treatment of ESRD is a low priority for cash-strapped public hospitals in the absence of a health insurance plans or private insurance. It is difficult to accurately track the incidence and prevalence of ESRD in developing countries due to limitations in surveillance and reporting. It has been estimated that approximately 30% of patients with diabetes progress to ESRD(U.S. Renal Data System, 2010) and the rest usually die from cardiovascular disease before reaching end stage in developing countries(Delanaye et al.,2009).

Several factors influence the development and management of chronic kidney disease and have profound impact on morbidity and mortality. The majority of people living with ESRD are unable to gain access to therapy because of poverty, lack of healthcare delivery systems and inadequate dialysis from many factors including insufficient numbers of trained personnel in hemodialysis centers. In addition, staff motivation and remuneration are equally poor with consequent disruption of services due to emigration of trained staff to the Middle Eastern and Western world (Fox et al., 2006).

Many people living with ESRD in developing countries who start hemodialysis die or stop treatment within the first three months because of cost constraints (Delanaye et al., 2009). In contrast, Thailand, which is considered a low- to middle-income developing country(Gilbertson et al., 2005) has been providing universal healthcare coverage since 2001. As a result of strong pressure from various stakeholders, universal access to peritoneal dialysis was provided to all Thai people effective January, 2008. Nine months later, the universal healthcare coverage (UC) for Thai beneficiaries was enhanced to include hemodialysis as well. This coverage protects the Thai population who are not eligible for the civil servant medical benefit scheme (CSMBS) or social security scheme (SSS) (Yot & Viroj, 2010).

There are approximately 100,000 new cases of the ESRD per year in Thailand (Yot & Viroj, 2004). The prevalence of chronic kidney disease among people aged over 40 is significantly higher than that reported in the U.S. for both stage III and IV ESRD disease. The incidence of ESRD is also higher than the reported rates in Taiwan and Australia. This high incidence and prevalence of chronic kidney disease in Thailand is also related to increasing rates of diabetes and has obvious implications for public health and for the allocation of healthcare resources (Imai et al., 2009). Although both private and government-sponsored home-based palliative care programs have been developed in Thailand for persons living with heart disease, cancer and HIV/AIDS, no standardized community-based palliative care programs for person with ESRD have been developed and evaluated in Thailand (Keith, Nichols, Gullion, Brown, & Smith, 2004).

Physical symptom was one part of suffering. The Edmonton Symptom Assessment System (ESAS) Guidelines was used to evaluate physical symptom for palliative care. This tool was designed to assist in the assessment of nine symptoms common in cancer patients and it will be apply appropriate with people living with ESRD in end of life stage: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. When people living with ESRD encounter with suffering from disease or long term treatment they felt uncomfortable in life, restricted in food, restricted in behaviors until condition change they have uncertainty in illness and lead to uncertainty in life.

Uncertainty in Illness

According to Mishel (2005) stated that uncertainty exists when an individual is unable to determine the meaning of illness-related events. Uncertainty arose when people living with ESRD had experiences with unfamiliar, complex and unpredictable. Mishel indicates that in illness situations, perception of uncertainty is influenced by such factors as the unpredictability of symptoms, familiarity with the illness outcomes and the cognitive abilities of the person. The theory composed the concepts of “stimuli frame”, “structure providers” and “cognitive capacities”. This theory has implications for people living with ESRD as they experience changes in daily activities, jobs; family roles due to pathophysiological, emotional and spiritual changes make a similar claim about information needs (Richard, Lazarus, &Folkman, 1984). The uncertainty in illness theory proposes that uncertainty exists in illness situations that are ambiguous, complex and unpredictable. However, it may be possible to relieve some of the early uncertainty and stress by providing information to family caregivers about the end of life care. The family will be required to provide care at home. Mishel (1990) defined uncertainty as "the inability to determine the meaning of illness-related events"(Smith &Patricia, 2008, p.58). The uncertainty theory was developed to explain how patients cognitively process illness-related stimuli and construct meaning for the illness event. The theory is organized around three major themes: the antecedents of uncertainty, the process of uncertainty appraisal and coping with uncertainty.

The components of the stimuli frame include (a) symptom pattern, (b) event familiarity, and (c) event congruence, all of which are inversely related to uncertainty. These components provide different types of information about the illness which are used by the person to decrease uncertainty. Symptom patterns refer to the degree of symptoms associated with the illness that have a consistent pattern. A desirable outcome for the person experiencing the illness is to be able to predict a pattern of symptoms (Mishel,1990). In symptom patterns relate to physical sensations experienced. Event familiarity refers to the degree which a situation is habitual, repetitive, or has cues that are recognizable to the person and it is concerned with the actual health care environment. In hemodialysis, persons may experience less uncertainty over time because the event is familiar(Kongsuwan & Locsin, 2009). Event congruence refers to consistency between an expected outcome and the actual outcome in illness related events. Moreover, event congruence is affected by the predictability and stability of the stimuli. So the palliative care will able to help people living with ESRD to maintain quality of life in their environment.

Palliative Care

According to the World Health Organization (WHO, 2002), palliative care is the total care of patients whose disease is not responsive to curative treatment and includes control of pain, other symptoms, and psychological, social, and spiritual problems. Palliative care is not limited to patients at the end of life but applies earlier in the course of illness, provided in conjunction with active treatment. The ultimate goal of palliative care is the best possible quality of life (QOL) for people and families experiencing illness that is both chronic and life-threatening. People with end-stage renal disease (ESRD) are especially appropriate candidates for palliative care as defined by the WHO. People living with ESRD and their families are appropriate candidates for palliative care because of their high symptom burden, shortened survival, and significant comorbidity. Palliative care has much to offer toward improving the quality of dialysis patients’ lives as well as planning for and improving the quality of their deaths.

Consequence, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. Palliative care focuses on prevention and relief of suffering by means of early identification, physical, psychosocial and spiritual needs (Elsayem et al., 2004). According to a fundamental paradigm shift in medical and nursing care is necessary to prepare healthcare providers to provide quality care for chronic illness at the end of life. There are many life interruptions and psychological changes that one experiences when dealing with chronic illness (Carlson, Devich, & Frank, 1988; Cowan, Walsh, & Homsi, 2002).

Kristian (2007) & Cynthia (2006) identified gaps in palliative care that are related to lack of research, and skills as well as specific problems affecting quality of life. Some studies reported obstacles to the delivery of palliative care including bureaucratic problems and the time necessary to arrange home care technology. These problems also exist in Thailand but different methods to solve the problems are necessary based on the social, cultural, economic, spiritual and environmental context.

In 2005, the National Palliative Care Network was established in Thailand. In the past eight years, the network has made progress in both rural and urban regions. However, in Bangkok, this network has not been effectively linked with community organizations, such as home-based palliative care services. In Thailand, people who need palliative care and end of life support live characteristically with extended families as they cope at home with their illness. The majority (74%) of Thai people prefer to die at home with their close relatives until their last breath (Pimpun, 1990). Palliative care provides physical, emotional and spiritual which support during the advanced stage of the disease in order to improve quality of life in their environment. Some hospitals have established palliative care working groups and are in the process of developing palliative and end-of-life care programs for their patients but home based palliative care in the community for people living with ESRD has received virtually no attention. Physical, emotional and spiritual care needs must be identified in order to develop a comprehensive community palliative care program for people living with ESRD.

Physical care needs. Pathophysiological changes in people living with ESRD lead to many problems such as ischemia of the extremities causing pain and numbness, bone pain, central nervous system symptoms including drowsiness and confusion, recurrent infections, muscle cramps and loss of appetite. The complex and unpredictable nature of the physical symptoms associated with ESRD are congruent with Mishel’s stimuli frame which acknowledges the potential for unpredictability and the need to establish some familiarity with the disease patterns.

In the study applied the Edmonton Symptom Assessment System (ESAS) Guidelines to use in assessment of physical symptom. This tool is designed to assist in the assessment of nine symptoms common in cancer patients and it will be apply appropriate with people living with ESRD in end of life stage: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 that it is of the worst possible severity.

Emotional care needs. Similarly, Mishel's Uncertainty Theory identifies structure providers as a key element to reduce uncertainty and provide social support. A component of palliative care includes taking the time to listen of people living with ESRD and families. Meanwhile, the concerns may be related to loved ones who will be left behind or fear of pain and discomfort toward the end of life. End-of-life care providers should be aware of cultural norms related to end of life traditions with the goal to provide or ensure a peaceful death. The palliative care provider evaluates the general well- being and social support system in order to assess the emotional care needs of people living with ESRD. Psychological problems such as depression or suicidal thoughts related to disease progression or death are often experienced and may require referral to mental health professionals.

Spiritual care needs. In addition to physical and mental health problems, some people living with ESRD may experience spiritual crises, related to a perceived lack of support based on religious, philosophical or cultural beliefs and traditions. Different cultures and religious traditions of people also may define life and death differently. Some people living with ESRD may need to explore thoughts about the meaning of life or concerns about what happens after death from a spiritual perspective in order to come to a sense of peace with their illness.

Thai imaginary meditation exercise SKT6 : SKT6 is an innovation of meditation healing exercise which related to bioneuropsychological markers. The SKT6 was a basic tool and develop by Dr. Somporn Kantharadussadee Triamchaisri since 1996. The SKT6 combines meditation, guided imagery and relaxation techniques. These lead to self-regulation to reduce anxiety, pain, tired, discomfort, and to improve the function of autonomic nervous system (Somporn,2008).

The scope of this study

The purpose of this study was to develop and evaluate a home-based palliative care model to serve people living with end stage renal disease. The goal was to ensure that they have best possible quality of life, minimal suffering and a dignified death. The program provided nursing care and support to people who choose to be cared for in their home environment. This home based program created a network of palliative care in the community, including health center units. Public health nurses need to embrace innovation and create evidence-based practice. This model used appropriate techniques to link physical, psychological and spiritual needs with meditation healing exercise (SKT6)in activities of caring, thus improving the outcome of the public health nursing service with palliative care in community level.

Consequence, home based palliative care model should be structured around patient problems. Meanwhile, lack of research focusing specifically on community nursing in palliative care represents an important gap in current knowledge, few hospitals provide palliative care services, bereavement services are not dominant in providing for families, healthcare staff and volunteers have inadequate knowledge concerning care for people living with ESRD and EOL and have no specific programs for continuous care and a number of barriers to supporting family carers have been documented, including a lack of resources.

The setting of home based palliative care in the study was in Bangkok where updates of the center of education, working, advance treatment and so on. So that it should have dominant in health care services in community level. At the present, there are 68 health centers in Bangkok and the responsible of health center divides in service inside health center and outside service such as home visit, home health care, school health, mobile clinic. The role of the public health nurses should have enable patients to stay at home as long as possible. So in the study find out people living with ESRD from one private hospital in religion organization because there were many level of economic status and the area around this hospital was different from luxury house to congestion area in community. These areas composed of Sathron, Yannawa, Bangruk and Pratumwan district where economic areas in Bangkok.

The first model was proposed following this:

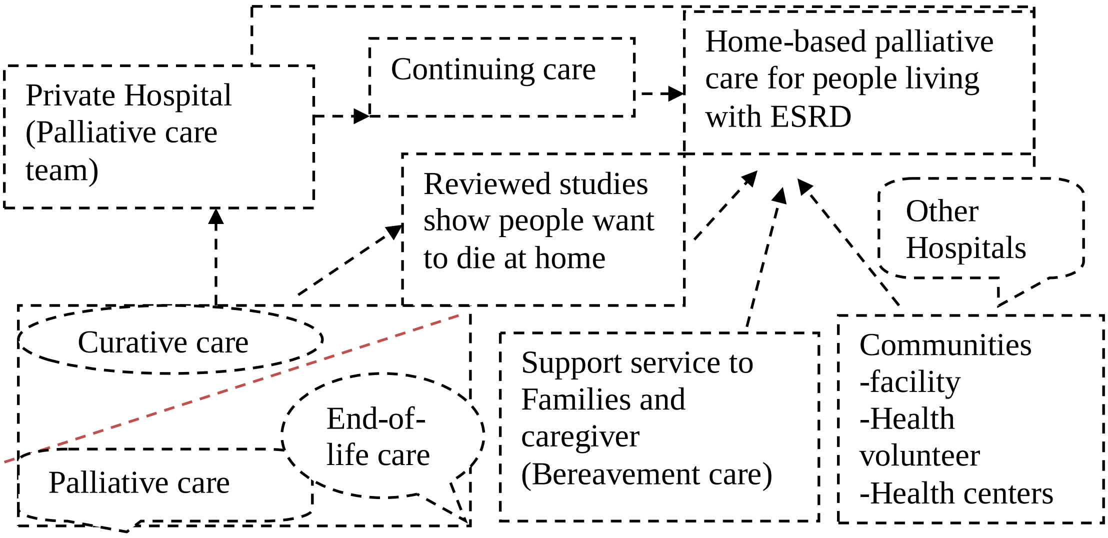


Figure 1.1: Proposed the first model of home-based palliative care in people living with ESRD

1.2 Research questions

1. What are the needs of home based palliative care for Thai people living with ESRD and their families?

2. What is the model of a home based palliative care program for Thai people living with ESRD?

1.3 Research objectives

General objective:

To develop and evaluate a home based palliative care model for people living with end stage renal disease.

Specific Objectives

1. To explore the palliative care needs of home based palliative care for people living with end stage renal disease.

2. To explore barriers or facilitators influencing home based palliative care for end stage renal disease.

3. To develop a model of home based palliative care for people living with end stage renal disease.

4. To evaluate the relationship between physical symptoms, uncertainty, and quality of life in people living with end stage renal disease.

5. To evaluate the effect of meditation healing exercise SKT6 on quality of life and biochemical substances in people living with end stage renal disease.

Research hypotheses

1. The outcome of people living with end stage renal disease who received home based palliative care will identify needs and suffering that will be support barriers or facilitators influencing to develop quality of life.

2. People living with end stage renal disease who received home based palliative care will decrease uncertainty in illness, physical symptom and will increase quality of life, satisfaction, spiritual& psychological, well-being.

3. There are relationship among uncertainty in illness, physical symptom, and duration of starting dialysis in negative correlation and there are relationship of quality of life, satisfaction, spiritual& psychological, well-being, blood test in positive direction.

4. People living with end stage renal disease that practiced in SKT will decrease uncertainty in illness, physical symptom and will increase quality of life, satisfaction, spiritual& psychological, well-being.

5. Meditation healing exercise SKT6 will regulate the biochemical substance in different time taken and duration of starting dialysis.

Hypothesized model showed in figure 1.2

1.4 Definition of Terms

Home-based palliative care refers to activities at home which can improve the quality of life of people living with ESRD and their families facing the problems associated with life threatening illness, through the prevention of suffering by early identification and treatment of fatigue and other problems, physical, psychological and spiritual in their environment. Progressive symptoms can be assessed by the ESAS

(Edmonton Symptom Assessment System) (Watanabe, Nekolaichuk,& Beaumont, 2011). This tool is designed to assist in the assessment of nine symptoms common in patients undergoing palliative care, especially in EOL: Pain, tiredness, nausea, depression, anxiety, drowsiness, loss of appetite, diminished feeling of well-being and shortness of breath.

End stage renal disease (ESRD refers to stage 5 of the condition with kidney function failure showing a glomerular filtration rate <15 mL/min/1.73 m^2 (Nation kidney foundation,2002).

Meditation healing exercise SKT6 refers to a meditation technique developed by Dr. Somporn Kantraradussadee Triamchaisri.This bioneuropsychological technique uses the concept of meditation, relaxation and integrated with guided imagery. It involves focusing on various parts of the body; from the head to toes achieve a state of relaxation.

Uncertainty in illness is the inability of individuals to determine the meaning of their disease process, treatments, and other illness-related events. A scale to measure uncertainty was developed Mishel (1987). The Uncertainty in Illness Scale-Community Form (MUIS-C) has been validated to examine perceived uncertainty in dialysis people living with ESRD. Mishel’s theory is comprised of three factors: the stimuli frame, the structure provider and the cognitive capacity. In the context of ESRD, these factors could be described as noted.

The stimuli could refer to the duration of hemodialysis, complications from hemodialysis treatment and advanced progressive symptoms associated with ESRD.

The structure provider refers to resources that facilitator care; provide social support and/or credible authority for people living with ESRD in the community.

Cognitive capacity refers to the ability to access and process information in palliative care including communication, accepting the truth and accepting that death is a natural part of life for people living with ESRD and families.

Physical symptom assessment refer to physical symptom in palliative care which assessed by using instrument of the Edmonton Symptom Assessment System (ESAS). Assessment of nine symptoms common in cancer patients and appropriate with people living with ESRD in end of life stage that composed of pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 that it is of the worst possible severity.

Quality of Life of people living with ESRD refers to the measure of people living with ESRD's functioning, well-being and general health perception in each of four domains: physical, psychological, social and spiritual. These measures which include family and social functioning can be measured by using the Quality of Life Index (QLI) developed by Ferrans and Powers (Ferrans& Powers, 1998).

1.5 Expected benefits of the study

For people living with ESRD:

- Improvement in quality of life, relief of suffering
- Helping people develop strategies to deal with EOL
- Helping people to reduce stress associated with uncertainty of their illness through relaxation meditation exercises**.**

For families:

- To help families to cope with feelings of guilt, grief and bereavement and to enable family members to access services
- An understanding of the process of disease and to accept death as a natural part of life.
- Helping families secure access to cost-effective, coordinated, high quality care for their family member with ESRD in the home based setting.

Organization level:

- Enhance access to palliative care in the community for health care services.
- Develop nursing care policy for home based palliative care in people living with ESRD.
- Promote a holistic approach to care and ensure that health needs of people living with ESRD are met.

Health Care Provider level:

- Community nurses will integrate the study results into their standards and guidelines for home health care.

- Home-based palliative care and quality of life for people living with ESRD will be established in Thailand.

- The results of this study will lead to ongoing development of palliative care networks among private hospitals, government hospitals and communities.

- The results of this study will lead to the reduction of unnecessary hospital admissions among people living with ESRD.

Public health education:

This model can be applied in the undergraduate and graduate nursing curriculum as well as in palliative care training programs for health professionals.

Hypothesized model

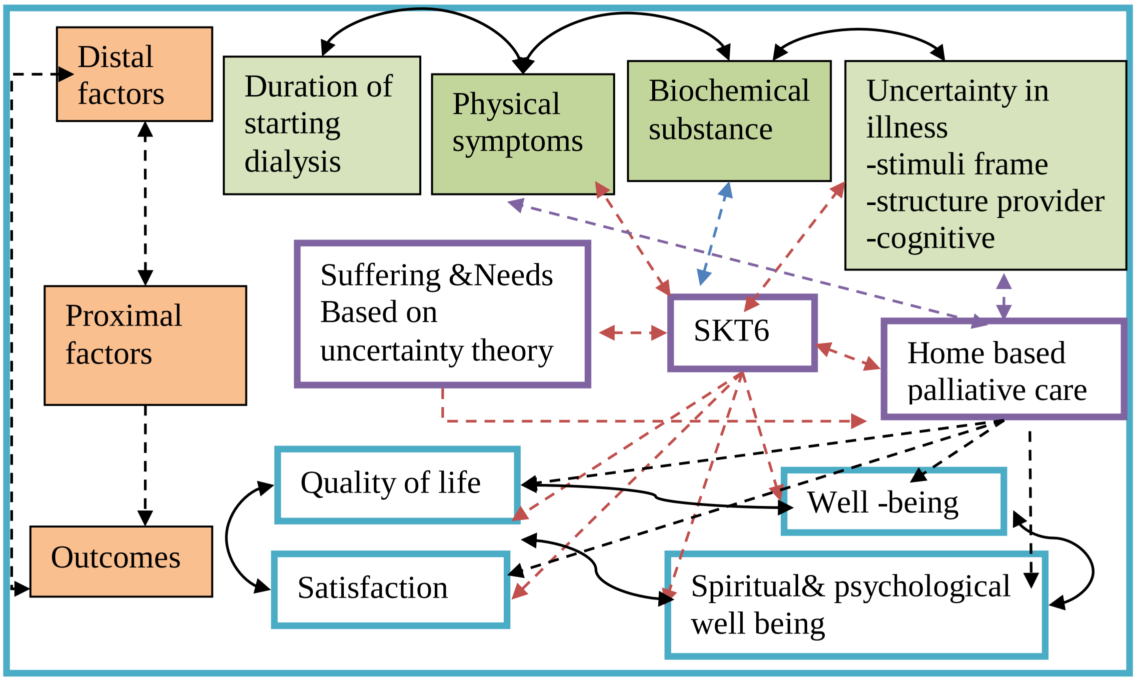


Figure 1.2 Hypothesized model

CHAPTER II

LITERATURE REVIEW

The purpose of this research was to develop home based palliative care for people living with ESRD. The in depth literature review was conducted and will be presented in following order:

2.1 The problems and the concept of end stage renal disease

2.2 The uncertainty in illness theory and its relevance for end stage renal disease

2.3 The variables concerned with end stage renal disease in home based palliative care including the intervention of meditation healing exercises

2.4 Research methodology review for mixed research design

2.5 Framework for program evaluation in public health

2.6 Related research

2.7 Conceptual framework of the study

2.1 The problems of end stage renal disease and the concept of end stage renal disease

End stage renal disease is complete or almost complete failure of the renal function. The renal function cannot remove wastes, concentrate urine, and regulate many other important body functions. This disease can be identified by a biochemical substance in blood for creatinine. High levels of creatinine indicate the falling glomerular filtration rate and as a result a decreased capability of the kidneys to excrete waste products from the human body. Creatinine levels may be normal in the early stages of chronic renal disease, and the condition is discovered if urinalysis shows that the kidney is allowing the loss of protein or red blood cells into the urine. To fully investigate the underlying cause of kidney damage, various forms of medical imaging, blood tests and often renal biopsy are employed to find out if there is a reversible cause for the kidney malfunction (Nation kidney foundation, 2002).

Recent professional guidelines classify the severity of chronic renal disease (CRD) in five stages, with stage 1 being the mildest and usually causing few symptoms. Stage 5 is a severe illness with poor life expectancy if untreated. Stage 5

Stages in Chronic kidney:

The stages depend on the glomerular filtration rate (GFR). In the case of the GFR is <60 mL/min/1.73 m^2 for 3 months, the diagnosis of chronic kidney disease can be made regardless of the presence or absence of kidney damage. All individuals with kidney damage are classified as having chronic kidney disease, irrespective of the level of GFR. The rationale for including individuals with a GFR < 60 mL/min/1.73 m^2 is that GFR may be sustained at normal or increased levels despite substantial kidney damage. People with kidney damage are at increased risk for the two major outcomes of chronic kidney disease: loss of kidney function and development of cardiovascular disease (Nation kidney foundation, 2002). The five stages of kidney disease include the following definitions:

Stage 1: Slightly diminished function; kidney damage with normal or relatively high GFR (>90 mL/min/1.73 m^2). Kidney damage is defined as pathologic abnormalities or markers of damage, including abnormalities in blood, urine or noted in imaging studies

Stage 2: Mild reduction in GFR (60-89 mL/min/1.73 m^2) with kidney damage; Kidney damage is defined as pathologic abnormalities or markers of damage, including abnormalities in blood, urine

Stage 3: Moderate reduction in GFR (30-59 mL/min/1.73 m^2); British guidelines distinguish between stage 3A (GFR 45-59) and stage 3B (GFR 30-44)

Stage 4: Severe reduction in GFR (15-29 mL/min/1.73 m^2), preparation for renal replacement therapy

Stage 5: Established kidney failure (GFR <15 mL/min/1.73 m^2, or permanent renal replacement therapy (RRT)

Incidence and Prevalence rate of ESRD:

The incidence and prevalence of ESRD are increasing globally with an increasing burden on health care systems. The reported annual incidence of people living with ESRD varies widely the estimated incidence ranges from 100 to 200 per million persons (Nation kidney foundation, 2002). In India, an estimated incidence of ESRD of 100 per million persons, or approximately 100,000 patients develop ESRD each year (White, Atkins,&Chadban,2008). This data congruence with report in Thailand, there was 100,000 cases per year (Ministry of Public Health, 2008).

Problems experienced by people living with ESRD:

People living with ESRD suffer from many physical problems. Hypertension is common and can lead cardiomyopathy, with its associated high morbidity and mortality (Snively &Gutierrez, 2004). Cardiovascular disease (CVD) exerts a major influence on the morbidity and mortality of dialysis, as demonstrated by the frequent occurrence of heart failure, very high mortality rates, and a high proportion of cardiac deaths. These adverse events can usually be attributed to disorders of cardiac muscle structure and function and/or disorders of effusion.

People with chronic kidney disease suffer from progressive atherosclerosis and are more likely to develop heart disease than the general population. People afflicted with chronic kidney disease and cardiovascular disease tend to have significantly worse prognoses than those who have CVD only. People living with CKD experience a myriad of symptoms such as: abnormally dark or light skin; changes in nails; bone pain; central nervous system symptoms including drowsiness, confusion, problems concentrating or thinking; numbness in the hands, feet, or other areasor cramps; breath odor; easy bruising; nosebleeds; or blood in the stool. Patients receiving dialysis will need ongoing laboratory testing to evaluate kidney functioning such as potassium, sodium, albumin, phosphorous, calcium, cholesterol, magnesium, and hematocrit. This disease also affected many other body organs and thus is also monitored for changes in the erythropoietin, parathyroid hormone (PTH) as well

Moreover, pruritus is a common disabling problem in people living with advanced end-stage renal disease. Few studies have evaluated the clinical characteristics of uremic itch. Major factors found to exacerbate pruritus include rest, heat, dry skin, and sweat (Inbar et al., 2003). ESRD is a life-threatening condition and survival can be maintained only with renal replacement therapy. Furthermore, the complications of ESRD, its treatment and co-existing diseases have been found to have a significant impact on the physical health of persons with this condition. It is well documented that the health status of the renal people is worse than that of the general healthy population.

The primary cause of ESRD is diabetes (30%) followed by renal vascular disease, including hypertension (20%) (Snively & gutierrez,2004) . The result of these conditions is the development of a pathologic condition that destroys the renal blood vessels and kidneys. The failure of kidney function leads to an accumulation of toxins in the body. The most common chronic illnesses among the elderly Thai population include hypertension (31.7%), diabetes mellitus (13.3 %), and heart disease (7.0 %) (Piriyapun,2009). Elderly persons with diabetes are at high risk to develop. Despite ongoing technological advances, people living with end-stage renal disease have a mortality rate of approximately 23% per year. For those who survive, cardiovascular, cerebrovascular, and peripheral vascular disorders often make life on dialysis an ordeal (David & Poppel, 2003). End-stage kidney disease occurs when the kidneys are no longer able to function at a level needed for day-to-day life. It usually occurs when the kidney function is less than 10% of normal. ESRD almost always follows chronic kidney disease. A person may have gradual worsening of kidney function for 10 - 20 years or more before progressing to ESRD. Patients who have reached this stage need dialysis or a kidney transplant (White, 2008).

Symptoms: CKD initially develops without specific symptoms and can only be detected by an increase in serum creatinin or protein in the urine. As the disease progresses, hypertension may be picked up and eventually consequences of the hypertension may be noted such as fluid overload and production of vasoactive hormones, increasing one's risk of suffering from congestive heart failure.

As the kidneys continue to fail, urea accumulates. This toxin can lead to azotemia and ultimately uremia. The presenting symptoms range from lethargy to pericarditis and encephalopathy. Urea is excreted by sweating and crystallizes on skin, which is sometimes called "uremic frost". Potassium accumulates in the blood with a range of symptoms including malaise and potentially fatal. Erythropoietin is decreased potentially leading to anemia, which causes fatigue. Fluid volume overload may develop with symptoms ranging from mild edema to life-threatening pulmonary edema (Viktorsdottir et al., 2005).

The prognosis for people with chronic kidney disease is guarded as all cause overall death rate increases as kidney function decreases (Perazella & Khan, 2006).The leading cause of death in patients with chronic kidney disease is cardiovascular disease, regardless of whether there is progression to stage 5 (Mitch, 2007). Renal transplant increases the survival of people with stage 5 CKD significantly when compared to other options; however, it is associated with an increased short-term mortality (Zhang&Rothenbacher, 2008).

Dialysis or kidney transplantation is the only treatment for ESRD. The physical condition primarily determines which treatment is used. Starting dialysis depends on different factors however, including lab test results, severity of symptoms, and readiness. People living with ESRD should begin to prepare for dialysis before it is absolutely necessary. The preparation includes learning about the purpose of and types of dialysis therapies, as well as an internal or external shunt for dialysis access. The diet should be low-protein with limited fluids, salt, potassium, phosphorous, and other electrolytes. Sufficient calories are recommended to avoid losing weight. Other treatments may include: treatment for anemia, such as extra iron in the diet, iron pills, special shots of a medicine called erythropoietin, to help prevent phosphorous levels from becoming too high, extra calcium and vitamin D.

Treatment in ESRD

The goal of therapy is to slow down or halt the progression of CKD to stage 5, whenever feasible, are the broad principles of management. Hemodialysis is a method of cleaning wastes and extra fluids from people living with ESRD’s blood using a machine. In hemodialysis, blood goes through a tube from patient’s body to a special filter called a dialyzer. The dialyzer filters waste and extra fluid from the blood. Then, the “clean” blood travels through another tube and back into body. The process happens through a place on body called an access or vascular access.

There are three types of access:

Fistula: An arteriole-venous fistula is a place where one of arteries connects to one of the veins. The fistula would be created during a minor surgical procedure and would need time to heal and "mature" before it can be used. During dialysis treatments, needles are put into the matured fistula. A fistula is the best kind of access because it is the least likely to get clots or infections. Fistulas also tend to last longer than other types of access. But, because fistulas can take long time to heal, it is important to plan ahead and discuss with the doctor about other options to decide whether a fistula is the right choice.

Graft: An arteriole venous graft is a special tube that connects an artery and a vein in the arm. Like a fistula, a graft would be placed under the skin during a minor surgical procedure. The graft needs time to heal however it might take less time to heal compare to a fistula. During dialysis treatments, needles are put into the graft. Grafts are not as safe as fistulas because they slightly increase the chance to become infected or develop clots in comparison to fistulas. However, many people have no problem with the grafts; therefore the affected people living with CKD should discuss the options with the doctor and decide if a graft is the right choice.

Catheter: a catheter refers to a tube used during dialysis treatments that goes directly into a vein in the neck or leg. During dialysis treatments, the machine takes blood from the catheter and returns blood through the catheter. However catheters are more likely to get infected or have clots. For this reason, catheters are only recommended in emergencies or for short-term use.

Peritoneal dialysis (PD) is a treatment for patients with severe chronic kidney disease. The process uses the people living with CKD's peritoneum of abdomen as a membrane across which fluids and dissolved substances are exchanged from the blood. Fluid is introduced through a permanent tube in the abdomen and flushed out either every night while the people sleep or via regular exchanges throughout the day. PD is used as an alternative to hemodialysis although it is far less commonly used in many developed countries, such as the United States. It has comparable risks but is significantly less costly in most parts of the world, with the primary advantage being the ability to undertake treatment without visiting a medical facility. The primary complication of PD is infection due to the presence of a permanent tube in the abdomen.

The fluid used typically contains, sodium, chloride, lactate or bicarbonate a high percentage of glucose to ensure hyperosmolarity amount of dialysis that occurs depends on the volume of the dwell, the regularity of the exchange and the concentration of the fluid. APD cycles between 3 and 10 dwells per night, while CAPD involves four dwells per day of 2-2.5 litres per dwell, with each remaining in the abdomen for 4-8 hours. The viscera accounts for roughly four-fifths of the total surface area of the membrane, but the parietal peritoneum is the more important of the two portions for PD. The high concentration of glucose drives the exchange of fluid from the blood with glucose from the peritoneum. The solution flows from the peritoneal cavity to the organs, and thence into the lymphatic system. Individuals differ in the amount of fluid absorbed through the lymphatic vessels, though it is not understood why. The ability to exchange fluids between the peritoneum and blood supply can be classified as high, low or intermediate. High transporters tend to diffuse substances well, easily exchanging small molecules between blood and the dialysis fluid, with somewhat improved results frequent, short-duration dwells such as with APD. Low transporters filter fluids better, transporting fluids across the membrane into the blood more quickly with somewhat better results with long-term, high-volume dwells (Alan, Glenn,Fan, McCulloch,&Hsu,2004).

Complications: the volume of dialysate removed and weight of the people living with ESRD are normally monitored; if more than 500ml of fluid are retained or a litre of fluid is lost across three consecutive treatments, the patient's physician is generally notified. Excessive loss of fluid can result in shock from hypovolemic or while excessive fluid retention can result in hypertension and edema. The color of the fluid removed is also monitored: normally it is pink-tinged for the initial four cycles and clear or pale yellow afterwards. The presence of pink or bloody effluent suggests bleeding inside the abdomen while feces indicate a perforated bowel and cloudy fluid suggests infection. The people living with ESRD may also experience pain or discomfort if the dialysate is too acidic, too cold or introduced too quickly, while diffuse pain with cloudy discharge may indicate an infection (Wong, 2007).

Risks and benefits: PD is less efficient at removing wastes from the body than hemodialysis, and the presence of the tube presents a risk of peritonitis due to the potential to introduce bacteria to the abdomen (Holtkamp et al., 2011). Peritonitis is best treated through the direct infusion of antibiotics into the peritoneum with no advantage for other frequently used treatments such as routine peritoneal lavage. The costs and benefits of hemodialysis and PD are roughly the same. PD equipment is cheaper but the costs associated with peritonitis are higher (White et al, 2008).The Cochrane review of three small trial in clinical found that no difference in clinically important outcomes such as morbidity or mortality for people living with end stage renal disease, nor was there any advantage in preserving the functionality of the kidneys (Barbara, Prowant, Moore, Roberta,& Zbylut,2010).

Other complications include hypotension due to excess fluid exchange and sodium removal, back pain, hernia or leaking fluid due to high pressure within the abdomen. PD may also be used for patients with cardiac instability as it does not result in rapid and significant alterations to body fluids. It may also be recommended for persons with insulin-dependent diabetes mellitus due to the inability to control blood sugar levels through the catheter. Hypertriglyceridemia and obesity are also concerns due to the large volume of glucose in the fluid, which can add as many as 1200 calories to the diet per day (Crowley, 2009).

2.2 The uncertainty in illness theory and its relevance for end stage renal disease

End stage renal disease can be associated with much uncertainty. Living with this diagnosis typically involves receiving dialysis treatment which significantly alters one’s ability to complete normal daily activities. With treatment cycles of 3 times per week, this can have an impact of one’s ability to adhere to a job schedule, and can lead to personal and family stress. In addition to the numerous pathophysiological changes identified in this review, the disease and its treatment can also result in mental and spiritual challenges. These multifaceted changes can lead to uncertainty regarding the illness and uncertainty in life. According to Mishel (1990), uncertainty exists when an individual is unable to determine the meaning of illness-related events. It is "the cognitive state created when the person cannot adequately structure or categorize an event because of lack of sufficient cues (Mishel, 1990 & Mary, p.57).

Uncertainty arises when illness experiences are unfamiliar, complex and unpredictable. Mishel (1988) indicates that in illness situations, perception of uncertainty is influenced by such factors as: the unpredictability of symptoms, familiarity with the illness outcomes and the cognitive abilities of the person. Mishel defined uncertainty as "the inability to determine the meaning of illness-related events". The uncertainty theory was developed to explain how patients cognitively process illness-related stimuli and construct meaning for the illness event. The theory includes antecedents of uncertainty. 'Stimuli frame' refers to the form, composition, and structure of the stimuli produced as part of the illness and as a result of illness-related events, structure providers, and cognitive capacities.

Compositions of the stimuli frame are included (a) symptom pattern, (b) event familiarity, and (c) event congruence, which are inversely related to uncertainty and provide different types of information about the illness. (Mishel,1990 & Mary,p.56).

Stimuli frame:

The 'Stimuli frame' refers to the form, composition, and structure of the stimuli produced as part of the illness and as a result of illness-related events, structure providers, and cognitive capacities

a) The symptom pattern refers to the degree of symptoms associated with the illness and those which have a consistent pattern(Mishel,1997) .A desirable outcome is for the person experiencing the illness to be able to predict a pattern of symptoms(Mishel et al.,2005). The symptom pattern information relates to physical sensations experienced.

b) Event familiarity refers to the degree to which a situation is habitual, repetitive, or has cues that are recognizable to the person. It is related with the actual health care environment. For example, hemodialysis people living with ESRD may experience less uncertainty because the event is familiar (Mishel, 1987). Event familiarity is concerned with the actual health care environment. When events are recorded in a person's memory, it becomes easier to attach meaning.

c) Event congruence refers to consistency between an expected outcome and the actual outcome in illness related events (Mishel, 1990). Event congruence was affected by the predictability and stability of the stimuli. Similarly, people living with ESRD experience great degree of event congruence related to increased familiarity. Stability is altered when anticipated outcomes do not occur; thereby increasing the amount of uncertainty and event congruence was affected by the predictability and stability of the stimuli. Health professionals, family member familiar with ESRD, and educators serve as information sources that can directly and indirectly affect knowledge about the stimuli frame components.

Structure providers:

Structure providers refer to education, social support, and credible authority, all of which are thought to reduce uncertainty, directly and indirectly. Stimuli frame components are positively affected by structure providers.

Education: The relationship between education and uncertainty is unclear. A number of authors have found that uncertainty has an inconsistent relationship with education (Mishel, 1984, Christman, 1988, Mishel & Braden, 1988 Wong & Bramwell, 1992). Education is proposed to have both an indirect as well as a direct relationship with uncertainty. In the indirect relationship, education enables the person to apply structure to events surrounding the illness and consequently attach meaning. Later, Galloway (1984), King & Mishel (1986), and Mishel (1985) found that having less education equated with higher levels of uncertainty. There is a gap in the literature about the relationship between uncertainty associated with diagnosis of people living with ESRD and associated uncertainty.

Social support: has been examined as a major influence of many health-related outcomes (Mishel & Braden, 1987). The role of social support with uncertainty is dynamic. Social support can directly and indirectly influence ambiguity, complexity, and unpredictability factors related to uncertainty in illness. The long-term social consequences and a lack of social support are additional stressors for relative or caregivers. Kozloff (1987) found that as post injury time increases, relative or caregiver social networks decreased. Lezak (1978) reported that social isolation was a factor in increasing caregivers' stress, as evidenced by their reports of feeling trapped and isolated. Feelings of embarrassment and abandonment by friends and extended family seemed to exacerbate the sense of isolation (John, Marilyn & McCubbin, 1993).These can affect people living with ESRD in terms of quality of life, family strain and life span. Social support can have different meanings to various people; it can function as a source of information exchange, a foundation for building dependable relationships that promote trust, as well as providing a stable environment during times of chaos. A strong social safety net helps people dealing with illness to better adapt to sudden, unpleasant life changes with a greater degree of ease. The vague, unexpected, subtle and frequently absent symptoms associated with ESRD diagnosis at the onset of the illness contribute to the need for social support. A supportive network of family, friends, and the health-care team can support the person with ESRD.

Credible authority: Credible authority is an essential component of uncertainty for participants having a terminal illness. People living with ESRD rely on health care providers for clarification of diagnostic test results and interpretation of the meaning of symptoms with end stage renal disease. Credible authority describes the ability of health care providers to reduce uncertainty. Health professionals have the ability to reduce uncertainty by providing information and promoting confidence in their clinical expertise (Mishel, 1988).

Cognitive capacities:

Cognitive capacity refers to the cognitive ability of the person suffering with the illness (Mishel, 1997). Information provided by health professionals may not be understood or retained at the end of life period. Nursing assessments to determine comprehension and retention levels of health information during the various stages of terminal illness will help to properly educate patients with accurate knowledge and provide emotional support. Symptoms associated with dialysis treatment, such as fatigue and anxiety may alter a person’s true cognitive ability. Due to symptom variability, coping with the diagnosis of ESRD can be very uncertain. Therefore, structure providers or resources are very important for people living with ESRD.

Uncertainty is a major source of stress for chronically ill individuals (Sarnak et al., 2003). Trying to adequately manage symptoms in the context of a potentially fatal illness such as CKD can significantly alter daily activities that previously gave one's life its meaning. Uncertainty experienced in illness situations in four ways: (a) ambiguity regarding the state of the illness and symptoms, (b) complexity of the systems of care and treatment, (c) lack of information about the diagnosis and seriousness of the illness and (d) unpredictability regarding the disease process and prognosis (Mishel, 1997). Uncertainty has been consistently associated with emotional distress, reduced quality of life, and poorer psychosocial adjustment to illness (Mishel et al., 2005).

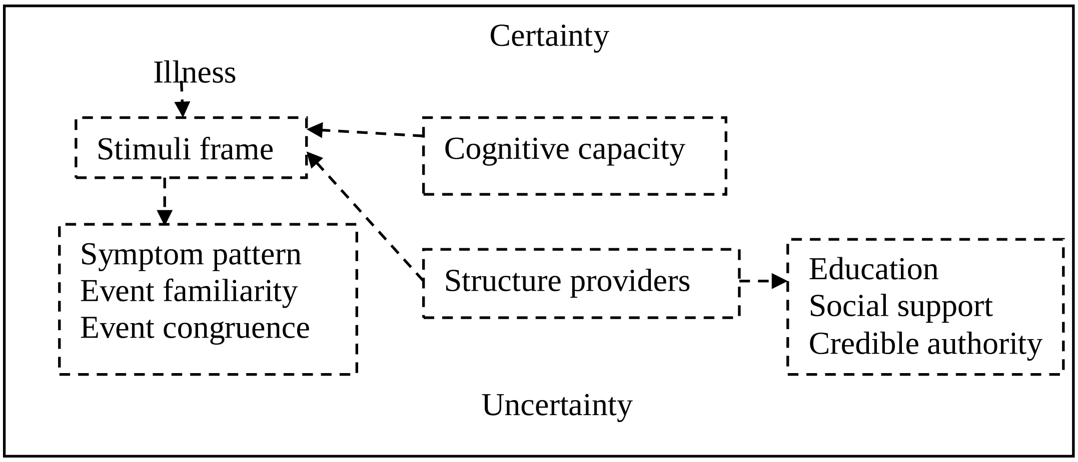


Figure 2.1 displays the interrelationships among the constructs of the Uncertainty in Illness Theory

Nursing implications

Mishel's uncertainty in illness theory provides a theoretical framework for nurses to better understand factors that contribute to uncertainty about disease adaptation and treatment options. Nurses who understand the role that uncertainty plays before and after a treatment decision is made have a unique opportunity in assisting the patient to understand the role of uncertainty on decisions surrounding a new diagnosis. Nurses may consider running support groups or referring patients to them, teaching about the importance of nutrition, exercise, preventing complications and stressing the need for balance in their lives. Providing social support may alleviate uncertainty and assist patients in coping with the diagnosis and making informed decisions. Patients need information about what is happening and what to expect before and after treatment, in addition to encouragement and reassurance that varying degrees of uncertainty are normal and part of the illness continuum (McCormick, Naimark, & Tate, 2006).

The measurement model of uncertainty (Mishel, 1981) incorporated the work of these primary sources to conceptualize uncertainty in illness and to develop the uncertainty illness scale. Drawing from the concepts in chaos theory (Prigogine & Stengers, 1984), uncertainty is viewed as a force that spreads from illness to other areas of person’s life and competes with the person’s previous mode of functioning.

An uncertainty management intervention was initially developed with cancer patients and later with other chronic diseases, including CKD patients on dialysis (Braden, 1998; Mishel, 1997, 2002, 2003). The initial interventions were effective in teaching patients skills to manage uncertainty including improvements in problem solving, cognitive reframing, treatment-related side effects, and patient-provider communication. Sociologists; Crawshaw & Bunton (2009) linked social, economic and technological change to a growth of uncertainty in contemporary society which is experienced by individuals and social groups as a threat to their wellbeing.

For this study applied a modification of Mishel’s (1988) uncertainty theory in the development of a home based palliative care program for people living with ESRD to examine barrier and facilitators which impacted their levels of uncertainty and improved their quality of life.

2.3 The variables concerned with End stage renal disease in home based palliative care and meditation exercise (biopsychological technique)

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness (WHO, 2002). The goal of palliative care is to achieve the best quality of life for patients and their families. Quality of life can be defined as the physical, psychological, social, and spiritual domains of health that are influenced by a person's experiences, beliefs, expectations, and perceptions (Carlson, Devich, & Frank, 1988).

Palliative care provides to relief from pain and other suffering symptoms. It is a philosophy that affirms life and regards dying as a normal process while integrating the psychological and spiritual aspects of care. Palliative care offers a support system to help people living with ESRD live as actively as possible until the last breath as death. This model of care provides a team approach to offering a support system to help the family cope during the patient's illness and later during their bereavement period. For people living in the community with ESRD, the physical problems include managing symptoms such as pain, sickness, tiredness or loss of appetite. Psychological requirements include the need for emotional support from those who care about the people with time to listen and empathy to understand their suffering. Social issues may arise that require support and advice on practical matters. Spiritual crises may lead to the need to explore thoughts about the meaning of life or what happens after death. Persons with chronic, potentially lethal conditions often experience spiritual needs which may be facilitated with an understanding of their religious beliefs.

Three as measures are required a foundation for developing palliative care with a public health approach, a government policy to ensure the integration of palliative care services into the structure and financing of the national health-care system, an educational policy to provide support for the training of health-care professionals, volunteers and the public; and a drug policy to ensure the availability of essential drugs for the management of pain and other symptoms and psychological distress. A public health approach to palliative care is required in all countries in order to address the needs of all patients and their families, ensuring universal access to the necessary services at all levels of care within the health system.

The focus of home based palliative care by families has changed from a simple caring role to more complex care, often involving advanced skills such as drug administration, symptom management and counseling for grief reactions. Grief reactions may occur in stages including denial, disbelief, confusion, shock, sadness, bargaining, yearning, anger, humiliation, despair, guilt, and acceptance. Techniques to facilitate psychological and spiritual healing may include helping the family to accept the death of the loved one, or sharing in their sorrow while encouraging them to talk and share their memories. Palliative care givers should encourage patience with the process of grieving as it can take a long time to recover from a major loss(World health organization, 2007).

Palliative care arose out of the change from acute to chronic causes of death and the emphasis on improving quality of life. Palliative care should become a gradually increasing part of care from life threatening disease diagnosis to death, rather than being concerned only with the terminal phase. A primary palliative care component and appropriate standards could be included in the needs assessment and the contracts for many hospital and community services (Ellershaw & Wilkinson, 2003).

Professional nursing and medical education before 2000 paid little attention to end of life care. Palliative and end of life care content had not been taught as a separate subject, but as a topic integrated into other subjects and into practical training. Moreover, teaching in palliative and end of life care was mainly at the basic level. However, the concept of palliative and end of life care recently became recognized in medical schools and nursing school. Public education has raised the public awareness of death and dying in contemporary society in religious-based, non-governmental, and governmental organizations, particularly public health institutions. Both Thai and Western experts working on palliative and end of life care were invited to share their knowledge and experiences during the establishment of this network.

The goal of palliative care is to improve the patient's quality of life when the patient may desire more than additional medical interventions and the prolongation of life. Community nurses should focus on providing compassionate care in concert with the patient's wishes, which is difficult if those wishes are not known. Nurses witness families in turmoil because they are asked to make decisions about a loved one's care without knowing what the person affected by the illness wants. Developing therapeutic relationships with patients and families provides nurses with the opportunity to be in a prime position to apply palliative care principles, such as advocating for and communicating patients' and family's end of life wishes (Scanlon, 2003). Facing the consequences of a progressive, life limiting illness can exhaust the physical and emotional resources of patients, primary caregivers and their families, and indeed can also deplete those of the health care professionals who care for them. It is essential in a caring and compassionate society, that health and social support systems are developed to ensure that the needs of all these people can be appropriately supported.

Home care: Home care services ease the transition from the hospital to home. Home care services enhance the quality of care at home following hospitalization (Williams, Blue, &Langlois, 1994). Home care patients are readmitted to the hospital less frequently than non-home care patients (Leiby & Shupe, 1992). The concept of home care is composed of continuing care, a holistic approach, self-care, and self-determination. For patients whose disease is not responsive to curative treatment, the control pain and other physical symptoms is as important as support for psychological, social and spiritual problems. The community health service system has to provide integrated health and social services for individuals and families at their own homes within their own communities.

The principles of home-based care are focused on holistic, physical, social, emotional, economic, spiritual, and community needs. These principles are, addressed though the integration of existing systems. They are person-centered, sensitive to culture, religion and value systems; they respect privacy and dignity. Providers of home care can empower and allow capacity building to promote the autonomy and functional independence of the individual and the family caregivers. Leadership needs to come from within the community to ensure access to comprehensive support services. National guidelines on home-based/community-based care allow choice and control over the extent that partners will participate, recognize diversity, and promote and protect equal opportunities, rights and independent living. Home based care adheres to the basic principle in health care and development, namely community involvement and provides a model that looks at a person as a whole, that is, as an integrated combination of body, mind and spirit, situated within a particular family and cultural context. Because primary palliative care manages a variety of conditions in patients at different stages of their illness, it follows that palliative care teams will offer a wide range of care not only in people living with ESRD but also in other chronic illnesses.

Quality of life (QOL): is used to evaluate the general well-being of people living with ESRD. The term is used in a wide range of contexts. The quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging (Frytak & Kane, 2000).The most widely used quality of life instruments in dialysis units, the Medical

Outcomes Study 36-Item Short-Form Health Survey (SF-36) (Ware ,1992) and the Kidney Disease QOL questionnaire (Hays,1994) do not directly assess patient self-report of troublesome symptoms or patient perception of overall QOL(Kimmel,1995). The SF-36also does not measure general life satisfaction, social support, and spiritual beliefs, domains found to be important to other groups of patients with chronic medical illnesses. Recent research suggests that patient perception may be more important than objective assessments in determining the QOL of patients with end-stage renal disease (Kimmel, 2000, Valderrabano, 2001, & Patel, 2002).

For this reason the assessment of quality of life of people living with ESRD has received considerable attention. In the study brought quality of life for dialysis of Ferran and Powers that composed of four dimension subscale; health & functioning, social & economic, psychological & spiritual, and family subscale. These subscales were considered in quality of life for people living with ESRD.

Meditation healing exercise (Biopsychological technique):

Meditation healing exercise is one of the proven alternative therapies in chronic illnesses such as chronic kidney disease, hypertension, cancer, asthma, chronic pain and symptoms that are not eradicated by conventional biomedicine (Ingelfinger, 1977; Bailar & Smith, 1986). Meditation is a method of calm and peace and enhancing its strengths and it is an intensely personal and spiritual experience. Meditation is not a method to solve the problems but to make the mind is relax and become more focus on breath or something deeper level. Meditation healing exercise works by investigating and understanding the nature of the mind. It is seen as nature, to devoid of any solid personality or lasting quality. The desired purpose of each meditation technique is to channel awareness into a more positive direction by totally transforming one's state of mind. The meditation way is to turn inwards, to concentrate on the inner self. So meditation healing exercise is important to help people from inner side to the body. This is accomplished as meditation brings the brainwave pattern into alpha and theta states which are level of consciousness that promotes the healing state.

The entire process of meditation healing exercise usually entails the three stages of concentration, meditation and enlightenment or absorption. The people prepare to meditate by harnessing awareness, such as focusing mind onto an object. Attention gets engaged; concentration turns into meditation and through continuous meditation healing exercise, the mediator merges with the object of concentration, which might either be the present moment. The state of relaxation and the altered state of consciousness were induced by meditation that especially effective in psychotherapy. Moreover, meditation is not necessarily a religious practice, but because of its spiritual element it forms an integral part of most religions. The basic objective of most meditation styles remains the same and it is performed in a state of inner and outer stillness.

There are two types of meditation: concentrative and mindfulness. Each will be described in the following sections.

1. Concentrative meditation focus on the attention on breathing, an image, or a sound in order to still the mind and allow awareness and clarity to emerge. The simplest form of concentrative meditation is to sit quietly and focus on attention of the breath. When the mind is calm and peace, focused, and composed, the breath will tend to be slow, deep, and regular which detection by brain wave. Moreover, focusing the mind on the continuous rhythm of inhalation and exhalation provides a natural object of meditation exercise.

2. Mindfulness meditation consists of opening the attention to become aware of sensations and feelings, images, thoughts, sounds, smells, and so forth without becoming involved in thinking about them. The people sit quietly and simply witnesses whatever goes through the mind, not reacting or becoming involved with thoughts, memories, worries, or images (Alexander, 2007, p73). Mindfulness meditation can be likened to a wide-angle lens, as opposed to the narrowing of sight to a selected field as in concentrative .Research has shown that meditation can contribute to an individual's psychological and physiological well-being (Borysenko, 2010).

The result of meditation:

Common chronic medical problems may be more effectively treated by a new collaboration among the primary healthcare provider and specialists in complementary care, and the patient. In addition, because of the frustration with conventional medical practices, many individuals are choosing to take more personal responsibility for their health by exploring a variety of self-regulatory, mind/body, and wellness practices, independent of the physician's input. Health promotion in chronic illness may be related to conventional methods, such as behavior modification for smoking cessation or weight loss, exercise, nutritional counseling, rehabilitation. Others may employ “alternative” methods by today’s healthcare standards such as acupuncture, meditation, or massage therapy. A growing body of evidence supports the relationship between attitudes, stress, feelings of hopelessness, anger, and loss of control on behavioral and health outcomes, including the ability to cope with illness and the frailties of aging.

Complementary or alternative care refers to those practices that often come from older, cross-cultural perspectives of health and healing, and that often focus on lifestyle reevaluation and the mind/body interaction. Meditation, broadly classified as a technique for working with the mind has been shown to be a proven alternative therapy which facilitates the natural process of getting to know the mind. It allows one to investigate and understand how the mind works and then improves the ability to focus through training. It takes a lot of practice to train the mind. The mind is referred to as the ‘leader’ as it directs the relationship with the world.

Meditation reduces activity in the central nervous system and other functional organs. The parasympathetic branch of the autonomic or involuntary nervous system predominates. This is the branch responsible for calming us. During anxiety and tension states there is a rise in the level of lactate in the blood. Lactate is a substance produced by metabolism in the skeletal muscles. During meditation blood lactate levels decrease at a rate four times faster than the rate of decrease in non-meditators resting lying on their backs or in the meditators themselves in pre-meditation resting. The likely reason for the dramatic reduction in lactate production by meditators was indicated when further studies of meditators which showed an increased blood flow (Davis, 2008).

Lazar (2000) used functional magnetic resonance imaging (fMRI) to identify brain regions that are active during Kundalini meditation as compared to a control period. Primary analysis found significant increases in activation of the putamen, midbrain, pregenual anterior cingulated cortex and the hippocampal/ parahippocampal formation in the meditation period compared to the control period.

Haimerl &Valentine (2001), investigated the effect of Buddhist meditation on intrapersonal (self-directedness), interpersonal (cooperativeness), and transpersonal (self-transcendence) levels of the self-concept. Advanced meditators scored significantly higher than prospective meditators on all three subscales, advanced meditators scored significantly higher than beginners on the interpersonal subscale, and beginners scored significantly higher than prospective meditators on the transpersonal subscale. Only the advanced meditators scored higher on the transpersonal than on the intrapersonal subscale.

Davidson, Kabat, Schumacher, Rosenkrantz ,Santorelli(2003) found that immune function was found to improve following an 8 week meditation program. At the end of the course, subjects were given an injection of an influenza vaccine. Meditation subjects showed a greater increase in influenza antibodies than controls. Similarly, in cancer patients, Carlson, Speca, Patel & Goodey (2003) found that meditation had a number of effects on immune parameters that are consistent with a shift to a more normal profile.

Richard (2003) studied alterations in brain and immune function resulting from mindfulness meditation. He noted that mindfulness meditation produces demonstrable effects on brain and immune function. These findings suggest that meditation may change brain and immune function in positive ways.

Ott (2004) 2004) has suggested that nurses have the unique privilege of witnessing and nurturing the healing process of the whole person, including the mind, body, and spirit. Teaching mindfulness meditation is a nursing intervention that can foster healing. The consistent practice of mindfulness meditation has been shown to decrease the subjective experience of pain and stress in a variety of research settings. Formal and informal daily practice fosters development of a profound inner calmness and non-reactivity of the mind, allowing individuals to face, and even embrace, all aspects of daily life, regardless of circumstances.

Dean (2005) had demonstrated that heart disease can be reversed with a comprehensive program that includes meditations. Many physicians consider meditation a key element of an integrated health program and prescribe meditation as a way to decrease blood pressure, to integrate a healthy exercise program for people with angina, asthma and insomnia. Meditation is safe and easy method to practice balance within a person's physical, emotional, and mental states. It is very simple but can be very beneficial. The use of meditation for healing is not new. Meditative techniques are the product of diverse cultures and peoples around the world. It has been rooted in the traditions of the world's great religions. The value of meditation to alleviate suffering and promote healing has been known and practiced for thousands of years.

Patricia (2006) studied meditative techniques and their impact on immune functioning in cancer, AIDS, and autoimmune patients. This researcher also used meditation in conjunction with neuro-feedback to normalize brain rhythms and chemistry in alcohol and drug addiction, as well as other addictive conditions.

Sompong (2008) found that SKT1 practice in type 2 diabetic patients had beneficial hypoglycemic effect and a slight reduction to systolic and diastolic blood pressure.

Dhar (2009) found that Quantum meditation works at the conscious level far beyond the molecules or atoms regressing difficult disease process with less and less sufferings. According to Ayurveda, human body is created out of consciousness; it first takes form as invisible vibrations called quantum fluctuations before it proceeds to coalesce into impulses of energy and particles of matter. This is where knowledge comes from like underlying intelligence in DNA, the seat of consciousness untouched by disease. One of the most interesting aspects of quantum meditation is prevention of all fetal abnormalities by mother.

In this study, the benefits of mindfulness meditation will be studied using the specialized knowledge technique (SKT) meditation healing exercise developed by Professor Dr. Somporn Kutraradusadee Triamchaisri(SKT).The specific healing technique utilized, the SKT 6(Thai imaginary meditation healing exercises). This concept is a type of biopsychological meditation which releases tension, tightness and gives relaxation to all muscles. It can be broadly classified as a mind–body medicine therapy as it is an alternative care method of healing using visualizations. The SKT 6 affects physical outcomes and the mind. Using guided imagery, it consists of visualization, drawing and using the imagination. This method integrates techniques based on the concepts of psychoneuroimmunology. It encourages people to use creative imagination techniques to decrease negative thinking which can then lead to the process of healing. The SKT 6 technique starts with a focus on the head and moves gradually to the feet to generate a state of mental and physical relaxation. It is relatively easy to practice even with a person living with complications from ESRD. Depending on the condition of the patient, one can practice this technique sitting or lying down on the bed. The meditation instructor will ask the people to focusing on relaxation on each body part. The instructions can be given in people by the teacher of given via a recording on a compact disk (CD).

The method in practice of meditation healing exercise (SKT 6), the method includes 5 steps which include:

Step 1: Prepare the place with quiet place and without any distraction environment

Step 2: Sit or lie down in the convenient place and put arm next to the body and gently closed two eyes.

Step 3: Deep breath and hold for 3-4 second and exhale via nose slowly then deep breath by count 1-5 during inhale and hold for 3-4 second then exhale again. Repeat this step 3 times.

Step 4: Pay attention with the feeling in internal and external organ follow these:

Step 5: Deep breathing do the same as step 3

Step four includes 23 unique cycles which include instructions to relax on various parts of the body – from head to toe. The full set of instructions can be found in the methodology.

From the literature reviewed, the mechanisms associated with meditation healing exercises are summarized in Figure 2.2.

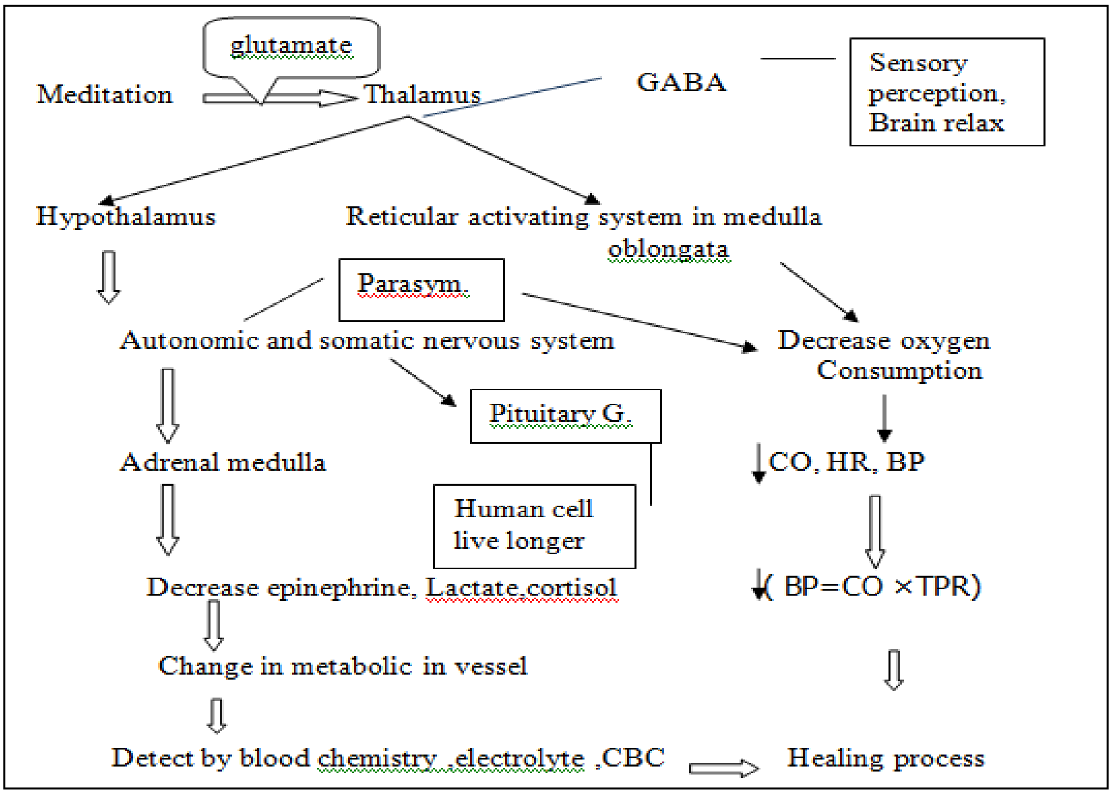


Figure 2.2: Effect of meditation

Management in palliative care model

Management is creative problem solving. This creative problem solving is accomplished through four functions of management; planning, organizing, leading and controlling. The intended result is the use of an organization's resources in a way that accomplishes its mission and objectives and is the method can learn to detect symptoms, recognize diseases and common sense ways to manage and illness. There are many symptoms such as pain, breathing problems, stomach upset, loss of appetite, insomnia, delirium, and even itching which can all be addressed by the palliative care team. For example, pain assessment should include the determination of the cause of the pain using a history and examination by palliative care team members in order to determine proper management. In this study palliative care management will include symptom management for relief of suffering from pain as well as general comfort care for persons with ESRD in the EOL stages. Moreover, this study has developed a meditation intervention to examine its effect on physical and psychological outcomes. Palliative care encourages open communication and truth-telling and empowers the patient to take an active role in the management of his/her illness. This gives the patient a sense of control, which has often been lost in the turmoil of the diagnosis and treatment of the illness. Thus palliative care personnel foster hope in realistic terms such as to gain a full night’s sleep by control of pain, to realize a life-long goal, to reconcile estranged family members and to facilitate a dignified and peaceful death (Gwyther, 2003).

Moreover, in this study has prepared intervention for link physical and psychological with meditation. Palliative care encourages open communication and truth-telling and empowers the patient to take an active role in the management of his/her illness. This gives the patient a sense of control, which has often been lost in the turmoil of the diagnosis and treatment of the illness. Thus palliative care personnel foster hope in realistic terms such as to gain a full night’s sleep by control of pain, to realize a life-long goal, to reconcile estranged family members and at the end for a dignified and peaceful death (Gwyther, 2003).

Management in palliative care is designed to achieve several purposes: assure the quality of the care provided, improve palliative care services, and ensure coordination and continuity of care across providers and disciplines. Palliative care management provides a means for assessing and resolving negative outcomes and events. At its best, quality palliative care management increases the probability of positive patient outcomes and decreases the likelihood of adverse events by continually assessing and improving governance, managerial, clinical, and support mechanisms that directly and indirectly impact outcomes (Kaiser, 2002).The process addresses the interests of several groups of stakeholders: healthcare administrators, program staff members, and, most importantly, the patients and their families. Care management serves two main functions: quality assessment and performance improvement.

Pain management

People living with a life-threatening illness may experience pain. Health care providers work with patients and their families to identify the source of the pain and ways to relieve it. Pain may be managed with drugs or alternative methods such as massage therapy and relaxation techniques.

Symptom management

Often people have to deal with a variety of other symptoms. These can include loss of appetite, nausea, weakness, breathing difficulty, bowel and bladder problems and confusion. Palliative care can help relieve these symptoms, which can be very distressing for the individual.

Social, psychological, emotional and spiritual support

Primary palliative care focuses on the person as a whole by offering a wide range of support services to the ill person. It also offers bereavement support and can help the family work through emotions and grief regarding the illness and death of a loved one.

Caregiver support

Seniors may be concerned about whether they will be able to cope, especially when the person they are caring for is living at home.

Primary palliative care services that help the family cope include:

-Advice and assistance from health care providers such as nurses and doctors who are skilled in providing palliative care; Instruction on how to care for the person (how to give medication, prevent skin problems, recognize signs, call for help, etc.);

-Home support services that provide assistance with household tasks such as meal preparation, shopping and transportation;

2.4 Research methodology review for mixed method research

Mixed Methods Research

Mixed methods research integrates quantitative and qualitative research techniques in the same research in order to answer the research question more than it used to do. This method was originated by the philosophical integration of at least 4 groups of researchers. The first group is positivists, and they mix their belief with the second group who can be naturalists, or constructionists. The mixed group can be called pragmatists, who believe that there are two types of reality as believed by both groups. The third group’s research emphasized both subjective and objective points of view. Population inference and theory of related phenomena are both important (Creswell &Plano, 2007, p 59).

Quantitative and Qualitative Data

Mixed methods research involves both collecting and analyzing quantitative and qualitative data. The collection of this kind of data might also involve using a closed-ended checklist, on which the researcher checks the behaviors seen. Sometimes quantitative information is found in documents such as census records or attendance records. The analysis consists of statistically analyzing scores collected on instruments, checklists, or public documents to answer research questions or to test hypotheses.

In contrast, qualitative data consists of open-ended information that the researcher gathers through interviews with participants. The general, open ended questions asked during these interviews allow the participants to supply answers in their own words. Also, qualitative data may be collected by observing participants or sites of research, gathering documents from a private or public source, or collecting audiovisual materials such as videotapes or artifacts. The analysis of the qualitative data typically follows the path of aggregating the words or images into categories of information and presenting the diversity of ideas gathered during data collection.

Mixing the Data

Mixed methods research provides more comprehensive evidence for studying a research problem than either quantitative or qualitative research alone. Mixed methods research helps answer questions that cannot be answered by qualitative or quantitative approaches alone and mixed methods research encourages the use of multiple worldviews or paradigms rather than the typical association of certain paradigms for quantitative researchers and others for qualitative researchers. It also encourages us to think about a paradigm that might encompass all of quantitative and qualitative research, such as pragmatism, or using multiple paradigms in research. Mixed methods research is “practical” in the sense that the researcher is free to use all methods possible to address a research problem. The value of mixed methods research seems to outweigh the potential difficulty of this approach.

A brief conclusion of the 4 designs of Mixed Methods is as follows (Kundalaputra, 200, p: 57-60).

-Triangulation mixed methods design: this is the research in which quantitative and qualitative methods are simultaneously implemented in order to analyze and combine the findings of the same question. Quantitative and qualitative data analyses are equally applied. After data interpretation.

-Embedded mixed methods design: this is the research, in which quantitative and qualitative methods are simultaneously implemented, but one method is mainly used and the other is embedded in order to answer different research questions. Each research question needs a different method. Embedded mixed methods are implemented when only one method cannot answer the research questions.

-Explanatory mixed methods design: there are 2 phases in this research design. The first phase is quantitative data collection, followed by qualitative data collection in the second phase.

-Exploratory mixed methods design: this research design has 2 phases. The first phase is qualitative data collection, followed by quantitative data collection in the second phase. Qualitative data are emphasized (Creswell &Plano, 2007,p 171 -172).

Triangulation

Triangulation is a term which was used both purpose and design since Denzin’s (1970/78) popularization of it. It was initially conceived as the conduct of parallel studies using different methods to achieve the same purpose, with a view to providing corroborating evidence for the conclusions drawn. It has, in more recent years, often been used loosely as a synonym for mixed methods without regard to either of the conditions inherent in the original concept and has as a consequence lost the power of its original meaning. It has been argued that, in any case, triangulation does not assist validation as each source must be understood on its own terms (Fielding & Fielding, 1986; Flick, 1992). The original model of triangulation assumes a single reality and ignores the symbolic integrationist foundation of much qualitative work which proposes that different methods will necessarily view or construe the object of the research in different ways. And as researchers use different methods, they play different roles and have different relationships with the researched—the latter, for example, being variously labeled as respondents, subjects, participants or informants (Barbour, 1998).

Writing up: Writing mixed methods is rather like writing qualitative analysis. In determining how best to present the ideas and evidence generated through the completed study, the issue becomes one of the degree to which quantitative and qualitative components can or should be integrated. The results and conclusions from one type of data or analysis are presented and then the results and conclusions for the other before an attempt are made to draw them together in a general conclusion.

Ethical Considerations: Relevant of people, authorities and committee are consulted and principles are accepted, all participants must be allowed to influence work and given the choice of opting out, the work must be visible and open to suggestion from others, permission is obtained before observing or examining documents, Must accept responsibility of maintaining confidentiality.

2.5 Framework for program evaluation in public health

This framework was developed by evaluation experts of public health program managers and staff, state and local public health officials, nonfederal public health program directors, public health organization representatives and teachers, community-based researchers, U.S. Public Health Service (PHS) agency representatives, and CDC staff. These information-sharing strategies provided the working group numerous opportunities for testing and refining the framework with public health practitioners.

The framework is composed of six steps that must be taken in any evaluation. They are starting points for tailoring an evaluation to a particular public health effort at a particular time. Because the steps are all interdependent, they might be encountered in a nonlinear sequence; however, an order exists for fulfilling each earlier steps provide the foundation for subsequent progress. Thus, decisions regarding how to execute a step are iterative and should not be finalized until previous steps have been thoroughly addressed. The steps are as follows Step 1: Engage stakeholders, Step 2: Describe the program, Step 3: Focus the evaluation design, Step 4: Gather credible evidence, Step 5: Justify conclusions, Step 6: Ensure use and share lessons learned (Dyal, 1995).

Steps in Program Evaluation

Step 1: Engaging Stakeholders: The evaluation cycle begins by engaging stakeholders. Public health work involves partnerships; therefore, any assessment of a public health program requires considering the value systems of the partners. Stakeholders must be engaged in the inquiry to ensure that their perspectives are understood.

Step 2: Describing the Program: Program descriptions convey the mission and objectives of the program being evaluated. Descriptions should be sufficiently detailed to ensure understanding of program goals and strategies. Aspects to include in a program description are need, expected effects, activities, resources, stage of development, context, and logic model.

Step 3: Focusing the Evaluation design: The evaluation must be focused to assess the issues of greatest concern to stakeholders while using time and resources as efficiently as possible (Taylor, Steele, &Douglah ,1996). Not all design options are equally well-suited to meeting the information needs of stakeholders. After data collection begins, changing procedures might be difficult or impossible, even if better methods become obvious. A thorough plan anticipates intended uses and creates an evaluation strategy with the greatest chance of being useful, feasible, ethical, and accurate.

Step 4: Gathering Credible Evidence: An evaluation should strive to collect information that will convey a well-rounded picture of the program so that the information is seen as credible by the evaluation's primary users. Information should be perceived by stakeholders as believable and relevant for answering their questions. Such decisions depend on the evaluation questions being posed and the motives for asking them.

Indicators define the program attributes that pertain to the evaluation's focus and questions. Because indicators translate general concepts regarding the program, its context, and its expected effects into specific measures that can be interpreted, they provide a basis for collecting evidence that is valid and reliable for the evaluation's intended uses. Indicators address criteria that will be used to judge the program; therefore, indicators reflect aspects of the program that are meaningful for monitoring.

Step 5: Justifying Conclusions: The evaluation conclusions are justified when they are linked to the evidence gathered and judged against agreed-upon values or standards set by the stakeholders. Stakeholders must agree that conclusions are justified before they will use the evaluation results with confidence. Justifying conclusions on the basis of evidence includes standards, analysis and synthesis, interpretation, judgment, and recommendations.

Step 6: Ensuring Use and Sharing Lessons Learned : Lessons learned in the course of an evaluation do not automatically translate into informed decision-making and appropriate action. Deliberate effort is needed to ensure that the evaluation processes and findings are used and disseminated appropriately. Preparing for use involves strategic thinking and continued vigilance, both of which begin in the earliest stages of stakeholder engagement and continue throughout the evaluation process. Five elements are critical for ensuring use of an evaluation, including design, preparation, feedback, follow-up, and dissemination.

Standards for Effective Evaluation

Public health professionals will recognize that the basic steps of the framework for program evaluation are part of their routine work. In day-to-day public health practice, stakeholders are consulted; program goals are defined; guiding questions are stated; data are collected, analyzed, and interpreted; judgments are formed; and lessons are shared. Although informal evaluation occurs through routine practice, standards exist to assess whether a set of evaluative activities are well-designed and working to their potential.

Standard 1: Utility standards ensure that information needs of evaluation users are satisfied. Seven utility standards address such items as identifying those who will be impacted by the evaluation, the amount and type of information collected, the values used in interpreting evaluation findings, and the clarity and timeliness of evaluation reports

Standard 2: Feasibility standards ensure that the evaluation is viable and pragmatic. The three feasibility standards emphasize that the evaluation should employ practical, no disruptive procedures; that the differing political interests of those involved should be anticipated and acknowledged; and that the use of resources in conducting the evaluation should be prudent and produce valuable findings.

Standard 3: Propriety standards ensure that the evaluation is ethical (i.e., conducted with regard for the rights and interests of those involved and effected). Eight propriety standards address such items as developing protocols and other agreements for guiding the evaluation; protecting the welfare of human subjects; weighing and disclosing findings in a complete and balanced fashion; and addressing any conflicts of interest in an open and fair manner.

Standard 4: Accuracy standards ensure that the evaluation produces findings that are considered correct. Twelve accuracy standards include such items as describing the program and its context; articulating in detail the purpose and methods of the evaluation; employing systematic procedures to gather valid and reliable information; applying appropriate qualitative or quantitative methods during analysis and synthesis; and producing impartial reports containing conclusions that are justified.

2.6 Related research

Lewis &Cohen, (**2001**) examined the meaning of a “very good death” while measuring quality of dying among a cohort of persons with ESRD. They reported on that presented of an exceptionally good death after discontinuation of dialysis. The authors traced the evolution of their attempts at measuring quality of dying in patients with end-stage renal disease. The quality of dying tool has corresponding domains to which it adds advance care planning and non-painful symptoms. Quantification of patient deaths combined with descriptive narratives can be used to establish benchmarks for the provision of terminal care. “Very good deaths” need to be recognized and valued as goals for palliative medicine.

Patel, Shah, Peterson& Kimmel (**2002**) studied about psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. They found that religious and spiritual aspects of quality of life (QOL) have not been fully assessed in patients with end-stage renal disease (ESRD) treated with hemodialysis (HD), and that psychosocial factors are associated with patient survival. The relationship between religious beliefs and clinical outcomes should be investigated further in patients with ESRD.

Brumley , Enguidanos & Cherin (**2003**) studied about effectiveness of a home-based palliative care program for end-of-life found that patients enrolled in the palliative care program were more likely to die at home than comparison group patients.

Peter (**2003**) conducted home-based support for palliative care families: challenges and recommendations found that providing adequate supportive services for the families of palliative care patients is a core principle of palliative care. Caring for a patient with terminal illness at home involves a considerable commitment on the part of family caregivers, and attention must be given to the caregiver’s needs as well as those of the patient. Enhanced supportive care strategies can ameliorate the challenges facing families of palliative care patients cared for at home. All health professionals need to improve the standard of family-centered palliative care, and more evidence-based.

Fage & Joan (**2004**) conducted an exploratory study to examine the palliative care role of the nurse working in community hospital: an exploratory study found that this study was to ascertain registered nurses’ and GPs’ perceptions of and influences on the nurse’s role in providing palliative care in community hospitals. They identified six key themes were identified through thematic analysis of the information: communication, teamwork and relationships, holistic care, resources, culture, professional role.

Scott (**2004**) examined the development of developing primary palliative care found that people with terminal conditions should be able to die at home with dignity. Developing palliative care services in primary care is essential for realizing the expectations of dying people. Primary care professionals have the potential and ability to provide end of life care for most patients, given adequate training, resources, and, when needed, specialist advice.

Carney (**2005**) studied about Erectile dysfunction in End stage renal disease: suffering in silence found about Erectile dysfunction (ED) is common in end-stage renal disease (ESRD) patients, particularly those on hemodialysis (HD), in whom the incidence is >80%. Such patients have a reduced quality of life and impaired social function. Furthermore, dialysis/pre-dialysis patients with ED were less likely to use sexual intercourse substitutes or to attempt medical therapy when compared to the normal/mildly impaired group (18% vs. 42%, $p<0.05$). Severe ESRD not only causes ED but is associated with a relative reluctance of patients to seek a remedy despite experiencing sexual dissatisfaction.

David (**2005**) examine about projecting the number of patients with end-stage renal disease in the United States to the Year 2015 found that a Markov model developed to predict ESRD incidence, prevalence, and mortality to the year 2015 and incorporating expected changes in age/race distributions, diabetes prevalence, ESRD incidence, and probability of death. The model predicted that by 2015 there will be 136,166 incident ESRD patients per year (lower/upper limits 110,989 to 164,550), 712,290 prevalent patients (595,046 to 842,761), and 107,760 ESRD deaths annually (96,068 to 118,220). Incidence and prevalence counts are expected to increase by 44 and 85%, respectively, from 2000 to 2015 and incidence and prevalence rates per million population by 32 and 70%, respectively.

Jean (**2005**) studied palliative care in end-stage renal disease: focus on advance care planning, hospice referral, and bereavement found the components of palliative care in end-stage renal disease (ESRD) include pain and symptom management, advance care planning, psychosocial and spiritual support, and ethical issues in dialysis. End-of-life care is not synonymous with, but rather a subset of palliative care. Advance care planning occurs within the patient-family relationship and is a dynamic process that prepares for death, strengthens interpersonal relationships, and allows a patient to achieve control over his or her life.

Robinson & Stacy (**2005**) reviewed the status of palliative care in the community focusing on setting practice guidelines for primary care teams**.** Developing multidisciplinary as opposed to medical guidelines for palliative care allows primary health care teams to create standards that are acceptable to them and stimulates individuals within the teams to accept responsibility for initiating the change necessary for more effective care. The process of facilitating teams to discuss their work allows for recognition and respect of individuals' roles and more importantly provides shared ownership, an important contributory factor in the implementation of guidelines.

Kristine (**2005**) examined a community needs assessment for palliative care services from a hospice organization found that the national interest in increasing access to palliative care grows, hospice organizations may consider expanding their missions to provide palliative care to individuals with chronic and life-limiting illnesses who do not meet traditional hospice criteria.

Cynthia (**2006**) sought to identify the gap of palliative care between research in developing and developed countries .Yet research remains difficult to establish not only in developing countries in Asia but in the more developed countries also. Some of the problems are generic: Lack of resources, Lack of "protected" time for research, Lack of skills in research, Low priority for research. There are specific problems: a frail population worries about consent intrusion privacy, high attrition rate, handling of missing values. Both the subjects & the subject use of proxies, measuring effectiveness of communication, measuring dignity, measuring suffering, and randomized controlled trials, there are many barriers to setting up, research in developing countries in Asia, Time, Money, Expertise, Priority, Research culture aswell.

Dominique (**2006**) studied decision-making and clinical outcomes among Octogenarians with ESRD. It is concluded that beside a patient's individual refusal, late referral, social isolation, low functional capacity, and diabetes may have oriented medical decision toward withholding dialysis in a significant proportion of pre-ESRD octogenarians. Although most patients on dialysis experienced a substantial prolongation of life, identification of mortality predictors in this age group should improve the process of decision-making regarding the expected benefit of renal replacement therapy.

Fayc &Joan (**2006**) examined the palliative care role of the nurse working in community hospital found that the themes were inter-related and gave valuable insight into the multi-dimensional nature and significance of the nurse's role in palliative care in the community hospital setting.

Jayln & Nel (**2006**) review on nurse and palliation in community found that a core component of community nursing practice in Australia was the provision of palliative care; however this area of practice has been minimally researched. Therefore, they undertook a broader review of the contemporary literature in community nursing; palliative nursing; and community nursing palliative care. Community and palliative nurses' ideals for care are compromised by competing practice demands. Changing health systems and philosophical views, limited resources and the perceived 'visibility/invisibility' polarity are identified as major job stressors. Therapeutic use of 'self and interpersonal communications are recognized as contributing to job satisfaction.

Daniel, **Mila & Jeremy** (**2007**) qualitative study examined preferences for place of death with terminally ill patients from the perspectives of general practitioners and community nurses in England. They reported that preferences for place of death frequently changed over time and were often ill defined or poorly formed in patients' minds. This inherent uncertainty challenged the practicability, usefulness, and value of recording a definitive preference. The extent to which the assessment of enabling such preferences can be used as a proxy for the effectiveness of palliative care delivery is also limited by this uncertainty. Generally, interviewees did not find discussing preferred place of death an easy area of practice, unless the patient broached the subject or led the discussions.

Groot, Vernooij & Verhagen (**2007**) research focused on the obstacles to the delivery of primary palliative care as perceived by GPs. The GP response rate was 62.3%. GPs experienced considerable obstacles in all aspects of palliative care. The most prevalent were: problems with bureaucratic procedures (83.9%), the time necessary to arrange home care technology (61.1%) and the difficulties accompanied with the wish or necessity to obtain extra care (56.3%). In general, more years of GP experience and the participation in (multidisciplinary) case discussions were associated with less perceived obstacles. Based on the results of their survey, they concluded that policymakers and practitioners can plan and set priorities in handling the obstacles. There is a high necessity to begin to overcome the barriers within organization and coordination of care.

Richard, Susan, Paula , Rae & Nora (**2007**) conducted a randomized trial of in-home palliative care and reported increased satisfaction with care and lower costs. The intervention consisted of in-home palliative care plus usual care delivered by an interdisciplinary team providing pain and symptom relief, patient and family education and training, and an array of medical and social support services. The control group received usual care only. The results revealed that the patients randomized to in-home palliative care reported greater improvement in satisfaction with care at 30 and 90 days after enrollment (*P*<.05) and were more likely to die at home than those receiving usual care (*P*<.001). In addition, in-home palliative care subjects were less likely to visit the emergency department (*P*=.01) or be admitted to the hospital than those receiving usual care (*P*<.001), resulting in significantly lower costs of care for intervention patients (*P*=.03).In-home palliative care significantly increased patient satisfaction while reducing use of medical services and costs of medical care at the end of life.

Sue (**2007**) developed a new model for delivering short term specialist palliative care at home. The new model offered short-term support for nurses trained in specialist palliative care who provide hands-on care, psychological support, night nursing care, advice and/or support. The service supplemented existing community teams in order to offer a quick response to patient need. The service was evaluated at the end of the first year using two methods: an audit examining the first year's activity; and a questionnaire to health professionals who had used the service. Insight into the origins of referrals, the tasks performed by the outreach nurses and the aims of each patient episode were gained. Healthcare professionals' feedback was positive and gave some areas for suggested improvement. Reflections included issues relating to collaborative working between services, gaining a greater understanding of the problems associated with facilitating a home death and exploring potential areas of service expansion.

Berzoff , Swantkowski & Cohen (2008) conducted focus groups to assist the development of a renal supportive care team. The focus group participants included patients, families, and palliative care staff. The researchers noted that although half a million Americans suffer from end stage renal disease **(***ESRD*), their quality of end-of-life care has been woefully inadequate. Respondents agreed that there needed to be greater education of both patients and families regarding all aspects of the disease process, open communication, on-going support between patients, families, and the staff, continuity of care, pain control, and assistance with advance care planning.

Helen (**2008**) examined supportive and palliative care for patients with ESRD and reported that as the numbers of patients presenting with ESRD increases, more are opting to withdraw from dialysis, often due to increased suffering and poor prognosis related to other comorbidities. As more patients decide to withdraw from, or not to embark on, dialysis, an enhanced approach to assessment and control of symptoms, as well as supportive management is required, including effective and high-quality palliative care. There is a necessity for renal nurses to change from disease management through interventions of a physiological nature to that of providing support and symptom management.

Dale, Petrova & Munday (**2009**) reported on primary palliative care entitled the gold standards framework. The self-ratings of quality found that implementation of the GSF seem to have resulted in substantial improvements in process and quality of palliative care. Further research is required to understand the extent to which this has enhanced physical and psychological outcomes for patients and their family caregivers.

Kristina, Peter & Lynn (**2010**) evaluated three home-based palliative care services in Australia found that while policy promotes comprehensive assessment of family caregiver needs and a plan to adequately meet family caregiver needs within palliative care, there is a lack of studies in the Australian context which examine the current type of assessment and types of care provided to family caregiver. A number of barriers to supporting caregiver were highlighted including lack of resources, and areas for improvement were also suggested by health professionals from the sites.

Related research in Thailand

Silpasuwan's (**1990**) **research examined** attitudes about death and choices related to place of death among of elderly people in Bangkok. This researcher found that 98% of elderly people accept the processes of birth, aging, illness, and death because they cannot be avoided or escaped from. Seventy-one percent reported that they wanted to die among relatives, and specifically 56% reported that they wanted to die at home.

Pucharee (**2003**) studied the effects of using a palliative care model on nurses' job satisfaction and cancer patients' satisfaction of nursing services. Major results of the study were as followed: 1. the nurses' job satisfaction before and after using Palliative Care Model was statistically significant difference, at the .05 level. 2. The patient's satisfaction before and after using Palliative Care Model was statistically significant difference,($p< .05$)**.**

Kittikorn (**2006**) also examined the status of End of Life Care in Thailand where cancer and malignant tumors are the leading causes of death. The hospital admission rate for people with cancer per 100,000 populations has increased from 34.7 in 1994 to 89.4 in 2003(Wibulpolprasert, 2005). Cancer therefore is considered as one of the major challenges facing the Thai health care system. Although the Thai government has developed and implemented the Cancer Prevention and Control program for more than three decades, the majority of people with cancer seek medical treatment only when their cancer is at an advanced stage. Palliative and end of life approaches therefore are appropriate in response to their needs.

Wasinee (**2007**) reported a situational analysis related to palliative care in Thailand. She found that the concept of palliative care has been applied in the health care system in Thailand depends on users' perception and understanding. The types of palliative care could be explained in 3 models of care at difference levels: 1) care which was not applied to full form, the health care providers have provided care to individuals on a case by case basis2) the care which was developing and for delivery to patients in hospital units and wards, and 3) the care which integrated the concept of palliative care, holistic care and applied to ill persons and their families even after death. The third model has only been delivered in the tertiary care system.

Ampornpan (**2008**) conducted a case study on development of a continuity of care model for the elderly with chronic illnesses living in the community. From this study, the needs/problems of care for older people were as follows: 1) older people had inadequate health knowledge; 2) healthcare staff and volunteers had inadequate knowledge concerning care for older people and had no definite plan for continuous care; and 3) no effective cooperation among people in the community.

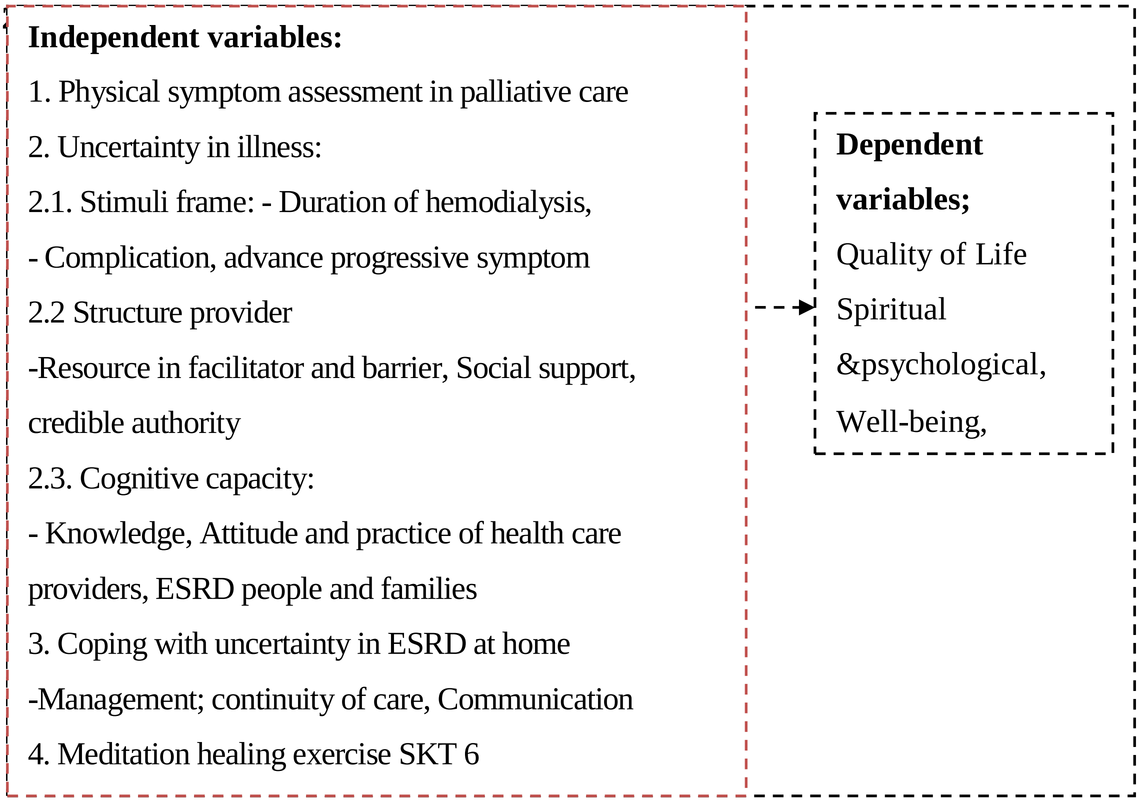
Pisit (**2009**) developed a guideline and model of health management of elderly and chronic patients to improve the quality of their life in a positive and happy environment. Pisit identified 5 necessary it components include: mental health, nutrition, medication compliance, exercise and choosing health service system in the community. The reported quality of using the guideline and model of health management in elderly and chronic patients was in good level (mean= 3.89) and the average of the benefit, the feasibility, the appropriation and the accuracy were 3.76. The key success of this behavior was "discipline".

The most important factor that helped them was the bonding with their social group who provided a source of help throughout their life.

Suzanne, Wowchuk, Lori, Marcelo, Mike & Harvey (2009) studied the palliative medication Kit which is an effective way of extending care in the home for patients nearing death. Community palliative care nurses recommended when to open the kit and received verbal orders from the supervising palliative care physician for the medications to be administered.

2.7 Conceptual framework

The conceptual framework used to examine factors which can impact quality of life, well-being and satisfaction among persons with ESRD in a home based setting in Thailand. Community nurses can provide skilled care to help people self-management their condition or attain a peaceful death, advocate when people need care and support people in decision making, bring caring presence to difficult situations and help patients and families to access high quality and cost-effective care from the health care system.



Independent variables:

1. Physical symptom assessment in palliative care
2. Uncertainty in illness:
2.1. Stimuli frame: - Duration of hemodialysis,
- Complication, advance progressive symptom
2.2 Structure provider
-Resource in facilitator and barrier, Social support, credible authority
2.3. Cognitive capacity:
- Knowledge, Attitude and practice of health care providers, ESRD people and families
3. Coping with uncertainty in ESRD at home
-Management; continuity of care, Communication
4. Meditation healing exercise SKT 6

Dependent variables;
Quality of Life
Spiritual
&psychological,
Well-being,

Figure 2.3 Portrays conceptual frameworks.

In conclusion, palliative and end of life care has become an emerging topic of great interest in Thailand. In community hospitals almost every province incorporates the provision of palliative care in at least one part of nursing care. Future challenges are to make the palliative and end of life care in Thailand more widely used and linked to community. Consequently, the researcher studied guidelines and trends to develop home based palliative care in the community setting in Bangkok, Thailand especially in spiritual and psychological care by applying meditation healing exercise SKT6 in development of home based palliative care for people living with ESRD.

CHAPTER III
METHODOLOGY

3.1 Research Design

This study used a mixed method intervention research study design using a quasi-experimental approach. The aim was to develop and evaluate a home based palliative care model for people living with ESRD. The qualitative component of the study explored the needs of people with ESRD and their families including assessment of their problems and barriers in developing a home based palliative care model. The quantitative component evaluated the impact of home based palliative care model using meditation healing exercise (SKT6) on quality of life, physical symptoms , and level of uncertainty.

3.2 Population and setting

3.2.1 Target population

The target population for this study was Thai people who living with ESRD in stage 5 and who are treated with hemodialysis. The accessible populations include persons with ESRD who live in the Pratumwan, Bangruk, Yannawa, Sathorn district. There were 194 people involving in the study; 120 people in qualitative study composed of 54 people for depicted the needs, barrier or facilitator and 66 people for home based palliative care development; there were 74 ESRD people in quantitative study.

Stakeholders

Stakeholders of the study included the patients, families, community health volunteers, and health care providers in the community. Health care providers included nurses who work in a hemodialysis unit or health centers, social workers, and family medicine doctors.

Inclusion criteria

ESRD people:

(a) Adult men and women with stage 5 ESRD who voluntarily agreed to participate in this study.

(b) Persons described in (a) who are living in the community of Pratumwan, Bangruk, Yannawa, Sathorn district.

Family or caregivers:

Family members of adults with ESRD who voluntary agreed to participate in this study

Health Care Providers:

(a) Nurses who care people living with ESRD in hemodialysis department with at least 3 years of experience who agreed to voluntarily participate in this study

(b) Public health or community nurses who work in a health center or other community based agency who agreed to voluntarily participate in this study

(c) Social workers who work in a community based agency and who agreed to voluntarily participate in this study

(d) Physicians who work with people living with ESRD or work in a community based agency and who agreed to voluntarily participate in this study

Health volunteers:

Lay community volunteers who agreed to voluntarily participate in this study were \Volunteers in the areas of research and willing to participate in the project.

Exclusion criteria:

(a) People living with ESRD or their family members or caregivers who were not willing to participate.

(b) People living with ESRD or their family members or caregivers who live outside of the Bangkok area.

3.2.2 Setting

Setting is the home of people who live with ESRD. The geographic area covers in Pratumwan, Bangruk, Yannawa, Sathorn District/Amphur.

3.2.3 Sample size

In the qualitative study:

The sample size depends on the level of complexity of the problem in qualitative design. Some qualitative experts suggest that fifteen is the smallest acceptable (Guest, Bunce, &Johnson, 2006). This research questions in this study reflected a range of complexity as the purpose was to examine facilitators, barriers, and general concerns of the people living with ESRD, his/her family and the community. Fifteen people living with ESRD were purposively selected, 10 on hemodialysis and 5 treated with CAPD to allow for maximum variation related to treatment types.

In the quantitative study:

Two convenient samples group of people living with ESRD were selected from two wards. The intervention group consisted of 35 people. Who received meditation healing exercises (SKT-6) in a palliative home based care program and 39 controls with ESRD who did not receive the mediation palliative care intervention? Both groups completed a questionnaire which included ESAS symptom assessment (ESAS tool), measurement of their uncertainty in illness (Mishel, 1997) and quality of life (Ferrans and Powers, year). The two groups had the same stage of ESRD and were all treated with hemodialysis.

3.3 Research instrument

3.3.1 The pre intervention stage:

The researcher received training on mindfulness meditation by using the special knowledge technique (SKT6) of. Dr. Somporn Kantraradusadee Triamchaisri (Triamchaisri, 2008). In addition, the researcher studied concepts of palliative care in a course taken at the University of Massachusetts Lowell, U.S.A.

3.3.2 The intervention stage:

3.3.2.1 Instruments for training on mindfulness meditation included a written SKT 6 guideline, and a recorded compact disc with guidelines for Thai imaginary meditation healing exercises.

3.3.2.2 A camera was used as a tool to record the picture of activities in training for palliative care, home based palliative care.

3.3.3 Instruments for gathering information

Quantitative data were used to test the quality of the tools by testing the validity and reliability. The translation process followed the standard guidelines, including forward translation, synthesis of the translation, back translation, and pre-testing.

3.3.3.1 A closed and open ended questionnaire was used to ask the general characteristic of the study participants. It was comprised of a set of questions on gender, age marital status, educational level, religion, length of illness and treatment for ESRD.

3.3.3.2 The questionnaire included symptom assessment, quality of life and uncertainty in illness to document physical, emotional and spiritual suffering. The instruments incorporated into the questionnaire are described next:

Physical symptoms

The Edmonton Symptom Assessment System (ESAS) Guidelines

This tool is designed to assist in the assessment of nine symptoms common in cancer patients. It was deemed appropriate for people living with ESRD symptoms by experts consulted for this study. Symptoms assessed included: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath. The severity at the time of assessment of each symptom was rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 reflecting the worst possible severity. The people living with ESRD and family were taught how to complete the scales. It is the patient’s opinion of the severity of the symptoms that is considered the “gold standard” for symptom assessment however. The reliability test for the Edmonton system assessment system –Revise version (ESAS-R) for progressive symptoms in this study was adequate with a Cronbach's Alpha of .87.

In spiritual and mind suffering will be evaluated by using:

The Mishel Uncertainty Illness Scale (MUIS) was used to assess the construct of uncertainty in illness among the study participants. The Mishel Uncertainty in Illness Scale–Community form (MUIS -C) (Mishel, 1997) is a 23-item self-administered measure. Items are rated on five-point Likert-type scales ranging from 1 (strongly disagree) to 5 (strongly agree). All items are summed. High scores indicate high levels of uncertainty. Construct validity has been demonstrated; internal consistency reliability of the MUIS -C ranges from 0.74–0.92(Mishel, 1990) and after permission requesting in Thai version. In this study, the construct of uncertainty as measured with this tool had a Cronbach's Alpha of .79.

3.3.3.3. QOL in palliative care

To measure quality of life (QOL) the tool developed for dialysis people living with ESRD by Ferrans and Powers was utilized (quality of life index (QLI):© dialysis version – III). The Quality of Life Index (QLI) was developed by Ferrans and Powers to measure quality of life in terms of satisfaction with life (Ferrans & Powers, 1998). Quality of life is defined by Ferrans as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life. The QLI measures both satisfaction and importance of various aspects of life. Importance ratings are used to weight the satisfaction responses, so that scores reflect the respondents' satisfaction with the aspects of life they value. Items that are rated as more important have a greater impact on scores than those of lesser importance.

The instrument consists of two parts: the first measures satisfaction with various aspects of life and the second measures importance of those same aspects. Scores are calculated for quality of life overall and in four domains: health and functioning, psychological/ spiritual, social and economic, and family (Warnecke et al., 1997). Internal consistency reliability of Ferrans and Powers Quality of life index has been reported previously in English speaking: health and functioning scale .87, social and economic subscale .82, psychological and spiritual subscale .90 and family subscale.77. For this study, test for internal consistency reliability of Ferrans and Powers Quality of life index subscales were: health and functioning subscale ,Cronbach's Alpha .88, Social and economic subscale, Cronbach's Alpha .89, Psychological and spiritual subscale, Cronbach's Alpha.87, and Family subscale, Cronbach's Alpha .74.

3.3.3.4 As noted, an in-depth interview was conducted to ascertain examine an in-depth interview on the spiritual aspect of life for the study participants. To guide these interviews, the literature was explored in three major areas: the general needs of the people living with end stage renal disease; problems identified with palliative care in community; and community support for persons with ESRD.

3.3.4 Physical examination form laboratory result

The laboratory examined before on hemodialysis at each month to compare the progression in SKT practice and non SKT practice. The study examined in BUN, Creatinine, electrolyte, albumin, calcium, phosphorus and hematocrit.

3.3.5 Tape recording and Field note

Field notes and a tape recorder were used to record data after the interviews and participant observation. It was very useful for data collection, ensuring the precision of data, and also assisting in the data analysis process. New questions were generated as data were analyzed in an ongoing process.

3.3.6 Focus group, Observation guideline

The researcher observed participants such as their facial expression their attention, ability and any obvious physical sign of discomfort.

3.4 Data collection procedure

3.4.1 Pilot study

Methods in pilot study

The researcher recruited a purposive sample of people living with ESRD and their families from one hospital in Bangkok, Thailand. Participating health care providers were recruited to the study. The first step was to conduct interview to assess the needs of the target group, people living with ESRD and living in an urban section of Thailand. After identifying problems and needs from the preliminary interviews, the researcher conducted 4 focus groups. In each group composed of nurses, people living with ESRD, family, health volunteer. The focus groups were audiotape and later transcribed verbatim. The purpose of the focus groups was to explore the physical, emotional and spiritual needs, problems and barriers in home based palliative care in order to determine the qualitative interview guide. The interviews were audiotaped with permission and later transcribed. In addition the interviewer and an assistant wrote field notes during and after the interview.

After the focus groups were conducted, a survey was designed which included the validated Edmonton Symptom Assessment System revise version(ESAS-r).The ESAS-r was translated into Thai by Jaturapatporn D. and the team from Ramathibodi Hospital, Thailand with the Edmonton group's permission. The tool assesses nine symptoms including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath. It had been used among Thai ESRD persons and validated with this population and this result of Cronbach’s alpha based on standardized items was 0.87.

3.4.2 The data collection in research

Qualitative study

Phase 1: Situation analysis

For this part of the study included: people living with ESRD, their family, community nurses working at health centers, health volunteers, social workers, and medical doctors. By interviewing with 8 nurses, 2 doctors, 15 people living with ESRD, 15 family members, 10 health volunteers, and 4 social workers. Totally 54 persons for identify the needs, barriers or facilitator.

The goal of this stage was to identify people who needed home based care and identify the problems with all stakeholders. 4 Focus groups were set and separate in 2 groups for depict the barrier and needs and 2 groups for depict the structure provider and cognitive capacity.

Method: Group Meeting

Participants identified problems using situation analysis to identify problems and concerns, during an in-depth interview. One way to gain this understanding is by analyzing the **s**trengths, weaknesses, opportunities and threats (SWOT) associated with the existing plan and activities. After the initial interview, the researcher conducted 4 focus groups. The first and second focus group was composed of families, public health nurses, and people living with ESRD. The third and the fourth focus groups were composed of public health nurses, psychiatric nurses, psychiatrists, social workers and/or health volunteers from various community settings. The researcher met with stakeholders by using an in-depth interview process. Using a questionnaire to explore knowledge, awareness, and community concerns, Next, the focus groups gave input in how to provide supportive, home based palliative care; they identified barriers and problems for developing palliative care programs in the community using the SWOT analysis framework. This process was completed within one month.

Phase 2: Model development

For development of home based palliative care model, the participants composed of 12community nurses at health center, 17health volunteer, 3social workers, 2psychiatrist, 2 doctors,1 phamacist,1 physical therapist,13 people living with ESRD ,13 families, and researcher. Totally 64 people join in phase2 for model development.

Step 1 Planning: Group activities in team capacity building

Set capacity building team from community in team home visits in the community. The team was composed of community nurses, health volunteers, social workers, psychiatrists and the researcher. The following steps were completed: The researcher first set up appointments for training of the home based palliative care team including health care providers and the health volunteers. The training included a palliative care concept, SKT technique, activities in palliative care.

Method:

1.1 Group Meeting:

An overall assessment of palliative care needs was based on information about the specific requirements of the patients concerned, as well as those of health-care providers. The purpose of assessing palliative care needs was to organize the services to meet those needs. Participants also discussed their expectations about the project and the application of reflective practice. They also identified methods to ensure confidentiality, trust and respect throughout the study process. .

1.2 Develop personal skills: in home based palliative care and training provided for health care providers in introduction to home based palliative care, communication skills in palliative care, symptom management in palliative care, decision making, and loss, grief and bereavement counseling skills, SKT meditation healing exercise training and for people living with ESRD and families were provided in SKT meditation healing exercise.

1.3 Planning collaboration: Researcher and stakeholders identified the gaps in services, as well as in data and knowledge, with regard to the burden of people living with ESRD and the palliative care services available.

1.4 Set up of study participant roles

The role of the researcher was to conduct focus group and all interviews, analyze them for themes, distribute and analyze survey data, supervise the intervention protocol and evaluate the intervention. The primary role of families was to promote comfort care and daily activities for their member with ESRD. Some also participated in focus groups. The role of health care providers in community was to prepare the educational, materials, conduct basic medical checkup, participate in training or focus groups when available, and participate in reflection of data analysis with the researcher.

Step 2 Improvement and implement: To develop the home based palliative care model

Target population: Community nurses, researcher, health volunteer, families.

2.1 Providing home based in palliative care by collaborating with family and community with the 4 components follows these:

2.1.1 Physical; managing symptoms such as pain, sickness, tiredness or loss of appetite;

2.1.2 Psychological; giving emotional support to the ESRD people and those who care about them, giving time to listen to them and understand their concerns

2.1.3 Social; giving support and advice on practical matters such as getting their affairs in order

2.1.4 Spiritual; a need to explore thoughts about the meaning of life, or concerns about what happens after death. All people are likely to have spiritual needs and some may also have practical things they need to do because of their religious beliefs. For the intervention group, special training knowledge in meditation healing exercise SKT 6 was added to promote spiritual support and healing with the following steps:

The method in practice of meditation healing exercise (SKT 6), the method includes 5 steps which include:

Step 1: Prepare people living with ESRD, the place with quiet place and without any distraction environment, SKT compact disk

Step 2: Sit or lie down in the convenient place and put arm next to the body and gently closed two eyes.

Step 3: Deep breath and hold for 3-4 second and exhale via nose slowly then deep breath by count 1-5 during inhale and hold for 3-4 second then exhale again. Repeat this step 3 times.

Step 4: Pay attention with the feeling in internal and external organ follow these:

Cycle: 1 Start from head and focus the mind with following words:

My head feel to relax, relax, relax, relax, relax
My head feel to relax, relax, relax, relax, relax
My head feel to relax, relax, relax, relax, relax
My head feel to relax, relax, relax, relax, relax, and continue to deep relax
My head feel to relax, relax, relax, relax, relax, and continue to deep relax

Cycle: 2 Start from the forehead and focus the mind with following words:

Forehead feels to relax, relax, relax, relax, relax
Forehead feels to relax, relax, relax, relax, relax
Forehead feels to relax, relax, relax, relax, relax
Forehead feels to relax, relax, relax, relax relax, and continue to deep relax
Forehead feels to relax, relax, relax, relax, relax, and continue to deep relax

Cycle3: Start from the temple on each side of the head and focus the mind with following words:

Temple feels to relax, relax, relax , relax, relax

Temple feels to relax, relax , relax, relax, relax

Temple feels to relax, relax, relax, relax , relax

Temple feels to relax, relax, relax, relax, relax, and continue to deep relax

Temple feels to relax, relax, relax, relax , relax, and continue to deep relax

Cycle 4 Start from the eyelids and focus the mind with following words:

Eyelids feel to relax, relax, relax, relax, relax

Eyelids feel to relax, relax, relax, relax, relax

Eyelids feel to relax relax , relax, relax , relax

Eyelids feel to relax, relax, relax , relax , relax, and continue to deep relax

Eyelids feel to relax relax , relax, relax , relax, and continue to deep relax

Cycle 5: Start from the cheeks and focus the mind with following words:

Cheek feels to relax relax, relax, relax, relax

Cheek feels to relax, relax, relax , relax, relax

Cheek feels to relax, relax, relax, relax, relax

Cheek feels to relax, relax, relax, relax, relax, and continue to deep relax

Cheek feels to relax relax, relax, relax, relax, and continue to deep relax

Cycle 6: Start from the chin and focus the mind with following words:

Chin feels to relax relax relax relax relax

Chin feels to relax relax, relax, relax , relax

Chin feels to relax, relax, relax, relax, relax

Chin feels to relax, relax, relax, relax, relax, and continue to deep relax

Chin feels to relax, relax, relax ,relax , relax, and continue to deep relax

Cycle 7: Start from the lips and focus the mind with following words:

Lip feels to relax, relax, relax, relax, relax

Lip feels to relax, relax, relax, relax, relax

Lip feels to relax, relax, relax, relax, relax

Lip feels to relax, relax, relax, relax, relax, and continue to deep relax

Lip feels to relax, relax, relax, relax, relax, and continue to deep relax

Cycle: 8 Start from neck and focus the mind with following words:

Neck feels to relax, relax, relax, relax, relax

Neck feels to relax, relax, relax, relax, relax

Neck feels to relax, relax, relax, relax, relax

Neck feels to relax, relax, relax, relax, relax, and continue to deep relax
Neck feels to relax, relax, relax, relax, relax, and continue to deep relax

Cycle 9-12 Start from shoulder arm and hand practice the same as cycle 8

Cycle 13 Start from hand and focus the mind with following words:

Hand feel more weight, increase weight, increase weight, increase weight, increase weight
Hand feel more weight, increase weight, increase weight, increase weight, increase weight
Hand feel more weight, increase weight, increase weight, increase weight, increase weight
Hand feel more weight, increase weight, increase weight, increase weight, increase weight
Hand feel more weight, increase weight, increase weight, increase weight, increase weight

Cycle 14-21 Start from chest back abdomen buttock thigh knee foot recall the same word in different position

Cycle 22: Start from foot

Feet feel more weight, increase weight, increase weight, increase weight, increase weight
Feet feel more weight, increase weight, increase weight, increase weight, increase weight
Feet feel more weight, increase weight, increase weight, increase weight, increase weight
Feet feel more weight, increase weight, increase weight increase weight, increase weight
Feet feel more weight, increase weight, increase weight, increase weight, increase weight

Cycle 23 Start from whole body and focus the mind with following words:

Whole body feels to relax, relax, relax, relax, and relax
Whole body feels to relax, relax, relax, relax, and relax
Whole body feels to relax, relax, relax, relax, and relax
Whole body feels to relax, relax, relax, relax, relax, and continue to deep relax
Whole body feels to relax, relax, relax, relax, relax, and continue to deep relax

Step 5: Deep breathing do the same as step 3

2.2 Design home based palliative care model focusing on people living with ESRD’s participation that can support in relief from fatigue and other distressing symptoms, affirms life and regards dying as a normal process, integrates psychological and spiritual aspects of people living with ESRD care, offers a support system to help patients live as actively as possible until death and to help the family cope during the patient’s illness and in bereavement. Preparing SKT6 (the relaxation technique) for people living with ESRD and families would be used in the home based palliative care.

2.2.1 Procedure in home based palliative care development

2.2.2 Discussion of the model of home based palliative care.

2.2.3 Selection of the inclusion criteria for study participants

2.2.4 Set up the model

Model 1 (People living with ESRD in community)

1. HBPC1: Develop relationship

Develop relationship with these activities; Giving people living with ESRD feel warm by creating a therapeutic relationship, explaining objectives, assessing physical, psychological and spiritual symptoms.

2. HBPC2: Develop understanding

Facilitate understanding of treatments and support needed Based on physical symptoms giving nursing care follow that symptom to relief suffering; suggest palliative care at home when appropriate.

3. HBPC3: Develop mindfulness;

Explain more in detail of palliative care and focusing on unfinished business assess acceptance of relative and people living with ESRD.

4. HBPC4: Develop acceptance

Facilitate acceptance and conduct evaluation; follow up; assess psychological need of people and uncertainty of life how to prepare. Evaluate satisfaction of care and quality of life at home.

Model 2 (People living with ESRD and End of life in community)

1. HBPC1: Develop relationship and understanding

Form therapeutic relationship and focus on understanding; explain objectives of assessment for symptoms related to physical, psychological and spiritual health.

2. HBPC 2: Develop mindfulness and acceptance;

Treatment and support of symptoms, suggest palliative care at home, assess acceptance of relatives and patients, and assess the religious and spiritual needs of people. Develop acceptation; follow up, assessment of acceptance or coping with uncertainty life, giving suggestions for preparing necessary documents, to prepare for a good death and for later family bereavement care .

3. HBPC 3: Evaluation and bereavement care

Evaluation satisfaction of care, quality of life of people and family members and follow up after death

Step 3 Review and change

Reflecting: focus group discussion for evaluation whole process

Phase 3: Evaluation

Participants: Representation from each group of all stakeholders

Method: The researcher presents the tentative model. Participants reflect on the model and all processes of the study after the final revision of the model for home based palliative care.

Quantitative study

The totally persons with ESRD in quantitative study were 74 people that divided in two group; 35 people living with ESRD for SKT practice and 39 people living with ESRD for non SKT group.

Step 1 Planning

1.1 The first step was to prepare the sampling method which was a purposive sampling technique to recruit people who living with ESRD from two wards. The case or intervention group was composed of 35 people who integrated meditation healing exercise (SKT 6) in their palliative care program. The control group consisted of 39 people.

1.2 Assessment of general information of sample , quality of life , symptoms ,uncertainty in illness in both intervention and control groups before starting intervention and repeat again after intervention SKT 6 .

Step 2 Explain concept and technique of special knowledge technique (SKT 6) and the time using in practice for 45 minutes in SKT depending on convenient time and record in the practice table. Moreover, explain regarding how this technique helps to relax and to heal the body.

Step3 Action in intervention; the researcher gave a compact disc to the intervention group to practice at home and during hemodialysis treatment for every cycle of hemodialysis treatment and every day for 3 months.

Step4 Evaluation ;the researcher followed the following laboratory results of study participants with ESRD: hematocrit , BUN, creatinine, albumin , calcium, phosphorus before and after intervention of meditation healing technique of SKT 6 in 1,2,and 3 months and in both groups of this study to examine the relationship among these values with uncertainty , progressive symptoms and quality of life in the model.

3.5 Data Analysis

3.5.1. Quantitative data analysis was used to identify areas for improvement for the model of home based palliative care with ESRD;

Descriptive analysis was used to identify demographic characteristics, and the frequency and percentage calculation of the results from the uncertainty in illness questions. Descriptive statistics were used to summarize all data. Examination of the data revealed that they met the assumption of normality necessary for the use of parametric statistical tests. Statistical analyses included repeated measures design, correlations and paired T tests.

To answer hypothesis 1: The outcome of people living with end stage renal disease who received home based palliative care will identify needs and suffering that will be support barriers or facilitators influencing to develop quality of life, the researcher used qualitative study explore suffering and needs to support barriers or facilitators.

To answer hypothesis 2: People living with end stage renal disease who received home based palliative care will decrease uncertainty in illness, physical symptom and will increase quality of life, satisfaction, spiritual& psychological, well-being, the researcher used descriptive statistics to compare before and after received home based palliative care.

To answer hypothesis 3: There are relationship among uncertainty in illness, physical symptom, and duration of starting dialysis in negative correlation and there are relationship of quality of life, satisfaction, spiritual& psychological, well-being, blood test in positive direction, the researcher used Pearson product moment correlation.

To answer hypothesis 4: People living with end stage renal disease who practiced in SKT will decrease uncertainty in illness, physical symptom and will increase quality of life, satisfaction, spiritual& psychological, well-being, the researcher used the paired T test

To answer hypothesis 5: Meditation healing exercise (SKT) will regulate chemical substance test in different time taken and duration on hemodialysis, the researcher used repeated measures design. The measures in blood tests at in 4 time periods: study onset, 1 month, 2 months, and three months.

Repeated –Measures Analysis of Variance:

MANOVA is an alternative to repeated-measures ANOVA in which responses to the levels of the within-subjects IV are simply viewed as separate DVs. In this study, the measurement of chemical substance for electrolyte, BUN, creatinine , albumin, calcium, phosphorus, and hematocrit were taken four times: study onset, at 1 month, 2 months, and 3 months after treatment . Results of blood test were analyzed as a two-way ANOVA, with treatment as a between-subjects IV and tests as a within-subject IV , or as a one-way MANOVA, with treatment as a between-subjects IV and the four testing occasions as DVs. (Tabachnick, (August, 2009)).

Assumptions of Repeated measure Analysis of Variance

1) The individuals represent a random sample from the population, and their difference scores for any one individual are independent from the scores for any other individual.

2) Normality test of normality by Normal Q-Q plot of dependent variable measured at different time;

3) Variances of dependent variable are equal across treatment (Homogeneity of variance).

4) Variance of each repeated measures are homogeneous or compound symmetry Paired Sample T-Test

Paired sample t-test is a statistical technique that is used to compare two population means in the case of two samples that are correlated. Paired sample t-test is used in 'before-after' studies, or when the samples are the matched pairs, or the case is a control study. By using the paired sample t-test, the researcher could statistically conclude whether or not training has improved the efficiency of the group study (Agresti, 2002).

Assumptions:

1. Only the matched pairs can be used to perform this test.
2. Normal distributions are assumed.
3. The variance of two samples is equal.
4. Cases must be independent of each other.

3.5.2 Qualitative data analysis was used to understand and explore the problems of home based palliative care based on data from the focus group discussion. Qualitative in-depth interviews were also then conducted over the course of the three month period. The open-ended guide for the qualitative in-depth interviews was designed using Mishel’s theory of uncertainly in illness with input from focus group participants. Questions related to Mishel’s concepts of structure providers and cognitive ability was explored with people living with ESRD and their family members. In addition the concept of cognitive ability as identified by Mishel was examined to explore the ability to do self-care and receive care from family members. Other supportive care was also explored including support from family, health professionals and other community services. Content analysis was used to identify construct issues and common themes. This study used data triangulation through data collection from many sources in order to identify major issues. This method helped to validate the method as it allowed data from observation and interviews to develop a coherent meaning and structure of the experience of living with ESRD in the community setting. All audiotapes of interviews were transcribed verbatim. The researcher read each transcript carefully to maximize the understanding of the interview data.

3.5.3 Evaluation of the program was facilitated by using a framework for program evaluation in public health. There were 6 steps: Engage stakeholders, Step 2: Describe the program, Step 3: Focus the evaluation design, Step 4: Gather credible evidence, Step 5: Justify conclusions, Step 6: Ensure use and share lessons learned. The method used both quantitative data in quality of Life of persons with

ESRD, chemical substance result, satisfaction, well- being and qualitative data: participation rate, Continue monitoring Training, Qualitative need assessment Assess feasibility, Acceptability

Establishing trustworthiness

In order to ensure trustworthiness of the qualitative components of this study, the researcher selected the criteria in evaluating qualitative research using the criteria of Lincoln and Guba (1985). Lincoln and Guba posit that trustworthiness of a research study is important to evaluate its worth. Trustworthiness involves establishing:

Credibility - confidence in the 'truth' of the findings.

Transferability- showing that the findings have applicability in other contexts

Dependability- showing that the findings are consistent and could be repeated

Conformability – a degree of neutrality or the extent to which the findings of a study are shaped by the respondents and not researcher bias, motivation, or interest.

3.6 Ethical Consideration

3.6.1. Protection of Human Subjects

The research procedures and subject consent forms were approved by the Ethics Committee of the Public Health Faculty, Mahidol University. The researcher gave participants information about the purpose of the study, the method, and benefits of this study. The researcher obtained a written consent form prior to conducting interviews from all participants.

3.6.2. Protection of confidentiality was assured through the use of confidential record keeping and no names were used in the study; all participants remained anonymous. The participants had the opportunity to ask questions and to decline or agree to participate in the study. Those who agreed to participate were asked to sign a consent form or to tape record their verbal consent. Participants had the right to refuse to sign the consent and not participate in the study and could withdraw at any time without negative consequences. Throughout the process, participants had the right to be protected from any possibility of discomfort or excessive burden.

Research framework

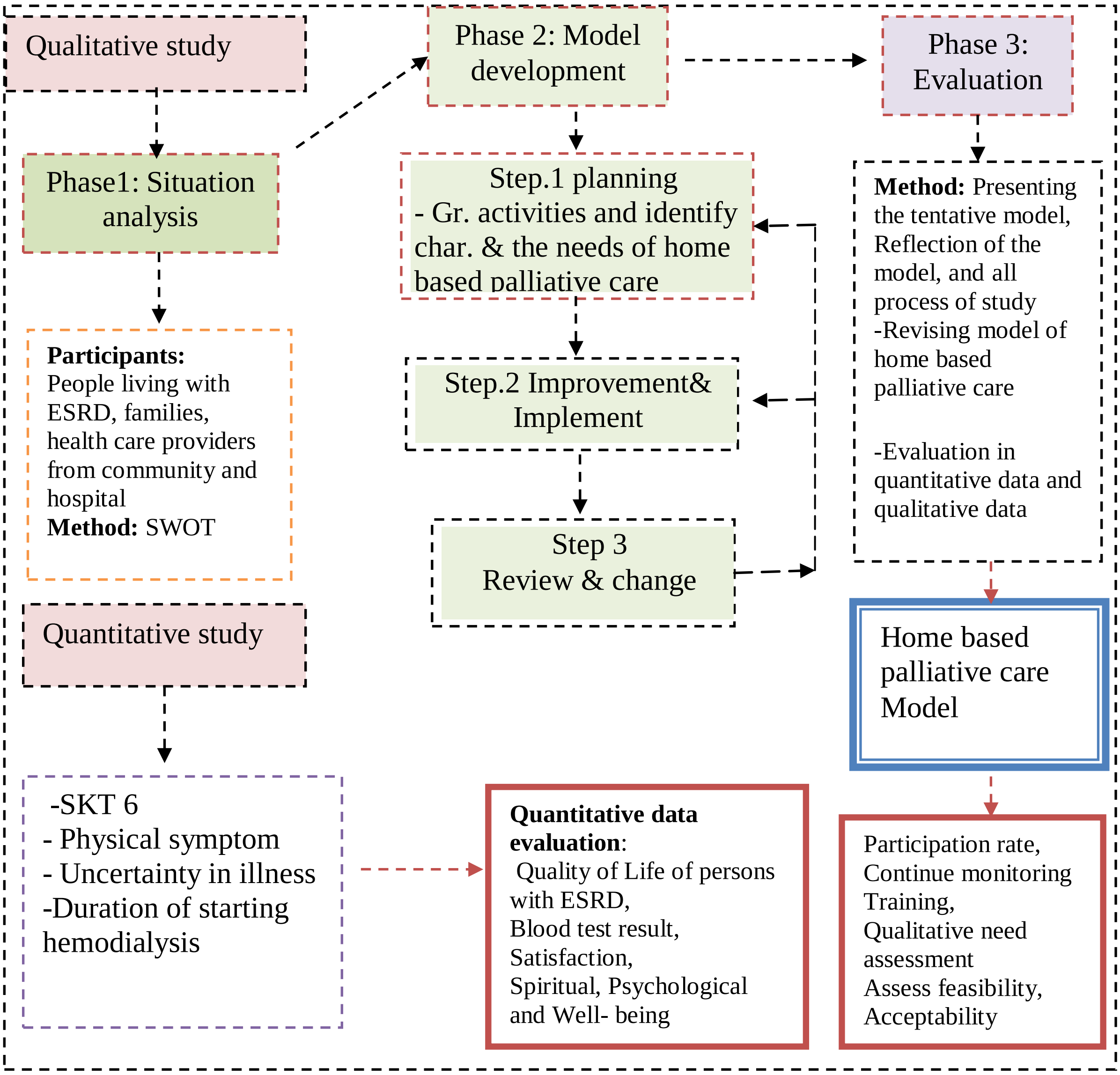


Figure 3.1 Depicts the research framework followed in this study to guide the complex process and multiple imbedded methods

CHAPTER IV

RESULT

The results of the development of the home based palliative care model for people living with ESRD are presented in the following sections:

4.1 General information of people living with ESRD and families

4.2 Depiction of palliative care needs of people living with ESRD and families, barriers, facilitators based on the uncertainty in illness theory of Mishel and coping with uncertainty in illness

4.3 Development of the model of home based palliative care for people living with ESRD

4.3.1 Model development

4.3.2 People living with ESRD undergoing with hemodialysis and continuous ambulatory peritoneal dialysis (CAPD)

4.3.3 Life satisfaction, well-being and psychological and spiritual aspects on home based palliative care

4.3.4 Evaluation: the home based palliative care model for people living with ESRD by using framework for Program Evaluation in Public Health

4.4. The result of meditation healing exercise SKT6 in people living with ESRD

4.4.1 General information of people who living with ESRD and families

4. 4.2 Depict palliative care suffering and needs of people living with ESRD people and families, barrier, facilitator and coping with uncertainty

4. 4.3 The model development of home based palliative care for people living with ESRD

4.4.4The results of meditation healing exercise SKT6 in people living with ESRD

4.1General information and assessment of people living with ESRD and their families

Quantitative data study

General information about people living with ESRD and families included age, gender, marital status, education, employment, and right in the type of health coverage**.** The average age of ESRD people was 65.63 years. Most of people living with ESRD were men (52.71%), and married (47.29%).This study was conducted in a private hospital so the number of patients who used out of pocket payment was the highest (55.41%). The general information is summarized in Table 4.1.

Table 4.1 Description of people living with ESRD in the study

Characteristic	Number	Percent
Age(range,year)		
41-50	12	16.21
51-60	17	22.97
61-70	19	25.68
71-80+	26	35.14
Gender		
Male	39	52.71
Female	35	47.29
Marital status		
Married	35	47.29
Single	14	18.92
Divorced	7	9.46
Widowed	18	24.33
Education		
Primary school	22	29.72
Secondary school/Technical school	33	44.59
Bachelor degree	19	25.68
Employment		
Employed	36	48.65
Unemployed	38	51.31

Characteristic	**Number**	**Percent**
The right in type of health coverage		
Out of pocket scheme	41	55.41
Social security scheme	21	28.38
Government servant welfare	12	16.21
Total(N)each part	**74**	**100**

For families or care givers in this study, most of people living with ESRD had families and some families hired caregivers to care for them during on hemodialysis and to help them get to the hospital. Most of care-givers were women (78.38%) and they were single (48.65%). Most of them graduated from secondary or technical school (55.41)

Table 4.2 Description of families / care giver.

Characteristic	**Number**	**Percent**
Age(range, year)		
20-30	11	14.86
31-40	33	44.59
41-50	21	28.39
51-60	9	12.16
Gender		
Male	16	21.62
Female	58	78.38
Marital status		
Married	24	32.43
Single	36	48.65
Divorced	5	6.76
Widowed	9	12.16
Education		
Primary school	11	14.86
Secondary school/Technical school	41	55.41
Bachelor degree	22	29.73
Total	**74**	**100**

Physical assessment

Physical assessment in persons with ESRD was assessed by Edmonton symptom assessment system (ESAS).The ESAS is a widely used, for assessing nine common symptoms in palliative care, with ratings ranging from 0 (none, best) to 10 (worst).The minimum of total score in ESAS was 0 and the maximum was 61 with a mean of 21.59 and a standard deviation of 16.68.The symptoms identified in the ESAS scale is shown in Table 4.3.

Table 4.3 The Edmonton Symptom Assessment System (ESAS) results reported by study participants

Symptoms	Number	Min-Max	$\overline{X} \pm SD$
Tiredness	74	0-10	3.50±2.46
Well being	74	0-10	2.79±2.78
Drowsiness	74	0-8	2.72±2.26
Pain	74	0-10	2.54±2.53
Shortness of breath	74	0-8	2.28±2.45
Anxiety	74	0-10	2.14±2.57
Lack of appetite	74	0-10	1.97±2.43
Other symptom	74	0-10	1.62±2.19
Depression	74	0-10	1.49±2.16
Nausea	74	0-10	1.35±1.95

Table 4.3 reveals that tiredness had the highest mean score among the symptoms (3.5). The second highest scored symptom was well being (2.79) which referred to quality of life of people living with ESRD and the third was drowsiness (2.72). Nausea (1.35) had the lowest mean score of this study it was the least problematic symptom experienced by the study participants.

Duration on hemodialysis

Participants reported a minimum of 3 months duration on hemodialysis: the maximum time reported was 12 years. The mean reported duration on hemodialysis was 2.91 years (SD 2.38).The data are displayed in Table 4.4.

Table4.4 Duration on hemodialysis

Years on hemodialysis	Number	Percent
<1 year	6	8.11
1-3 years	35	47.29
>3-5 years	21	28.38
>5-8 years	4	5.40
>8-11 years	3	4.06
>11 years	5	6.76
Total	74	100

Complication of persons with ESRD

The study participants reported complications from dialysis including edema (83.78%), pallor (81.08%), itching (uremic) (70.27%). Most of the people living with ESRD also reported related co-morbid conditions such as hypertension, diabetes and heart disease. In addition, some study participants who were treated with CAPD reported complications such as infection, general uncomfortable feelings from dialysis, and lethargy.

Table 4.5 Complication of people living with ESRD

Complication	**Number**(**74**)	**Percent**(**%**)
Edema	62	83.78
Pale	60	81.08
Numbness	50	67.56
Uremic pruritus	52	70.27
Hypertension	67	90.54
Diabetes	52	70.27
Heart disease	32	43.24

According to Mishel (1988) uncertainty exists when an individual is unable to determine the meaning of illness-related events. It is the cognitive state created when the person cannot adequately structure or categorize an event because of lack of sufficient cues (Mishel, 1988). Uncertainty arises when illness experiences are unfamiliar, complex and unpredictable. This study used Mishel's uncertainty in illness theory, community form as a framework. Mishel uncertainty in illness scale – community (MUIS-C) is composed of a 23 item scale. A score was obtained for the total scale which represents the one factor. Scores can range from 23 to 115. High MUIS-C scores indicate greater uncertainty. The results are shown in Table 4.6.

Table 4.6 Mishel's Uncertainty in Illness Scale-Community Form(MUIS-C)

	N	Min-Max	$\overline{X}$ ±SD
Uncertainty in illness	74	29.00-86.00	50.65±11.44

Table4.6 reveals that the minimum score of uncertainty in illness was 29 and the maximum score was 86. The mean score of 50.56 on a possible range of 23-115 suggests that the study participants with ESRD scored in the middle range for uncertainty in illness.

Table 4.7 displays the Ferrans and Powers Quality of Life Index (QLI) scores with a possible range from 0 to 30. The possible range for the final scores is the same for all four subscales and for the overall (total) score. Consequently, the sample's overall mean score of 19.38 reveals a rather low overall QLI. The highest score was the family scale index (21.8) whereas the lowest score was the health and functioning index (17.43).

Table 4.7 Quality of Life Reported by ESRD Study (N= 74)

Scale	$\overline{X}$ ± SD
1.Health and Functioning	17.43±4.94
2.Social and Economic	19.70±4.21
3.Psychological /Spiritual	21.25±5.26
4.Family scale	21.80±5.51
Total QoL score	19.38±4.24

4.2 Depict palliative care suffering and needs of people living with ESRD and families, barriers or facilitator and coping with uncertainty in illness

Qualitative data study:

4.2.1 Depict palliative care suffering and needs of people living with ESRD and families, barriers or facilitator

Mishel's uncertainty in illness theory was used to depict suffering following these

Stimuli frame;

a) Symptom pattern;

Tremendous suffering including stress and exhaustion

After diagnosis with ESRD, the affected person must face a life with hemodialysis or peritoneal dialysis treatment. Many people living with ESRD said that they felt stressed trying to manage many things for their life around the ESRD treatment. They did not want to have to be treating with dialysis. They tried to avoid this until they could no longer live without the treatment. Most of the families' schedules were disturbed with the need to make the arrangements to take the patient to the hospital for dialysis treatments. Not only were the people living with ESRD stressed but also the families experienced stressed with this burden. The participants shared their experiences of not only physical suffering from the disease but also emotional and economic consequences. One of people living with ESRD said "I work in my own business. Since the doctor diagnosed my kidney problems, I need hemodialysis treatment. Now I am so tired I cannot do my business all day. After dialysis treatment which takes a half day I lose this time and also need the rest of the time to recover but my life is not complete like it was formerly." In contrast, several people living with ESRD mentioned that their overall well-being was better after hemodialysis treatment.

This theme reflected suffering at a physical, emotional and spiritual level. Although the basic philosophical assumption of palliative care is to encourage people living with ESRD to play an active role in self-management in order to optimize energy and function, this was not always achieved as a result of the complexity of symptoms. Another ESRD participant shared that he knew his life would be coming to the end soon. He felt bad and sometimes did not want to do dialysis and had requested to die at home. One woman said "Why do I suffer so much in my life and it is not only from the disease but also as part of a couple?" She had lost her husband through divorce which she attributed to her illness. Their real struggles were emotional and spiritual. Many people wrestle with letting go. As one participant commented “I want to stop dialysis treatment; I don’t have anything to inspire me to live longer”.

During in-depth interviews, the ESRD participants shared many problems as their symptoms progressed over time. They shared stories of tremendous suffering including severe bone pain due to poor circulation which led to gangrene and amputation of the toes. Some participants with ESRD shared stories which reflected their ability to adjust to the demands associated with ESRD over time. At times they attributed the dialysis itself as the cause of improvement in their symptoms to some degree. Before this treatment I felt so uncomfortable inside myself. I lost appetite, and thought everything in my life was boring”. One of them said “I am feeling blue and get bored in everything in my life” “I feel so bad because all these symptoms have changed my life”. Moreover, 5 people living with ESRD were talking about the idea of committing suicide when they got ESRD. One of these people living with ESRD had led to financial problem related to the cost of the treatment with hemodialysis. She said “How can I live with this disease? It costs too much money”.

Hope to have new life with new kidney

Many people living with ESRD who were older did not want to have a new kidney but they wanted to have the best quality of life as possible during this time. Some prayed to recover from the disease. Many of them said “It is very good luck without dialysis and this disease”. Some of them wished to have a grandchild, money, and/or travel around the world. One said “My life after treatment with dialysis means that I never go to some places, just only to the hospital and home”. The younger people living with ESRD expressed the need to get a kidney transplant. Many hoped while waiting for a kidney donation from someone. One said “I want to have new kidney and I ask many doctors when I will get it?”

Hope to have happiness return to life

Many relatives want to have a good quality of life after one member of the family got this disease. One relative said “My happiness has gone away but I hope my mom will get better and have less complication”. Many relatives spoke about money for use in treatments and finding the good places to go for dialysis because many relatives believe that many people living with ESRD die during hemodialysis which led many to have a feeling of fear related to hemodialysis treatment. In the hemodialysis clinic, one relative stared at her relative during hemodialysis until the nurses asked her why she stared a lot. She told them that because so many people have negative beliefs about hemodialysis, she feared her mother might be harmed from the treatment.

b) Event familiarity;

People living with ESRD reported that this disease leads to severe suffering not only physical, but also psychological and spiritual suffering. Most of the ESRD participants talked about their difficulty in adjusting to their life and coping with this disease. The event familiarity included concern about suffering related to:

Psychological and Spiritual aspects

Fear to have a tube for treatment

One participant said “I felt terrified to have a tube in my body. When the doctor mentioned about CAPD and HD for treatment, I was so scared therefore I needed some time to calm down and cheer up”. One said that “first of all to have a tube or line for dialysis made me feels scared, like my life was on a thread and this led to uncertainty in life”. One said “I was so scared about the tube or line when I saw a patient who had it. I am afraid to have it because it does not only look scary but I also do not know how to handle it”. Among the sample interviewed, many of them tried to avoid or delay for treatment with dialysis until they were admitted to an intensive care unit (ICU) and after that they started on dialysis. One shared her experience in the dying process due to waste products in the body until the doctor said sorry she died, Dr. could not help. One of them said “I am feeling that what really makes these decisions hard choices’ is to include dialysis in the decision process.

Many people living with ESRD perceived that this disease requires severe restrictions in food intake. ESRD changed eating behavior. The diet had restrictions in food and liquid intake, including water. One said “First time in changing my eating behavior I felt suffering from being limited in drinking water;

even though I felt very thirsty I just only could put ice in the mouth. For food I cannot eat everything I used to so I was thin and tired. Later I ate more and learned about the food I can eat".

Tolerate life

These words "tolerate life" came from many people who suffered with ESRD. One of them said "To live with this disease we must tolerate a different life, if we did not tolerate it we will die. You know, my relative got this disease and she was bored with hemodialysis which took many hours, three times per week then she did not want to be on hemodialysis .She died just only a few months after she stopped the hemodialysis. Whoever has this disease must have high tolerance". The others said "my life has no choice. Since I have gotten this disease, my life has been changed and I must tolerate it". One said "my body and my mind have to be strong in order to cope with this disease". Many of them said about "during on hemodialysis for 4-5 hours, it was so boring to be in line or sit at the same position but we have to be patient".

High level of responsibility to get a cure

Many people living with ESRD said that whoever gets this disease must have a high level of responsibility to continue the treatment. In addition one has to spend a lot of money to cure this disease. One of the study participants shared: "For me, I am fortunate enough to have a lot of money. I had even donated 10 million baht to the public hospital but at the present I have to save all my money for the hemodialysis. I paid it out of my pocket because I do not want to use a free service as a VIP member of the hospital due to unimpressive service there". One said "My life has been changed. I have to wake up very early many times because of the hemodialysis treatment schedule. There are so many people living with ESRD at the hospital; therefore I cannot choose the time that is convenient for me".

Hemodialysis for survival

Many people living with ESRD said "the hemodialysis is the most important thing at this time of my life, without it we might be dead soon so the hemodialysis is for survival". One of them said "I am old and I don't want my daughter to donate a kidney for me even though she wants to so I decided to continue my life with hemodialysis". One guy said I have never thought about kidney transplant not only because of the high cost but I also don't want to take a kidney from my son. One of them said "if someone wants to donate the kidney, I would much appreciate it". These feelings were linked with a physical concern as well. One said "I fear to die alone because no one stays at home during the day" "I have feelings of faintness and vertigo quite often so I must be careful".

Bad karma from the former life

Many people living with ESRD felt that they got this disease because of bad karma in the former life so in this life they must be patient and live with this disease. One said "I got this disease because my life was so busy and stressful from lots of business. It might be that the former life I must take care of a lot of people so in this life I must manage everything for many people".

c) Event congruent

From the expectation of outcomes and actual outcomes of people living with ESRD and families, the following themes emerged;

Lost happiness

One of relatives said "I don't think before this disease came that my mom and I were unhappy". One of the family members shared: "My happiness has gone after my mom got this disease. We used to be happy from travelling, shopping, and eating but now my happiness has gone".

Confusion about life

When one a family member got the ESRD diagnosis, there were many things that occurred at home. First of all, a non-affected family member needed to plan to take responsibility for the people living with ESRD. The families identified someone to take care of the people living with ESRD. If the family had many sons or daughters, the families identified someone based on marriage status. The single one would typically be chosen to take care of the sick family member. In terms of expense, the family would pay for the treatment and the caretaker. In addition, the care taker could be chosen based on educational level. One who has lower educational background than others in the family was typically chosen to care for the family member with ESRD.

Many families said that this disease was bad news for them. The families need to share their thoughts with each other in order to cope with this disease because it disturbs so many people in the family. They identified someone to look after the patient but the family members were still often confused about the disease, how to organize their life, how to cope with the disease, and how to continue their life with this disease. One of the family members had bad experience with this disease in the past and believed that whoever gets this disease it will mean death soon. One son shared his story that he stared at his mom during hemodialysis treatments all the time until the nurse found out that he misunderstood the disease.

For some family caregivers, the physical, emotional, financial and social impact of providing care for their relative was accentuated by social burdens such as restrictions on personal time, disturbance of routines and diminished leisure time.

Losing the job

Not only did people living with ESRD lose their job but also many relatives of people living with ESRD lost their jobs. One relative said “I am worried about the future due to retirement from the job”. One said “After I knew my mom was ill with ESRD, I decided to quit my job immediately because her life is so important to me. I have only one mom so I have to take care of her the best I can and my family can help to support the expense”. In one case a man resigned from his job because he had a lower income and lower education than everyone in the family. He said “I have to take my mom to the hospital and help her in daily activities. My brother helps with the expense but we have to use it carefully. Right now I do not care about my life; I just want to only care for my mom”.

This disease not only caused suffering in the people living with ESRD but also in relatives. During visiting his relative with ESRD in the community one relative said “Ta, you should hang yourself, I am so sick of you with all of these complications and complaints all days. I spend lots of money and time to take care of you. I do not even have time to have breakfast yet”. This is the reality of life in the community when one participant’s husband got ESRD. Even though in this case, the patient had a gold card in Thailand, which means treatment in health care is free still there were uncovered expenses such as travel to the hospital. When they went to the hospital they cannot go by bus because of his poor condition and thus had to take taxi which was a lot more expensive.

Live for the day

Many people living with ESRD said with this word “I live for today and do not think about anything else in my life”. Many of them said “I think only about today, I don’t think about tomorrow”. “My life was terrified by this disease”. One said “I don’t know what I am living for?” One said “I am still breathing but my life is so boring. I just spend time waiting for the treatment”.

Mishel’s Uncertainty in Illness Theory was used to depict needs following these constructs:

Structure provider

Inadequate community supports

Another major finding from the interviews with ESRD participants and their family members was that supportive services in the community were not adequate. In addition, several noted that teamwork among clinical staff and home-based care services in the community was not effective which also resulted in a diminished capacity to care for their loved ones. Several people living with ESRD and their family members expressed the need for support and EOL care for them as they learned to navigate this disease in the home setting. The study participants recognized the need for professional caregivers and family members to work together so that families and those living with ESRD can learn about the process of dying and how to best provide end of life care.

Over half of the family members thought that there was not enough emotional support for them especially in the community where existing palliative care networks or resources to service end of life care are scare or nonexistent. Even the health care provider study participants from the two health centers in Bangkok identified deficits in knowledge and palliative care capacity in the community and home setting for people living with ESRD. One provider asked “What is palliative care in the community? I want to learn more about this technique. Another provider shared “It is difficult to practice palliative care, we don’t have the tools.” The providers concurred that more attention needs to be paid to palliative care in the home setting. They suggested that it would be beneficial for people living with ESRD and their family members to have access to a standardized palliative care program in the home and community setting.

Challenge to do the new things

Based on interviews of the public nurses who worked in community they said that “it is interesting to do the new thing in community such as palliative care in community ” One of them said “ I have never thought about this care but I did not know what we need to do, how can we set up home based palliative care. I appreciate the need to work in palliative care on the community level”. On the other hand, some said it is not practical to set up home based palliative care at the present because of the heavy case loads of community nurses. One commented that “it is difficult to develop a new thing in the community”. These were needs for information to develop home based palliative care at the community level for public health nurses.

Economic consequences

Many people living with ESRD and their loved ones were concerned about the future. As one participant noted, it was quite difficult to become accustomed to this disease which causes physical suffering and also resulted in significant economic consequences. Many were forced to retire early. The economic consequences also affected their self-image as a provider of the family in many cases as well as their ability to secure economic necessities they has previously been accustomed to. It was difficult for some family caregivers to manage multiple responsibilities and take care of their own needs in addition to the demanding needs of their sick relative.

Social restriction

Many people living with ESRD complained about how their activities changed after dialysis treatment. One said “Before dialysis treatment I usually go outside with my friend in group meeting but now I changed my behavior with my group”. One said “even though I want to travel but I cannot due to many factors. When I went somewhere it did not make me feel happy, instead I felt tired”.

Cognitive capacity

How do we do? , **How do I do?**

Many people living with ESRD and families raise this question .How do they do the hemodialysis treatments? , How do they treat this disease? How do they adjust to the changes in life for both patient and family? How do they manage with this disease? These questions meant that they need coping strategies for life and they expressed the need for some help with suggestions and planning.

What is palliative care in community and how can it be set up?

To examine the knowledge in palliative care among health care provider interview were conducted with 12 community nurses, 8 health volunteers, and 4 social workers. There were many questions from health care providers such as "Is there a model of this care for the community?" "What is palliative care in the community?" "Can you give me some idea in this aspect?" "What would be the outcome of palliative care?" "How can we set up home based palliative care?" The data reflected health care providers need for an increase in cognitive capacity/ knowledge.

Attitude toward palliative care in people living with ESRD

Death is near and coming

Most of the people living with ESRD felt that life with this disease was terrible and they felt despair. Some people living with ESRD however had a different attitude about death, that it was not terrible for them if they would soon leave from this world. The attitude about life in this case was not important. One man said "I live for the death whenever it is coming, I will have independent life." One woman said "I prepare for death. I am not afraid of the death." Moreover most of people living with ESRD mentioned that they have accomplished many things in life and that death is a normal process in life. One said that "palliative care is good for this disease because it involves so much suffering". One participant asked what it is, how does palliative care help me? These were reflections on the attitudes from people living with ESRD. The data showed that people living with ESRD had to prepare both physically and mentally to accept their fate as part of a normal cycle of life. They did not seem to express the awareness of the process of preparing for death including such challenges as how to prepare for death and die peacefully following the tenets of their respective religions.

The disease from hell

Many relatives found that this disease disturbed their lives and made everyone feel unhappy. One said that "Once this disease occurs with someone you know well, you will know the hell that is now part of their life”. One said “you know without this disease is the excellent gift of the life, with the disease everything in life has changed”. Most of them did not think about how to provide palliative care for people living with ESRD. When palliative care was mentioned, most of them agreed with the process of dying without resuscitation. Many families tried to encourage the people living with ESRD to have hope. Most of them preferred to die at home but in case of emergency they preferred to go the hospital. However, at the end of life, most preferred to go back and die at home.

Practice in palliative care of health care providers

Very useful for setting up palliative care programs

In the community they did not have palliative care. One of the health care providers asked ‘How can we set up palliative care? ”. One provider from a health center commented: “I would like to bring palliative care to my community if you have the model”. From the interviews, the data reflected community nurses’ concerns about palliative care because nowadays there is not a model to provide this care in the community. Many community nurses felt interested in the concept of palliative care for the community.

One community nurse shared her experience in working with people living with ESRD who have gotten a kidney transplant. She said that “one of people living with ESRD who got a kidney transplant could continue his normal life with the new kidney for 7 years. After that the kidney was atrophied, so he returned to CAPD”. After him return to CAPD, this person became infected and later died. She said that with the basic treatment she only saw this patient at the hospital however if care was provided in the community she would see the whole process of kidney transplantation from after transplant until the kidney atrophied.

Credible authority

Trust in doctors and nurses

Many health volunteers said that people in community believed in the suggestion of doctors and nurses but when health volunteers suggest anything sometimes people in the community did not trust their advice. They suggested that if a palliative care team went to patients’ homes in the community they should include both professional and lay volunteers. As one health volunteer shared “Once I went to dress a wound in a child and her mother stared at me and asked many questions I know she did not trust me”.

Palliative care for people living with ESRD:

Want to die at home;

Many people living with ESRD talked about the place where they want to live at the end of life for example “I want to die at home among my relatives”. One of them said “I want to die in the hospital because I am single and I don’t want to disturb anyone. I have a lot of money so I can pay for treatment and die at the hospital”. Most of the people living with ESRD wanted to die at home because they had a good relationship with their families. For example some single people living with ESRD shared that they want to die at home and said that “I want to die among my brothers and nephews because they are so kind to me and helped me get through this when I was sick”.

Palliative care of families:

Don’t know how to do?

Based on the interviews with families about palliative care, most of them did not know how to practice or prepare for palliative care but they appreciated the concept of it. One of them said “I did not think about this before, it is important thing! Please tell me how I should give this palliative care”. The other one said “It is quite unusual to talk about death but for me it is a reality and everyone has to face with it. So I totally agree and support the researcher that it is something we should do”. Many families needed suggestions to prepare to provide palliative care for their family members with ESRD. In Buddhism, many people are familiar with the words related to the cycle of the life which is composed of birth, aging, illness, and death so when people accepted the cycle of the life it appeared to be easier to understand and prepare for the practice of palliative care.

4.2.2 Coping with uncertainty in ESRD:

4.2.2.1 Management of people living with ESRD and families

For many families, the diagnosis of a life-threatening illness of a family member is their first major confrontation with death. The researcher noted that although most of the participants with ESRD shared stories that revealed an increased familiarity with their disease over time, they also shared many unexpected things that occurred in their lives that concerned them. The impact on the families who were caring for their loved ones with ESRD was also difficult in many cases. Examples included the lack of knowledge related to how to care for their love one at home as he/she became increasingly ill. Another issue that arose was who would be the decision maker for the people living with ESRD and when must that be determined.

Concern for the future of the life

Many people living with ESRD and their families were concerned about the future especially the families who had many concerns related to caring, transportation between home and hospital, the many associated expenses. Some study participants with ESRD were concerned about kidney transplantation in terms of who would look after them because they might need more help. Some people living with ESRD tried to take care of themselves by going to hemodialysis alone but they still had concerns that something unexpected might happen and they would die alone without any relatives with them.

How to have continuity of care

Home based palliative care consists of continuity of care during the assessment, planning, action, and evaluation phases. . In this study, a model was designed to provide a home visit every week during which information was shared and suggestions were given to provide palliative care for people living with ESRD. Many of the study participants were satisfied with the home based palliative care program. One of the people living with ESRD said “This team is different from other teams that visited me because this team talked about preparing for death and thinking about the nature of life”. One said “It is good to have doctors and nurses visiting at home like this”.

The health care providers expressed concern about continuity of care so in some health centers they hired part-time community nurses to help them with visits in the community.

Communication

Communication with heart

The heart of palliative care is communication. If the health care provider gives the right information, it will create understanding and help to prepare for the family to provide palliative care. The important thing is the families must understand the concept of palliative care in order to reduce unnecessary treatments to extend life and the suffering of both patients and families. The communication process in this study began with making relationship with families, and then explaining the whole concept and making sure that everyone understood and agreed to the palliative care program. The main components of this communication included telling the truth, breaking the bad news, and addressing confidentiality issues. From the study, the following information was found:

Telling with the truth

Many people living with ESRD knew the truth about the fact they were at the end of life from the hospital. After that they typically decided to stay at home to die. One said “I know that this disease will kill me soon but I just do not know precisely when”. Basically in the hospital the doctor who treated the patient is the one who talked about the end of life. On the other hand, in the community if the patient is under responsibility of the health center, the community nurses will be the ones who talk about how to prepare for when the time of death is near. The relatives would accept that death was coming from seeing the progressive symptoms.

Breaking with the bad news

Many people living with ESRD said the first time when they knew about the bad news for their life expectancy was during treatment with hemodialysis or peritoneal dialysis. Sometimes they reported refusing or delaying treatment until their body could no longer cope with high level of waste product. . One said “I tried to avoid the treatment with hemodialysis until I was admitted in ICU so the doctor said I must be on hemodialysis” Another shared: “For me I had the experience of death because I delayed the treatment. I could hear when the doctor informed my family that I died but I just could not respond anything. My relatives told me later that my body was changed in color from pale to dark green”.

Confidentiality in some issues

Confidentiality issues occurred with some families. For example rich people living with ESRD shared the issue about their property especially if they have many sons and/or daughters, or the persons with ESRD who have many wives. The results of this study revealed several themes:

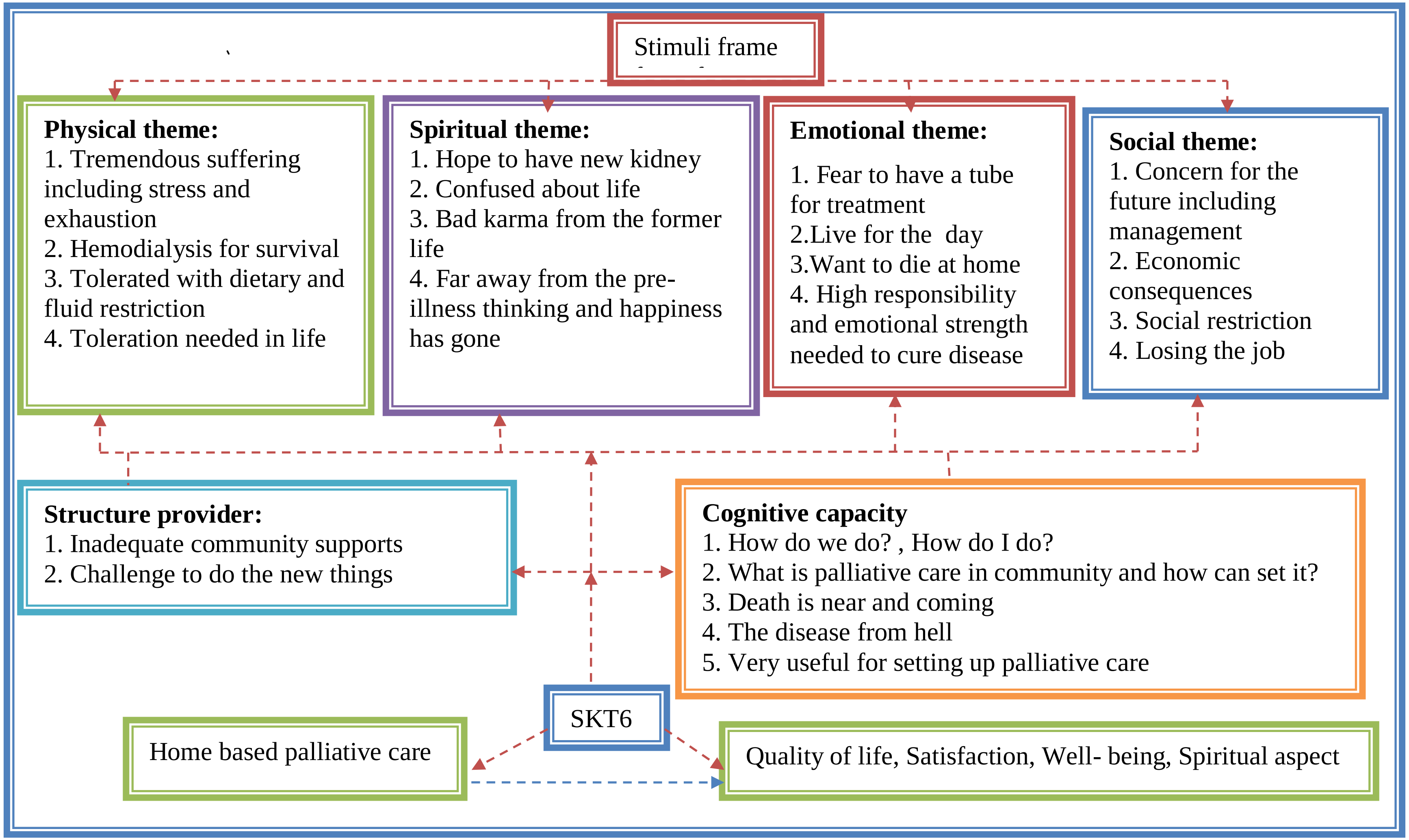


Figure 4.1 Themes related to uncertainty

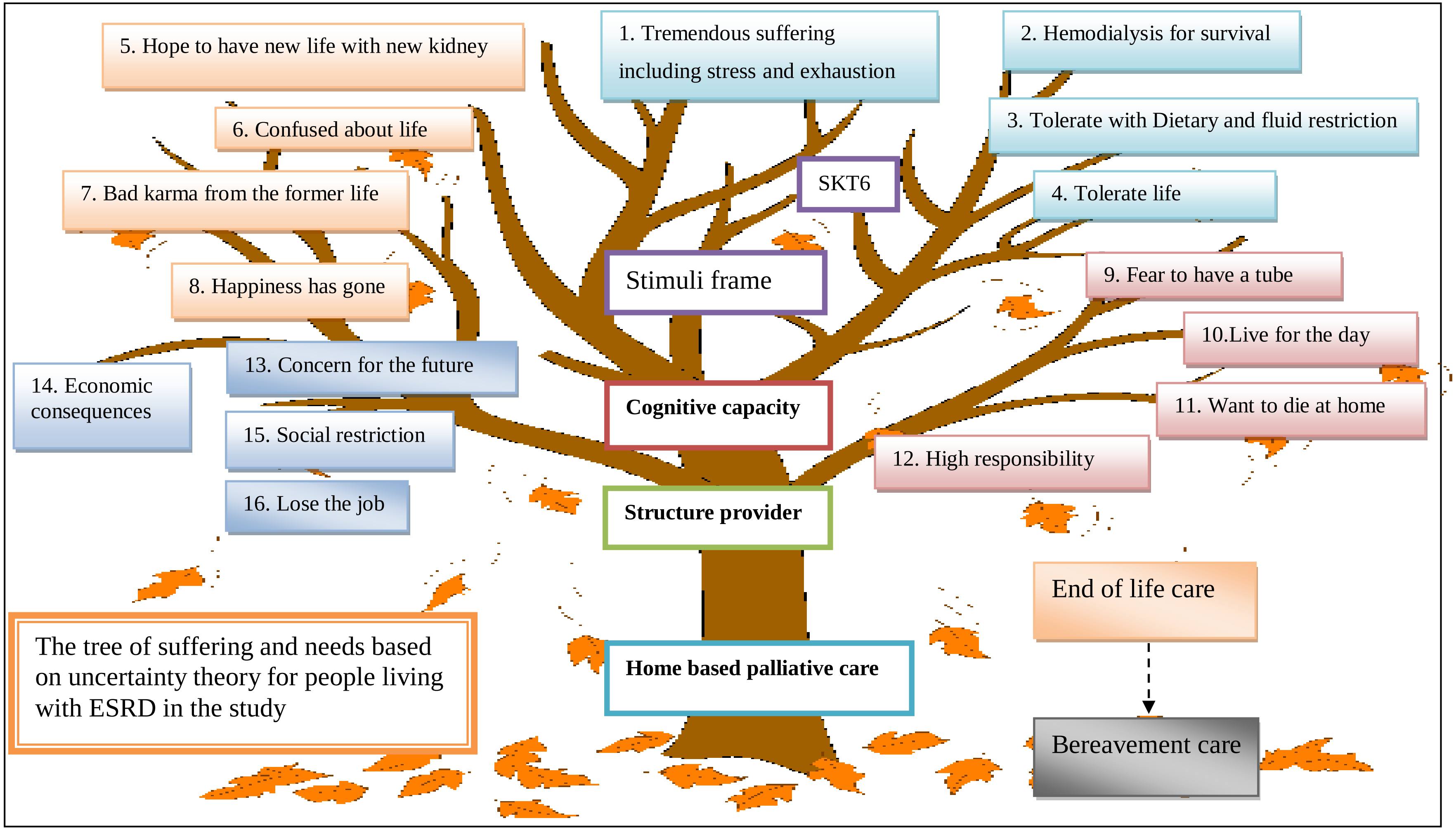


Figure 4.2 The tree of suffering based on uncertainty theory for people living with ESRD in the study

People living with ESRD on palliative care themes	**Relative themes**	**Home based palliative care**
Physical theme aspects: 1. Tremendous suffering including stress and exhaustion 2. Hemodialysis for survival 3. Dietary restriction and fluid restriction 4. Toleration needed in life	**Physical aspects:** Uncomfortable , Exhausted	Physical symptom management
Spiritual theme aspects: 1. Hope to have new kidney 2. Confused about life 3. Bad karma from the former life 4. Far away from the pre-illness thinking and happiness has gone	**Spiritual aspects:** Far away from the pre-illness thinking and happiness has gone Confuse about the life The disease of the hell	Explore thoughts about the meaning of life, or concerns about what happens after death and also have practical things they need to do and SKT to promote healing.
Emotional theme aspects: 1. Fear to have a tube for treatment 2. Live for the day 3.Want to die at home 4.High responsible and strong in emotional for curing disease	**Emotional concerns:** How to Management? Don’t know how to do?	By giving emotional support to the people living with ESRD and relative those who care about them, giving time to listen to them and understand their concerns
Social theme aspects: 1. Concern for the future including management 2. Economic consequences	**Social concerns:** Concern for the future Losing the job Economic consequence	By giving support and advice on practical matters such as getting their affairs in order

Table 4.8 People living with ESRD and families theme

4.2.2.2 Cycles of adjustment after ESRD diagnosis

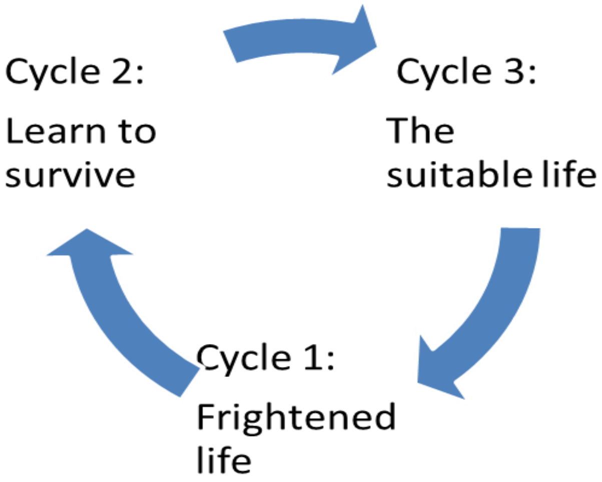


Figure 4.3 The cycle of people living with ESRD who got diagnosis with the disease

Cycle 1: Frightened life; many people living with ESRD got frightened after realize that in order to live they must be treated with dialysis. The steps of Kubler Ross (2004) start with denial. All of the study participants denied the need for dialysis treatment until they got progressive symptoms and some of them were admitted in ICU leading to dialysis treatment immediately. Some of them tried to use alternative treatments such as Thai herbs for delaying dialysis treatment. This was similar to the bargaining step identified by Kubler Ross.

Supporting factors: Diagnosis, symptom, blood result

Obstacle factors: fear, confusion, lack of knowledge of disease, physical problems.

Planning: people living with ESRD and families planned together to find someone who could take care of the people living with ESRD. In the families who had support for expenses related to ESRD treatment, they only needed to find caretakers and the other members of the families helped with the cost of treatment. For the poor people, they experienced many problems so they had many difficulties coping with the disease and the problems when they arose.

Reflection: Many people living with ESRD were frightened and tried to refuse extended treatments. The treatment itself made people living with ESRD suffer more so it was an enormous burden on all when someone was sick with this disease. The reflections shared from the study participants were that people living with ESRD and their families were scared by this disease. The families had extensive experience with this disease, noted that they will change their behaviors and learn how to avoid this disease. Many shared: “Everyone who does not have this disease is very lucky”.

When encountering this diagnosis in life, many engaged in the stage of Kubler-Ross who originally studied the stages of people suffering from terminal illness. The researcher of this study saw the phenomena with these processes:

Denial: This can't be happening. Persons diagnosed with ESRD often tried to refuse treatment until they developed severe problems from the kidney disease.

Anger: Why me? I did not understand? Some expressed anger with everything surrounding them. One said “because I must be responsible in the family and it brings a lot of stress to manage a big business, controlling the workers to do the job”.

Bargaining: I will give my life savings if I can return to the former time, one participant said if there was any treatment for this disease. One of the people living with ESRD used an alternative treatment such as Thai herb from the rural area. After using this Thai herb he went to see a nephrologist doctor and he said that what he was doing was improving his lab results such as BUN and creatinine. This case finally end up with hemodialysis however because the Public Health Ministry requires ingredient testing for all Thai herbs so he could not continue to treat with the Thai herb.

Depression: "I'm so sad, why bother with anything?"; "I'm going to die. After treatment with hemodialysis or CAPD, one of CAPD people expressed:” life was not stable some days he felt good and some days he felt badly but it was better than the former”. One month later, he complained about his life being so terrible that he wanted to stop with treatment .He had experienced many problems including economic issues even though he got the 30 baht card for treatment but it did not fully cover the travel expense to the hospital or food because he had retired from his job and his wife had lost her job as well.

Acceptance: It's going to be okay in this situation. Many of people living with ESRD felt better about their lives. Some of people living with ESRD were willing to follow instructions for a better life. These phenomena were observed after treatment with dialysis. In time, they learned to survive with dialysis, to eat better and to improve their quality of life

Difference environment, difference situation

Coping among the participants varied depending on the family situation, For example one person lived in a large family so his coping style was different from those who lived alone or in small families even though he got the same treatment, in the same community. One of the study participants with ESRD who lived with his wife but no children lost his job and his wife had no job so they experienced financial difficulties. The wife reportedly asked him: “When will you die?” During home visits, the researcher noted that many people living with ESRD appeared sad and hopeless. In contrast though some had hope such as one man who had a big family composed of his wife, son, daughter, and grandchildren. He shared: “I feel bored and hopeless. I don’t know how I can live and what the reason to live for is? But when I look at my grandchild I feel better and I get the answer of why I should continue to live”.

Cycle 2: Learning to survive

Supporting factors: Diagnosis and blood result

Obstacle factors: The time in management, the high cost in treatment,

Planning: People living with ESRD and their families have planned to change their life style in order to make it more flexible to undergo dialysis. Some of them needed to change their job, or even retired from their job. The families had to find someone to care of the patient who could be a family member or a professional care taker; they also needed to learn more about this disease and how to prepare food for the people living with ESRD.

Reflection: When the life has crisis situation, the natural mechanism is to try to fight for survival. Many of them spoke about the karma of each person and because of this they could accept and try to cope with this disease.

Some of the study participants with ESRD could not cope with this disease and felt bored with treatment so they decided to stop dialysis treatment.

Cycle 3: The suitable life

Many of the people living with ESRD encountered severe problems in their lives. Some could cope and some died during the suffering process. Those who survived had to learn to understand and learned by living with their new life style. They learned about how to deal with hemodialysis, complications and how to manage their lives. One said “I learned a lot in the new life style, it is filled with so much suffering but I can accept it”.

Supportive factors: Experience in dialysis, talking with the same group in dialysis, feels better after dialysis treatment.

Obstacle factors: Complications during dialysis treatment such as headache, being tired, a hoarse voice.

Reflection: After dialysis treatment, the people living with ESRD typically felt better and were more comfortable because the waste products in the body were decreased. This resulted in their ability to be more able to enjoy life, to be more positive and start learning new things; they felt that could live with the disease with more understanding. This stage is an important one because some people could cope with the disease in the presence of family support which helped them to make the decision to continue treatment. But other study participants expressed lack of family support and felt hopeless.

The sample in this study expressed much suffering. Some of the persons with ESRD expressed guilt because of bad karma, helplessness, sadness, fear, a sense of burden, role reversal, and stress from economic worry as well as having to do the dialysis treatments.

4.3 The model development of home based palliative care for people living with ESRD

Before development of the model, the qualitative data identified the needs related to palliative care during interviews with 54 participants composed of 8 nurses, 2 doctors, 15 people living with ESRD, 15 family members, 10 health volunteers, and 4 social workers. The information was shared with the community in order to identify the problems, barriers and to determine how to set up palliative care in the community. The model of home based palliative care for people living with ESRD was developed by stakeholders including 12community nurses at health center, 17health volunteer, 3social workers, 2psychiatrist, 2 doctors,1 phamacist,1 physical therapist,13 people living with ESRD ,13 families, and researcher. Totally 64 people, then the group analyzed the situation using SWOT analysis and SWOT matrix. After that the model of home based palliative care was created. The first model was tested in the community and evaluated by a focus group. The first model was then improved and tested again until the model best fit with the community needs.

4.3.1 Model development

This study used several steps to guide the model development. There were 3 cycles composed of cycle 1, current situation analysis; cycle 2, improvements implemented; and cycle 3, review of changes in each cycle. Figure 4.4 displays these steps.

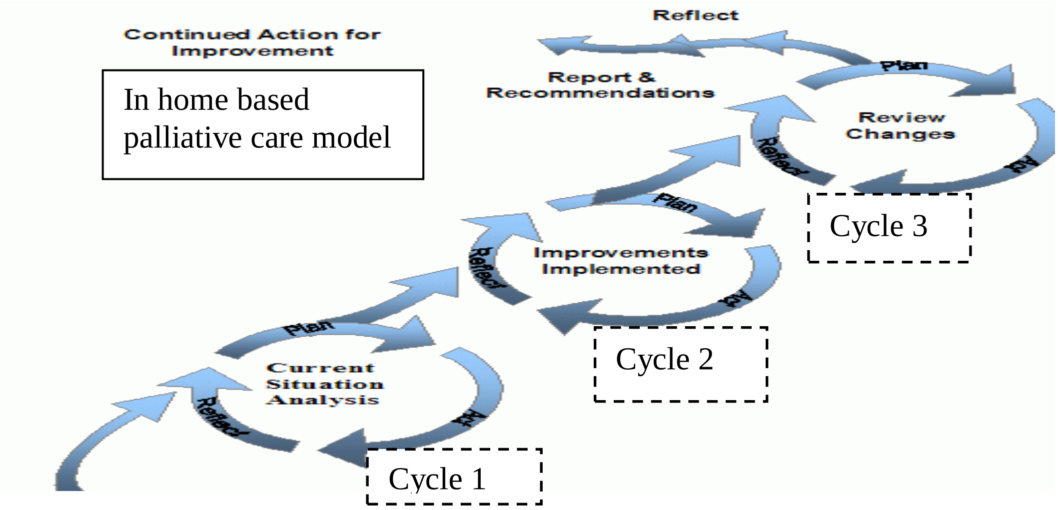


Figure 4.4 The steps in research study

Cycle 1: Current situation analysis

Plan: The problems and needs necessary to build a picture and describe the situation

Act: Focus groups and interview stakeholders for the problems and needs of ESRD people, family and health care providers. The results are shown above in

Cycles 1, 2, and 3. Discussions were arranged to conduct SWOT analysis and a SWOT matrix was used to access the trends related to palliative care in community.

Vision of strategic plan for home based palliative care model

Continuing development with standardization, service mind and participation of community

Mission

1. Development of quality service to standardize care and bring satisfaction to clients
2. Multidisciplinary and holistic care team to integrate care service
3. Active care service in the community with community participation

Objectives of Strategic plan

1. To promote proactive health promotion in palliative care until end of life
2. To build a strong community health system and primary care network.
3. To protect and prepare system for minimizing the impact of illness and health threats in a timely manner.
4. To create a model of home based palliative care in community

Situation analysis

SWOT Analysis	
Strength	**Weaknesses**
S1: Nurses are caring ,willing and open to new ideas S2: Most of nurses graduated in master degree level , certificate in NP S3: There is information technology (IT) for recording health data in HC S4: There is adequate staffing and it is an organized system. S5: Teams should be teams and volunteer should be volunteers S6. The referral system in HC is effective.	W1: Shortage of manpower W2: Lack of knowledge in palliative care for community W3: No guideline of home based palliative care in community W4: Heavy workload of nurses W5: There are many cases in the community but nurses do not have the time to provide care for all

Opportunities	**Threats**
O1: Organization and people in the community actively participate O2: Free of charge for service in community when compare to other private Hospitals O3: The Nursing Council has a policy to support palliative care in the community O4: There are multidisciplinary teams involved in home care visits O5: There are part time community nurses to help in delivering home care	T1: High expectation of relatives T2: Shortage of manpower to take care of severely ill cases T3: Shortage of knowledge and skills in home based palliative care T4: Relatives ignore the sick family members

A SWOT matrix of health center

SO	**ST**
S1O1, Ready to develop new things. S2O2, Campaign health promotion. S4O3O4O5, Develop effective of home based palliative care	S2S3S4T1T3, Improve health service. S5T4, Cooperate to develop home based palliative care
WO	**WT**
W1O5, Organize and distribute the routine job.	W3T3, Develop cooperation between medical doctor and professional health W2T3, Improve service.

Figure 4.5 SWOT analysis and SWOT matrix

Key success factors in home based palliative care model

These keys lead to satisfaction and needs.

- No fee for service in the community.
- Continuing development of nursing care
- Human caring by health care providers to people living with ESRD

- Home based care and service care for people

Project from SWOT analysis: Home based palliative care model

The goal of palliative care is to improve the quality of life of both people living with ESRD and families by responding to pain and other distressing physical symptoms, as well as to provide nursing care and psycho-social and spiritual support. This is the reason to have an interdisciplinary, multi-dimensional team, comprised of doctors, nurses, counselors, social workers and volunteers among others.

The health center in Bangkok provides two kinds of services including home visits and home health care. These two kinds of services do not include palliative care so the researcher set strategies for integrating palliative care into home health care involving the following:

- Training and education,
- A supportive policy environment,
- Mentoring,
- Linkages and referrals,
- Evaluation

Home visiting is a general aspect of all service delivery models. Counseling and basic care are part of home visits. Volunteers sometimes assist with transporting people to clinical facilities for appointments and may arrange for material support to be provided to homes. Mostly the community nurses set the time to visit only once per year.

Home health care includes service for people living with chronic illness that need suggestions for care at home or possible a change in medical home treatments. The community nurses typically set the time to visit at one time per month.

Home based palliative care is becoming increasingly popular as it provides where people are most comfortable at the end of their lives, at home surrounded by their loved ones. It is also well suited to conditions in Thai society where a family member is usually available and willing to care for the sick person. It provides family caregivers with the backup and support needed to plan care and to prepare for what lies ahead during the course of a long and potentially life threatening illness at home. Home based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence.

Reflect: The reflection from the first cycle has indicated that

Supportive factors:

- Participation of palliative team,
- The place to meet,
- Policy of palliative care service,
- Willing to care of community nurses

Obstacle factors:

-The convenient time of participants

Lesson learned from cycle 1:

The strategies reflect the principles of the model and include the following: strategies for involving all stakeholders ensuring commitment and support; strategies for mobilizing and managing resources building on the existing system; and strategies for developing and implementing appropriate health information systems.

Willingness of health volunteers was an important role as it allowed them to do something in community.

Community nurses were the key persons to manage new programs in the community.

Corporation is an important aspect in the development of palliative care programs.

Many people living with ESRD in the community need some help to manage their lives.

Some people living with ESRD had inappropriate high risk behaviors and showed lack of interest in managing their disease even though health care providers tried to help them.

Cycle 2: Improvement and Implementation of the home based palliative care model

Providing home based palliative care model

Plan:

The detailed planning of the project needed to be done in an intelligent way, which meant not disrupting local traditions, customs and structures. In instances where the need had been clearly identified by the people living with ESRD and families, it was nevertheless necessary to try out the basic idea as a pilot scheme involving only a sample of the population.

Providing home based in palliative care by collaborating with family and community with the 4 components including:

Physical – managing symptoms such as pain, sickness, tiredness or loss of appetite;

Psychological – giving emotional support to the residents with ESRD and those who care about them, giving time to listen to them and understand their concerns.

Social – giving support and advice on practical matters such as getting their affairs in order

Spiritual – a need to explore thoughts about the meaning of life, or concerns about what happens after death. Many people had spiritual needs and some also needed help with practical aspects of dying. Meditation healing exercise SKT 6 was provided to promote spiritual support and healing.

Design home based palliative care service in palliative care focusing on people living with ESRD's participation that provides relief from fatigue and other distressing symptoms, affirms life and regards dying as a normal process, integrates psychological and spiritual aspects of patient care, offers a support system to help people live as actively as possible until death and helps the family to cope with this illness and later during the bereavement process.

The component of home based palliative care model

1. Willingness of health care providers and ease to use service

The people living with ESRD should be satisfied to be looked after at home or in his/her live-in environment by the team. The home of people living with ESRD should not be too inaccessible or far away so that the team has difficulty reaching there or spends hours in travel.

2. An available caregiver or families of people living with ESRD

The families have an important role to make decisions together and to know about the needs or the will of people living with ESRD to allow them to meet the need of people living with ESRD.

3. A properly trained team in home based palliative care

The team must have the requisite qualifications and should have received training in home based palliative care. This training must extend to all of the team including community nurses, doctors, social workers, and health volunteers. One of the most important and basic requirements is that the team be trained to listen and communicate with people living with ESRD and their families.

4. On duty any time any where

People living with ESRD and their families or caregivers should be able to contact the home based palliative care team outside their regular visiting hours. Provision for 24-hour support, including emergency support, may take the form of a helpline number which is given to people living with ESRD and responded to by members of the team in case of an emergency.

5. Network for supportive home based palliative care

Links with other communities or hospitals should be built up by the home based palliative care teams so that they can refer people living with ESRD for supportive care when the need arises.

6. Home care kit

Availability of essential medicines and equipment must be assured to the palliative care team. They should carry a bag with a properly maintained medical kit on visits. Among the range of items that a kit could contain are pain killers such as paracetamol; medication such as antihistamines; multivitamins; bandages, cotton wool and swabs for dressing and applying medication to wounds; antiseptic soap; disinfectant; disposable and heavy duty gloves; plastic sheets; aprons; anti-diarrhea tablets; and aqueous cream .

The component summarized in figure 4.6.

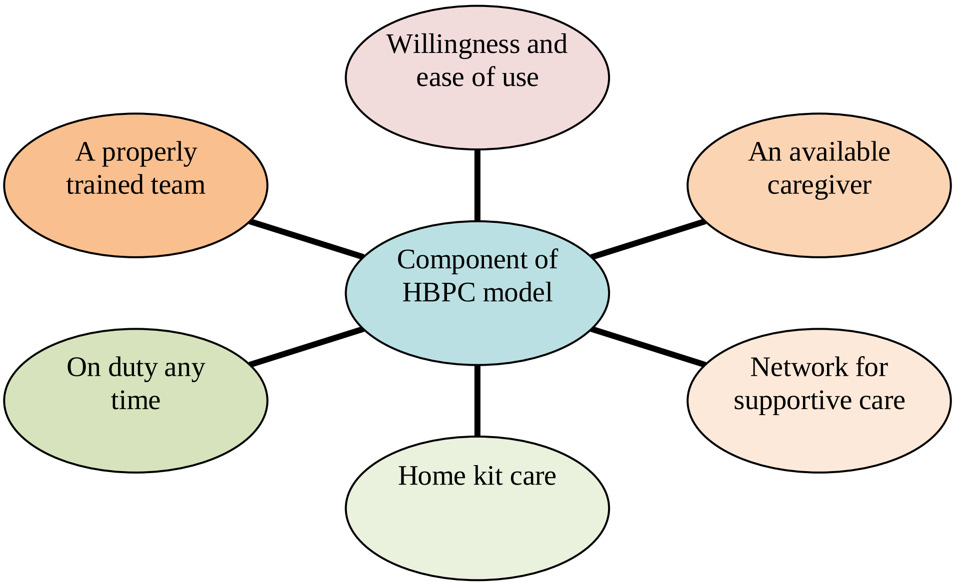


Figure 4.6 Component of home based palliative care model

Act: Implement HBPC for people who living with ESRD

The researcher developed a nursing care plan that provides a written means of planning the care for people living with ESRD and to meet their needs. Care planning provides a "road map" of sorts, to guide all who are involved with people living with ESRD's palliative care team. The care plan has long been associated with nursing, and many people in the palliative care team support that nursing role. The palliative care team, especially community nurses, implemented the care plan to resolve nursing problems which happened to the people living with ESRD during treatment with hemodialysis or CAPD at home. The nurses identified people living with ESRD’s entire problems by accurate and comprehensive assessment. The development of the care plan was guided by the following process:

Training

There were 4 health centers that joined in the training which were composed of 12 community nurses, 4 social workers, and 20 health volunteers.

The results from training included an increase in the understanding of palliative care, 90.9 %, the utility palliative care, 97.8%, and the need to provide palliative care in the community, 96.96 %.

Home based palliative care implementation

Model 1

1. HBPC1: Develop relationship;

Nursing care: explain objective, assessment symptom, psychological and spiritual

2. HBPC2: Develop understanding;

Nursing care: symptom management and support with palliative care concept at home and support psychological and spiritual with mind fullness meditation in SKT 6.

3. HBPC3: Develop mindfulness;

Nursing care: explain more in detail of palliative care and assess acceptance of relative and people living with end stage renal disease, unfinished business.

4. HBPC4: Develop acceptance;

Nursing care: follow up; assess psychological need of persons with end stage renal disease and uncertainty of life how to prepare until the last breath and bereavement care

5. HBPC5: Evaluation of satisfaction, quality of life at home

Model 2

1. HBPC1: explain objective, assessment symptom, psychological and spiritual
2. HBPC2: Treatment and support from symptom, suggest palliative care at home, assess acceptance of relative and patients, and assess the needs of people, religious practice
3. HBPC3: Follow up, assessment of acceptance or coping with uncertainty life, giving suggestion in preparing document or good death and preparing bereavement care
4. HBPC4: Evaluation of satisfaction, quality of life of people and family

Reflect: The reflection from the second cycle has indicated that the work done during this cycle 2, should give precise information on the needs, customs and traditions, and on the political, social, cultural and economic context. This information is essential and needs to be systematically studied throughout the period of identification and planning.

Build networks: The home based palliative care team must build a network of support with other organizations /institutions that can offer further care to their people living with ESRD, such as hospices, and hospitals.

Handling of death and bereavement: When the time comes, death occurs. The family should be instructed to keep an emergency medical kit at home which can be used by the visiting team if necessary. With regard to bereavement, the team should make at least one post bereavement visit after the death of the patient. If necessary, referral to a trained counselor may be suggested for members of the family who appear to be especially distressed and inconsolable. It is important for the home based palliative care team to support for setting. They should also meet regularly under the guidance of a trained counselor to share their experiences and feelings as the work they do is emotionally demanding and does cause burn out.

Supportive factors:

Health center was able to support the income of newly hired part time community nurses. Part time community nurses helped to visit cases in community.

Health volunteers were willing to help people in community. When the team went to the community the health volunteers would provide information about illness of people in community.

People in the community were concerned about their health more than they were prior to the project.

In rural areas, there was a rural culture of care in the communities which depended on their religious and cultural beliefs.

Obstacle factors:

The data were collected in rainy season so there were some problems with making home visits.

No vans or no drivers were available in the community on some days.

People living with ESRD were busy because they must help their families to do some tasks and sometimes they were not available at home.

Lesson learned from cycle 2:

The life style of people living with ESRD reflected the symptoms of the disease.

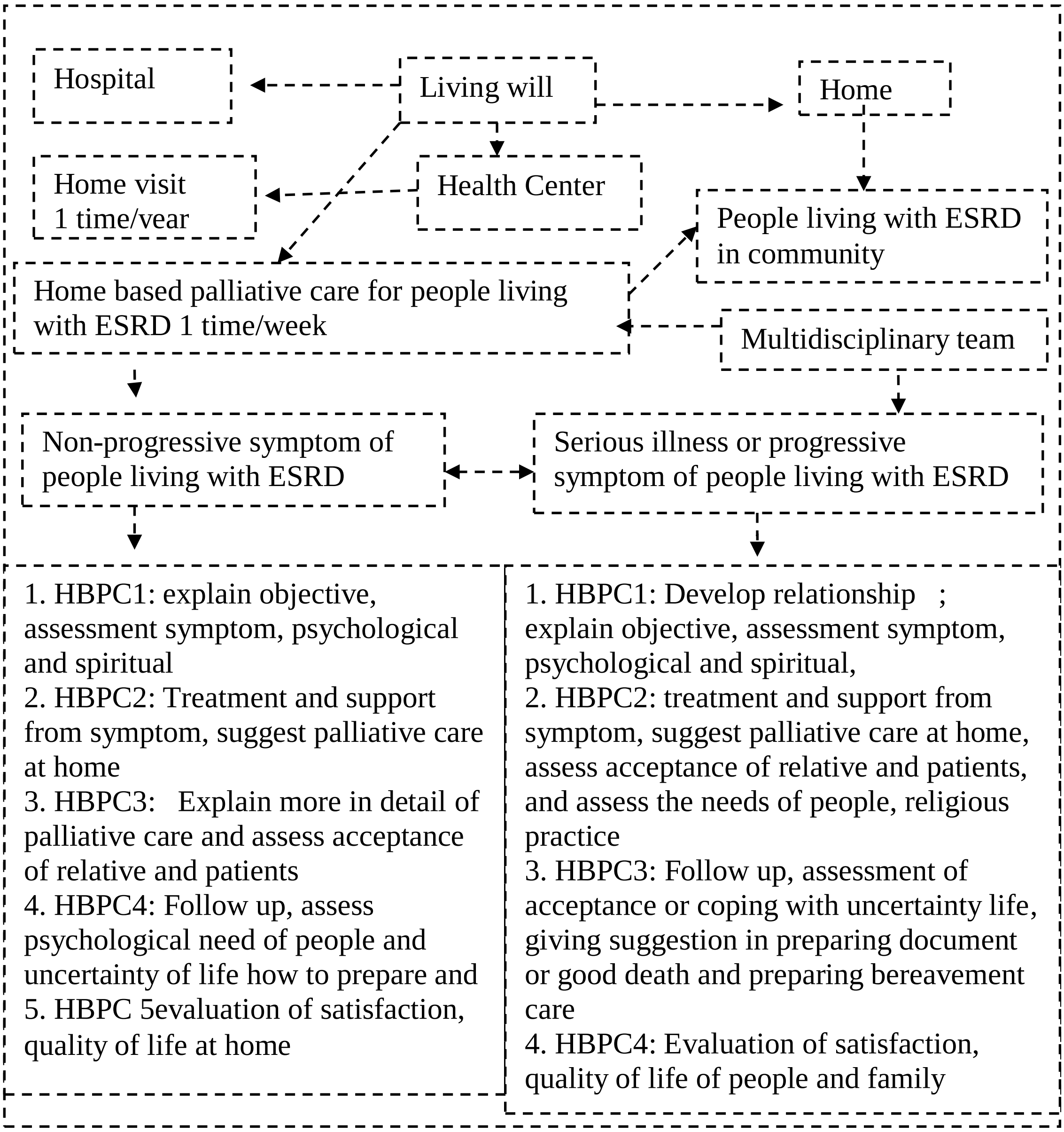
Good karma was important thing to have happiness.

The causes of an unhappy happy life varied with each family.

Good karma leads to good life.

Positive thinking was shown to lead to happiness and it can bring or create many things.

Learning occurred by observing and discussing signs and symptoms of study participants: One person said I always got a benefit from dialysis but these symptoms would worsen. The researcher asked about his habits related to CAPD from his neighbor and was told the person always lied when doctors or nurses visited him. Thus the researcher learned how to assist him to correct his problems.



1. HBPC1: explain objective, assessment symptom, psychological and spiritual
2. HBPC2: Treatment and support from symptom, suggest palliative care at home
3. HBPC3: Explain more in detail of palliative care and assess acceptance of relative and patients
4. HBPC4: Follow up, assess psychological need of people and uncertainty of life how to prepare and
5. HBPC 5evaluation of satisfaction, quality of life at home

1. HBPC1: Develop relationship ; explain objective, assessment symptom, psychological and spiritual,
2. HBPC2: treatment and support from symptom, suggest palliative care at home, assess acceptance of relative and patients, and assess the needs of people, religious practice
3. HBPC3: Follow up, assessment of acceptance or coping with uncertainty life, giving suggestion in preparing document or good death and preparing bereavement care
4. HBPC4: Evaluation of satisfaction, quality of life of people and family

Figure 4.7 The draft of home based palliative care model

Cycle 3: Review and change

Plan: Review**;** Focus group in discussion regarding model of home based palliative care

Act: Changed the model

Model 1

1. HBPC1: Develop relationship; explain objective, assessment symptom, psychological and spiritual

2. HBPC2: Develop understanding; treatment and support from symptom, suggest palliative care at home

3. HBPC3: Develop mindfulness; explain more in detail of palliative care and assess acceptance of relative and patients

4. HBPC4: Develop acceptance; follow up, assess psychological need of people and uncertainty of life how to prepare and evaluation satisfaction, quality of life at home

Model 2

1. HBPC1+ HBPC2; Develop relationship and understanding; explain objective, assessment symptom, psychological and spiritual. + HBP2: Develop mindfulness; treatment and support from symptom, suggest palliative care at home, assess acceptance of relative and patients, and assess the needs of people, religious practice

2.HBPC3+ HBPC 4; Develop acceptance ; Follow up , assessment of acceptance or coping with uncertainty life, giving suggestion in preparing document or good death and preparing bereavement care. HBP4: Evaluation satisfaction, quality of life of people and family.

Reflect:

The reflections from the third cycle indicated that people living with ESRD need some help sometimes even when their condition was still stable. The condition was not stable long typically sometimes changing for the better for only 1-2 days but after that it would worsen again. When using the model, the researcher discussed always with the team how to provide care in a practical way in the real situation of working in community. The palliative care team helped to reflect some feelings when doing these activities in community. The community nurses, social worker, health volunteers, doctors reflected on the activities in palliative care and noted that it felt good to help people living with ESRD to cope with their lives.

Cost and Sustainability; An approach to assessing costs and benefits such as a systematic analysis of the economic, material and human costs of providing palliative care services across all levels of health care was beyond the scope of this study and thus was not conducted. This study did support human resources and technical expertise, allowing the palliative care services to develop in response to perceived needs. Much credit was given to those involved in its development. However for long term sustainability, health centers need to identify a sustained funding mechanism to provide and support palliative care within the community.

Challenges to expansion of palliative care: For the development and implementation of an effective national approach to palliative care, there needs to be consensus and a commitment from all relevant national government departments. This requires sensitive and collaborative engagement with all stakeholders and academic faculty to come to a clear understanding of what palliative care is and includes addressing delicate issues such as regulation of roles and responsibilities of different disciplines involved in care, including the extended role of the nurse, incorporation of palliative care education into existing undergraduate training programs, and assuming responsibility for ensuring implementation of a national palliative care policy.

Lesson learned from cycle 3:

- Perception of the innovation was important to develop the new program of care.
- Increasing awareness is necessary to learn more and it is useful for every situation.
- Characteristics of palliative caregivers are important to do palliative care because palliative care needs a willing mind to provide this type of care.
- Contextual factors in home based palliative care; Palliative care needs leadership and management systems because the situation of each family is different.

- The activities of home based palliative care should have specific purposes and concise concepts because the real situation was restricted in time so the health care providers should be concerned with both quantity and quality of working.
- Home based palliative care did take time to visit cases in community; the skills of palliative care nurses in community can be applied to both physical and psychological care during each visit.

After discussion and review, the researcher summarized and created the new model and presented it at a conference for stakeholders. Palliative care model are relatively new additions to the range of services available in rural area's health care system. The guide started with a general definition of palliative care and then discussed how that definition is operationalized by the palliative care team. The group discussed how it is similar to and yet different from most hospital programs. The guide includes a wide range of educational material, technical assistance, and other support materials that address every aspect of program development for home-based palliative care. Providing palliative care to people with chronic kidney disease should begin at the time of diagnosis and continue throughout the people's life. With the progression of kidney disease, palliative or supportive care assumed increasing importance with time and was integral to "good deaths”. For the time using in each model followed these, model 1:30-45 minutes, model2: 45-60 minutes per time of visiting in each week. The team understood and agreed with the home based palliative care model displayed in Figure 4.8.

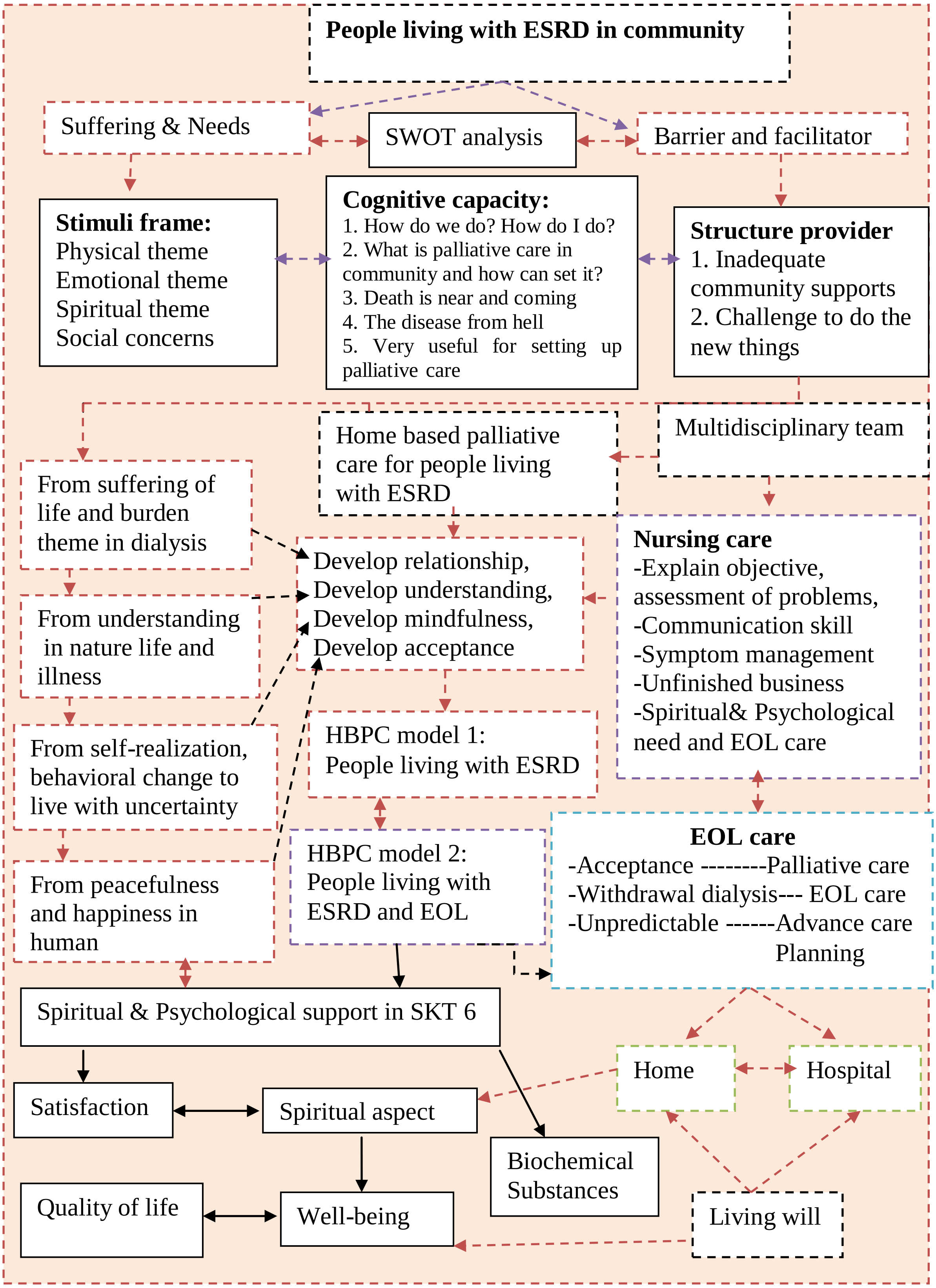


Figure 4.8 The revised model of home based palliative care

Nursing care in home based palliative care (HPBC) model

Model	HBPC / Time in using	Objective	Nursing care in home based palliative care
1	HBPC 1 (week 1: 30-45 minutes)	Develop relationship,	1.explain objective ,assessment physical symptoms, psychological and spiritual aspects
	HBPC2 (week 2: 30-45 minutes)	Develop understanding	2. Treatment and support from symptoms ,suggest palliative care at home and psychological and spiritual support with SKT 6
	HBPC3: (week 3:30-45 minutes)	Develop mindfulness	3.Explain more in detail of palliative care and assess acceptance of relative and patients, unfinished business
	HBPC4 (week 4: 30-45 minutes)	Develop acceptance	4.Follow up ,assess psychological need of people and uncertainty of life how to prepare until the last breath and evaluation satisfaction, quality of life at home
2	HBPC 1 (week 1 45-60 minutes)	Develop relationship& understanding	**Develop relationship and understanding** ;explain objective ,assessment symptom, psychological and spiritual
	HBPC 2 (week 2: 45-60 minutes)	Develop mindfulness& acceptance	**Develop mindfulness** ;Treatment and support from symptom ,suggest palliative care at home, assess acceptance of relative and patients, Do not attempt resuscitation, medical futility, assess the needs of people ,religious practice , **Develop acceptance** ; Follow up , assessment of acceptance or coping with uncertainty life ,giving suggestion in preparing document for the EOL and preparing how to have good death
	HBPC 3 (week 3 :30-45 minutes)	Evaluation& Bereavement care	Evaluation of satisfaction, quality of life. Bereavement care visiting for grief counseling of relatives

Table 4.9: The Nursing care in home based palliative care model

As a consequence of the revised palliative care model, the processes related to program development were revised as noted in Figure 4.9.

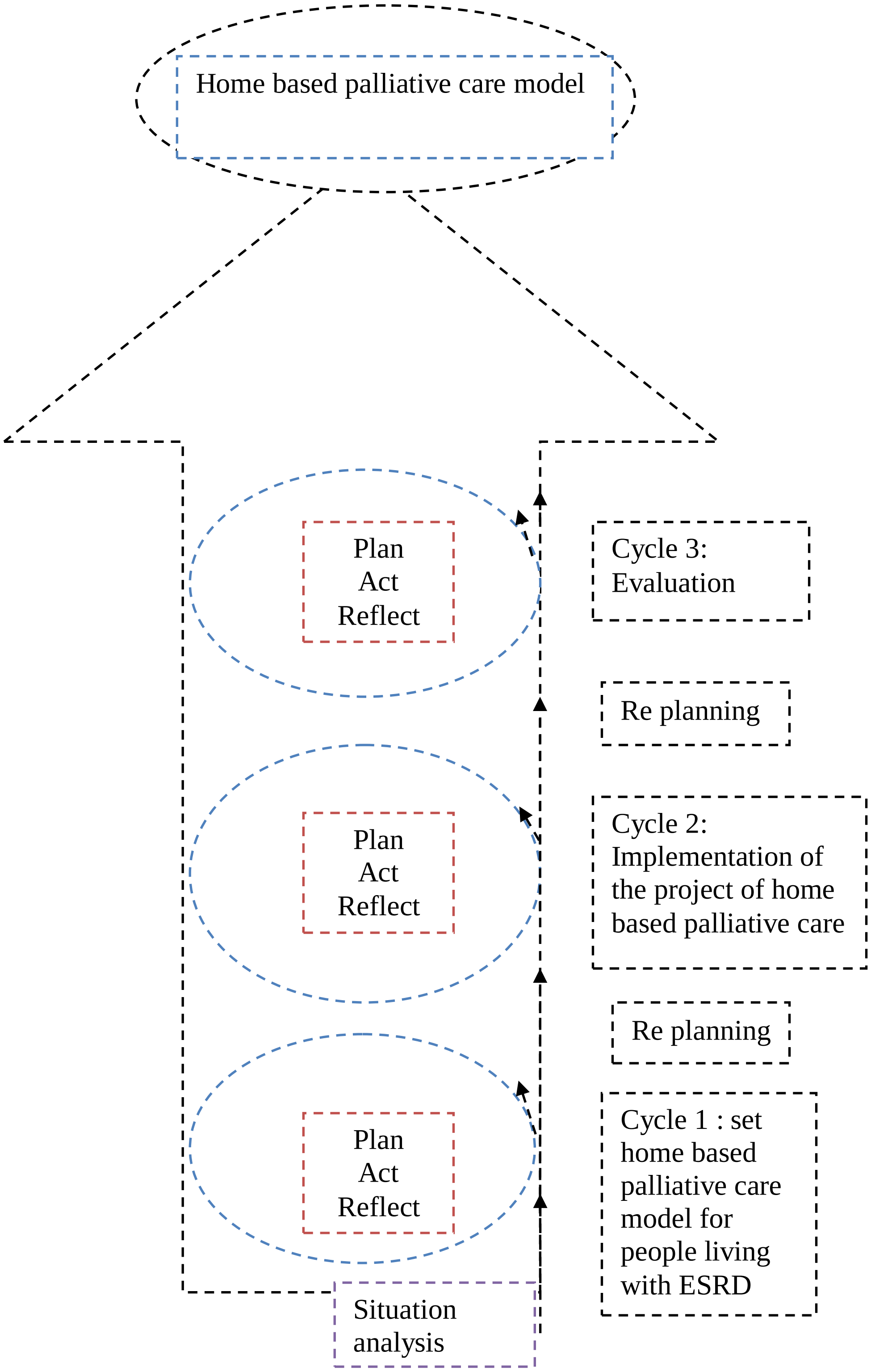


Figure 4.9 summarize the process in the study

4. 3.2 People living with ESRD undergoing hemodialysis and continuous ambulatory peritoneal dialysis (CAPD)

In this study, the researcher used a questionnaire to evaluate physical symptoms based on the ESAS tool, constructs related to uncertainty in illness, and quality of life. The results revealed that before and after the implemented HBPC program there was a reduction in the mean score of reported physical symptoms, and uncertainty in illness decreased. On the other hand, quality of life increased after implementation of the home based palliative care program. Data showed in Table 4.10.

Table 4.10 The dependent variables before and after giving HBPC model

Variables	Before HBPC $\overline{X}$ ±SD	After HBPC $\overline{X}$ ±SD
ESAS	39±22.12	23.67±13.30
Uncertainty	55.13±11.48	42.46±9.86
Health &Functioning	17.03±4.77	22.07±2.69
Social &Economic	18.01±4.17	21.62±3.30
Spiritual well-being	19.71±6.13	24.62±3.31
Family	21.16±5.59	24.21±3.84
Quality of Life	18.44±4.46	23.65±3.28

People living with ESRD undergoing hemodialysis: Exemplars

1. Hemodialysis Case Study Exemplar 1: Aunt A

Aunt A was 76 years old and lived in a condominium. There are two bedrooms, one is hers and another is for her grandchildren. She was started on hemodialysis treatment 7 months ago and receives hemodialysis for 2 days per week on Monday and Thursday. She has a double lumen catheter at the right side of her neck. She pays for hemodialysis by herself. She had a lot of money in the bank she said that her deposit interest is enough to live on to cover her expenses. She donated 10,000,000 baht to the public hospital. She was disappointed with this hospital because they did not care for her like a VIP case as she expected. Therefore she decided to choose a private hospital to treat her renal disease with hemodialysis. For physical problems, she had a mastectomy for breast cancer in the past in addition to being diagnosed with heart disease, and hypertension. For her activities, she travels to her banks to transfer her accounts based on the better current interest rates. She has hired a woman to help her to shop for food and to clean her house. She usually takes a taxi to the hospital but often complains that it is difficult to get to the hospital because of the traffic.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The community nurse and researcher introduced themselves and explained the objective of home visiting. She was happy to have the nurses visiting her at her home. She said "many times I feel lonely because I am single". She shared her story about when she was young regarding her work, boyfriend, and personal life. The researcher asked her about current symptom, uncertainty in illness and quality of life to pre-test the study instruments.

HBPC 2: Objective was to develop understanding

The researcher explained about palliative care for kidney disease and suggested the special knowledge technique (SKT). For palliative care at home, she said she just only wanted help sometimes. She agreed to visits as she sometimes feels lonely and needs someone to talk to. She often felt tired after hemodialysis until the next day when she typically would feel better. She had insomnia and it made her unhappy. Some nights she complained that she could not sleep until nearly the next day.

HBPC 3: Objective was to develop mindfulness (encourage mind)

During the home visit Aunt A said "I want to die and I am not afraid to die. I am 76 years old; it's time to discard everything. I have a lot of money but I still try to save everything". The researcher observed that she had a comfortable life style and yet knew how to spend money wisely. From the assessment, the researcher noted that she had prepared herself for the current uncertainty in her life. She had planned for her estate after her death by having a will that designated her property to her relatives.

HBPC 4: Objective was to develop acceptance and evaluation

When talking about the progressive symptoms associated with ESRD during the visit, Aunt A reported that she had problems with tiredness at times. She tried to do the best thing for her health, for example whenever she wanted to eat something, she would go and buy it. She did not want to do anything more with her life and wanted to die peacefully among her relatives. She agreed with the concept of palliative care and she had signed the documents regarding her living will to die with dignity and no resuscitate

HBPC 4: Objective was to develop acceptance and Evaluation

When talking the progressive symptom she had problem with tiredness in sometime. She tried to do the best thing for her life for example whenever she want to eat something, she will go and buy it. For her life, she did not want to do anything more and want to die peacefully among her relatives. She agreed with the concept of palliative care and she had attention to sign willing will in the document.

Evaluation: The researcher assessed needs and asked about satisfaction of home based palliative care using the questionnaire. After that the researcher then identified this case to receive home health care. As long as she still had a good quality of life in her environment, the team will provide her with home health care. On the other hand if the symptoms worsened, the team would change her status to receive the home based palliative care (model 2) for her end of life period.

2. Hemodialysis Case Study Exemplar 2: Aunt P:

Aunt P was 59 years old. She had been treated with hemodialysis for 7 years. During the night, she had problems with insomnia. She liked to gamble. Her husband gave her 500 baht per day before he went to sell goods at the market. She had been sick with this disease for 7 years. She knew how to take care of herself in terms of diet and daily exercise. At home during the day she would not open the door to bring anyone to visit her because her son is afraid that someone might kill her at home when she was alone. During the night the son and husband were back at home. She went to the hospital by taxi on her own with no help from anyone. At home she liked to listen music, especially dharma music.

Home based palliative care (HBPC) model:

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objective of home based palliative care, assessment of the symptoms, uncertainty in illness, and quality of life. During the assessment interview she had problems with a cough so she just listened.

The researcher suggested the SKT technique to promote healing during the day and night.

HBPC 2: Objective was to develop understanding

During the second visit, the researcher talked about the progress of the disease, and how to observe the symptom changes. Aunt P said that she understand about this disease and knew how to take care of herself. She said that she was so happy when her family picks her up to go to the restaurant on the weekend. Her son has a business in selling the Yun Wor Yun soy sauce.

HBPC 3: Objective was to develop mindfulness (encourage mind)

The research observed that she looked very tired. The community nurse asked her about her symptoms. Aunt P responded: “I am fine but sometimes I feel bored”. She complained with the researcher about her family. Her husband had asked “When will you die? ”. She said “I am sad with this word as my heart dropped to my feet but I try to ignore him and pay attention to other things”.

HBPC 4: Objective was to develop acceptance and Evaluation

During a subsequent visit, Aunt P looked better, her face was bright and she said: “I am happy and I practice SKT every day. I like to practice it because it makes me calm and peaceful”. When the researcher asked about uncertainty in life and illness, she answered that “I am ready to go whenever my time is coming; I will go without worrying about anything”.

Evaluation; For this case, the participant accepted the normal process of life and she was able to develop mindfulness without concerns about anything because everyone in her family was managing well themselves. The researcher assessed needs and asked about satisfaction of home based palliative care using a questionnaire. After that the researcher determined that she would receive home health care as long as she still had a good quality of life in her environment.

3 . Hemodialysis Case Study Exemplar 3: **Uncle C**:

Uncle C was 85 years old and used to work as a pilot. He started treated with hemodialysis 3 years ago. He was healthy until 3 years ago when he found he had problems with his kidneys and went to a private hospital. He got a severe problem from pulmonary edema so the doctor decided to treat him with hemodialysis. The researcher observed that Uncle C spoke with a sad expression on his face. He said that the first time he was on hemodialysis he was so sad and so bored because it was so time consuming. He cannot go anywhere except to the hospital 3 days per week for hemodialysis. He wanted to decrease the frequency of hemodialysis so he decided to follow the nurses' suggestions about his diet. After that he was able to reduce the days on hemodialysis from 3 days to 2 days per week .He felt much happier with this schedule. He knew how to restrict water; he did take only a sip of water after meals and if he still felt thirsty he would put ice chips in his mouth. These actions made him feel better with hemodialysis. He complained that he had difficulty eating as he had lost his appetite from boredom. He said that it was not my life that he was now living.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explain about the objectives of home based palliative care, including assessment of the symptoms, uncertainty in illness, and quality of life.

HBPC2: Objective was to develop understanding

The researcher talked about the progress of disease and how to observe the symptom changes. For this case, he said that he had problems with hunger often even though at other times he lost his appetite from boredom. He decided to buy some soup to make at home during the night in case he was hungry. He said that he knows and understands life because "I am old and there is no more time to live".

HBPC 3: Objective was to develop mindfulness (encourage mind)

He said that he accepted everything in his life. He also mentioned about his wife that get bored with him because he has a hearing problem and his wife does not want to speak louder with him. Therefore during the day he just only listens to music, watches television and practices SKT.

HBPC 4: Objective was to develop acceptance and Evaluation

When visiting Uncle C, he liked to talk about his life. He said "My friends are far away. So I am bored with my life. I cannot go somewhere for a holiday. I must stay at home and go to the hospital only because of this disease. If the time is coming I have to leave this world, I am ready".

Evaluation; The researcher assessed needs and asked about satisfaction of home based palliative care using the questionnaire. After the assessment the researcher determined his needs would be best met with home health care while he still had a good quality of life in his environment. It was planned that if his symptoms worsened, the team would provide the home based palliative care (model 2) for end of life.

4. Hemodialysis Case Study Exemplar 4: P:

P was 30 years. He had hypertension and ended up with ESRD 4 years ago.He had treatment with dialysis for 2 years. He is a student in a technician school. He complained about his life "I am sad with my life and I am tired when I study in the class. I could not pay attention to my studies well so I failed in many subjects". His family paid for his treatment with hemodialysis. He had an A-V shunt in the left arm.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of symptoms, uncertainty in illness, and quality of life. P shared that he felt tired and had problems with itching so the researcher suggested he try SKT 1 breathing exercise. During the conversation with P, his mother interrupted and said "If I die, you will die too, you cannot survive with this disease without me". After hearing these words, the researcher explored the family's stress more in detail and tried to help them cope. The researcher and the team suggested how to cope with the expenses of the treatment by applying to get the social welfare for working people and try to take care of him to avoid complications. This would save future treatment costs.

HBPC 2: Objective was to develop understanding

The researcher asked about his symptoms and explained about the progress of disease, how to observe for symptom changes. He said that "After I practice breathing exercise, I have fewer problems with itching". The researcher observed that his face was brighter and he felt less stressed than the previous week. At this visit P. complained about headaches and the high cost of treatment. His mother paid a lot for his treatments .The researcher supported him by teaching him to help himself by practicing SKT 6. This could help avoid complications and help reduce the cost of treatment.

HBPC 3: Objective was to develop mindfulness (encourage mind)

On the third visit, P said that sometimes he felt bored and he wanted to have a new kidney by transplant. He hoped that someday, someone will call him for a kidney transplant. This week, he complained about complications during hemodialysis such as headache, his voice was also hoarse. His itching was relieved on subsequent visits. As time went on, the researcher found that he appeared happier than formerly which he attributed to the SKT technique. He said “I practice SKT every day and I feel better. Thank you so much for suggesting it to me”. The researcher and the team members discussed with him about the uncertainty in life so that he should prepare to practice with good thoughts in the mind. He shared that he wanted to change his damaged kidney so his life depended on something or someone to give or donate a kidney .In the concepts of Buddhism it is believed that if one thinks good thoughts and does good deeds in life, he will meet with the suggested things that he thinks about for life .The palliative care team explained in detail about the kidney transplant procedure and the life after transplantation. He appeared to understand and continued to do the best he could one day at a time to reach his goal.

HBPC 4: Objective was to develop acceptance and Evaluation

During the fourth visit P looked different from the first time. He was more concentrated on learning and accepting the cycle of life and his disease. He still had hopes to get a kidney transplant. He had many questions about the kidney transplant and the palliative care team made suggestions to him about how to find out more about the detail for queuing for a kidney transplant. He complained that he was often forgetting to do many things and had to practice his concentration to slowly think about everything. His face was better and bright from the decreased buildup of waste products in his body from the dialysis treatments.

Evaluation, The researcher assessed his needs and asked about his level of satisfaction of the home based palliative care using a standard questionnaire. After that the researcher determined that he would receive home health care as long as he still had quality of life in his home environment. The team would provide home based palliative care (model 2) for end of life if his quality of life worsened.

5. Hemodialysis Case Study Exemplar 5: Uncle Sit

Uncle Sit was 65 years old. He had diabetes for 20 years, in addition to heart disease. He had been treated with hemodialysis for two years. He had a caregiver to take care of him. He had problems with his wife even though he and she lived in the same house. He had psychological problem and the left foot had a circulation problem in the small toe. So he needed a consult from the palliative care tram to the medical doctor and a psychiatrist.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained on the first visit about the objectives of home based palliative care, assessment the symptoms, uncertainty in illness, and quality of life. He had planned with the doctor to have an amputation of his toe because it had gangrene. The researcher suggested SKT to help stimulate the blood circulation.

HBPC 2: Objective was to develop understanding

The researcher talked about the progress of disease, how to observe the symptoms and their potential changes and how to follow up about his symptoms. He had improvement in his toe so the doctor had postponed the amputation. His daughter set up the room for practice of SKT with a new CD player .Uncle Sit acknowledged: “I understand my disease”.

HBPC 3: Objective was to develop mindfulness (encourage mind)

Uncle Sit expressed that his life was still OK and he could still do many things for his family. He enjoyed eating. He said “You know? During the day I prepare some stuff for my wife to eat. I recall when he would do this after I used to work. Regarding his disease he shared: “I don’t think about anything but just live day by day”. The researcher talked more about how to support his mind by using positive thinking and doing good things for others .This action is similar to do good karma and then it will bring feedback with good things in life. Moreover, the researcher and Uncle Sit talked about how to die without worry and how to go to the good new life. At the end of this conversation, he said his relationship with life was terrible and he worried about the medical expenses even though he had a gold card for free health care services in Thailand. Despite this card, he needed to spend extra money to hire a caregiver with his own income from the rent of his house. He had a small house and had many renters to get extra money. The researcher and team assisted him to provide his own self-care during this rehabilitation period.

HBPC 4: Objective was to develop acceptance and Evaluation

By the fourth visit, Uncle Sit expressed that he accepted the uncertainty of his illness. He felt proud to have learned to help himself to do many things.

Evaluation, The researcher assessed needs and asked about his level of satisfaction of home based palliative care using the standardized questionnaire. After that the researcher determined that he would receive home health care as long as he still had good quality of life in his home environment. The team would provide home based palliative care (model 2) if his symptoms worsened toward the end of his life.

6. Hemodialysis Case Study Exemplar 6: Uncle Su

Uncle Su was 50 years old. He had diabetes, hypertension and ESRD. He had an AV shunt placed and was treating withed with HD for 3 days per week. Formerly, he had followed his diet closely buy now he expressed boredom with life. His wife said that his behavior had changed over time. He wanted to live alone, did not want to meet or to see anyone. When the team met with him the first time, he was not interested in speaking with the team members. However after interacting with the team and hearing their suggestions, he felt better and changed his behavior. He appeared to better accept the cycle of his life than he formerly had.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptoms, uncertainty in illness, and quality of life. Uncle Su could perform his normal activities as he could before treatment such as helping his wife prepare food to sell. He even helped prepare food every day, including the day of his hemodialysis when he prepared everything before he went to the hospital for dialysis. He ate only the whites of 10 eggs per day which helped avoid edema. He had 30 baht cards for dialysis but had to pay 500 baht for using this right. Basically ,for dialysis cost persons with dialysis need to pay approximately 2000 bath and sometimes he chose to pay more for an extra filter used in dialysis which cost 1000 baht to use for 20 times. The researcher suggested that he learn to practice healing exercise in SKT 1, 6.

HBPC 2: Objective was to develop understanding

During the second visit, the researcher talked about the progress of disease, and how to observe the symptoms and their potential for changing. Uncle Su understood about his progressive disease. He said that he still enjoyed eating and everyday he would go to find something to eat. Every Sunday he took his family out to eat at various places including the floating market. He said he didn't have any other stress in the life other than his disease. At this visit, the researcher recommended that he continue to practice SKT.

HBPC 3: Objective was to develop mindfulness (encourage mind)

On the third visit, Uncle Su looked great and was very willing to meet with the palliative care team. He said that "Formerly, I felt so discouraged about the disease I tried to do everything for this disease but I felt hopeless. Since then I have begun to rethink about the disease and I thank you for supporting me to feel better.

HBPC 4: Objective was to develop acceptance and Evaluation

At this time Uncle Su's face was bright and he did not appear fatigued. He said that he always practices SKT every day and it feels good for him. The researcher explained about the palliative care program for helping him accept the normal cycle life and the need not to be careless in life.

Evaluation, The researcher assessed his needs and asked about his level of satisfaction about his home based palliative care using a standard questionnaire. He expressed his thanks for the visits and the suggestions that made him feel good about life. At the conclusion of the visit, the researcher designated him to receive home health care as long as he still had quality of life in his environment.

7. Hemodialysis Case Study Exemplar 7: Aunt Suy :

Aunt Suy was 89 years old. She had a tracheotomy tube and a lot of secretions. She had heart disease, diabetes and hypertension. She had problems with hearing. Her daughter retired from her job to take care of her. She was incontinent of urine and had severe difficulties with constipation. She was unable to walk.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptoms, uncertainty in illness, and quality of life. The researcher suggested SKT 1, 6 to practice.

HBPC 2: Objective was to develop understanding

The researcher talked about the progress of disease, how to observe the symptoms as they changed. Her daughter was interested in SKT and tried to stimulate her mother to practice every day. The researcher talked about how to prepare for situations which they may not want to think about but could happen due to the uncertainty in life. Her daughter said “In reality I don’t think about anything, I just only take care of her every day. It is good to think and prepare in case she might die one day. Thanks for talking with me about this”.

HBPC 3: Objective was to develop mindfulness (encourage mind)

When visiting Aunt Suy, her daughter, who provided good care, and her mother were interested in the concept of palliative care to prepare for the uncertainty of life for both of them. The process helped them think about this uncertainty and encouraged them to make the best choices in their lives.

HBPC 4: Objective was to develop acceptance and Evaluation

When Aunt Suy’s daughter was asked about her feelings toward her mother she said that she can accept the progressive symptoms of her mother until the last day that is coming.

Evaluation, The researcher assessed needs and asked about their satisfaction of home based palliative care using a questionnaire. At the conclusion of the visit, the researcher determined that she would receive home health care as long as she still had quality of life in her environment.

8. Hemodialysis Case Study Exemplar 8: Aunt Ra;

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptoms, uncertainty in illness, and quality of life.

HBPC 2: Objective was to develop understanding

The researcher talked about the progress of disease, how to observe the symptoms as they changed.

HBPC 3: Objective was to develop mindfulness (encourage mind)

Aunt Ra shared: “I can make my mind to accept the uncertainty of life in the future. I know about the disease. I had planned to do many things in my life and I try to do the best thing. If one day the end of my life comes, I am ready to go without any concerns.

HBPC 4: Objective was to develop acceptance and Evaluation

When talking about the uncertainty in the life she said that “I accept the normal life cycle and if I will die I request to die with peace and without medical instruments”.

Evaluation, The researcher assessed needs and asked about her level of satisfaction with home based palliative care using a standardized questionnaire. Aunt Ra still had energy to do daily activities in her life. After the conclusion of the visit, the researcher determined that she would receive home health care as long as she still had quality of life in her environment. The palliative care team set up home health visits 1 time per month.

9. Hemodialysis Case Study Exemplar 9: Uncle Boon:

Uncle Boon was 75 years old. He lived with his wife and his son lived nearby. He had hemiplegia on the right side. He had been receiving dialysis treatments for 7 years. He had an AV-shunt in his right hand. His son supported him for expenses related to hemodialysis treatments.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptoms, uncertainty in illness, and quality of life. He had problems with hemiplegia and also had difficulty with speaking and communicating.

HBPC 2: Objective was to develop understanding

The researcher talked about the progression of the disease, how to observe the symptoms and their changes. Despite his illness, he expressed that his life was so happy because of the good care his sons gave him. He said that he understood well about the uncertainty of his illness and the uncertainty in his life. When visiting him he always spoke about his family and the good care they gave him. He was also proud that he and his family had started with nothing and had worked hard to become millionaires.

HBPC 3: Objective was to develop mindfulness (encourage mind)

The researcher asked him about how to help provide support for his mind. He responded that he did not need anything to improve his thinking about his life. At the present he thought that he lived his life well and if he died in the future he would die without any regrets. He did not want to use medical instruments to extend his life .He said that “I would like to die with peace”.

HBPC 4: Objective was to develop acceptance and Evaluation

At this time the researcher shared with him about how to prepare everything for his life and death such as a living will or how to do the thing which he still wants to do in the life. He accepted the life cycle well. He had much happiness in his life and was proud of his son and daughter – they were his success in life. He said that he was so happy and did not worry about anything in life as he spoke with pride about his son again. He shared: “If the day is coming that I die, I can do so without concern and I will think about my good karma”.

Evaluation, The researcher assessed needs and asked about his level of satisfaction with home based palliative care using the questionnaire. At the conclusion of the visit, the researcher designated that he would receive home health care as long as he still had quality of life in his environment.

End stage renal disease patients undergoing continuous ambulatory peritoneal dialysis (CAPD)

CAPD Case Study Exemplar 1: Uncle dul :

Uncle Dul was 65 years old. He had diabetes; hypertension and ESRD. He had been treated with CAPD for 3 years and received it 4 times per day at 6 am, 12 am, 6 pm, and 12pm. Since he got this disease had had considered committing suicide. He lived with his wife and his daughter. He lived in a small home with little space. Mostly, he benefitted from the exchange of dialysis fluid.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptom, uncertainty in illness, and quality of life.

At the first visit, he felt sick with a cold and also had a swollen wound on a toe in his left foot. He appeared uncomfortable and unhappy.

HBPC 2: Objective was to develop understanding

The researcher talked about the progress of the disease, how to observe the symptoms and their changes. At this visit he still had the cold symptoms which he treated himself. He explained more about his suffering from this disease and stated that he felt better because he understood more about his symptoms by learning from his past experiences.

HBPC 3: Objective was to develop mindfulness (encourage mind)

On the third visit, he looked better and had been trying to do something for his family such as helping fix up the house. He stopped working and talking with the palliative care team. When he had to cope with the disease he tried to make himself better because he had a grandchild to stay with him he said that "when I saw the face of my grandchild I had something inspire me to cope or to continue to live." He said that sometimes when he stayed at home he felt alone but when the palliative care team visited him, he felt good .He said that "It is good to visit because I felt that there are many people concerned about my health".

HBPC 4: Objective was to develop acceptance and Evaluation: At this visit Uncle Dul looked good and he had helped his wife to continue to fix the house. He had more energy to do his activities of daily life. He said that "I must have a high threshold of pain to cope and struggle with this life.

Evaluation; The researcher assessed needs and asked about the level of satisfaction for home based palliative care using the standard questionnaire. After that the researcher determined that he would receive home health care to help improve his quality of life in his home environment. He still would also need some visit from community nurses.

CAPD Case Study Exemplar 2: Aunt Or:

Aunt Or was 56 years old. She had been treated with CAPD for 3 years and was treated 3 times per day, at 6 am, 2 pm, and 10 pm. She had a husband but her husband had problems with his brain and had disappeared, no one knew where he was. So she lived alone and tried to survive on her own. Sometimes she felt depressed and didn't do dialysis because he felt hopeless. Sometimes she gave dialysis solution to other people with ESRD because she didn't use it. Her health care provider must take care and try to follow her in treatment compliance. Mostly she did not regularly use her dialysate fluid.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptom, uncertainty in illness, and quality of life.

HBPC 2: Objective was to develop understanding

The researcher talked about the progress of the disease, how to observe the symptoms and their changes. Aunt Or felt that she lived alone and so if she died one day, everything would be finished. "I understand well about this disease but for me it is not necessary to treat it, let me die, my life is not worth living because I did not have relative I did not have someone to care me".

HBPC 3: Objective was to develop mindfulness (encourage mind)

She still had problems with the loss of dialysate fluid, hypertension, itching, and tiredness. She said that "Sometimes I was unconscious and asleep in front of the house. I am hopeless so I did not want to do anything. Some days I felt uncomfortable, I would use 4.5% of dialysate fluid help me. It is better than 1.5% dialysate fluid". This reflects that she understands her condition well but she did not have anything to inspire her to do the best things for her life. When her life was full of suffering and lacked something to hold onto, she felt alone and did not have the aim to survive. She has no children, no husband, and no relatives.

HBPC 4: Objective was to develop acceptance and Evaluation

When talking about the life cycle with her, she said that "If I die on any day I will die alone. I am not sure who will arrange the funeral for me. If no one takes my body to temple to burn, my body will decompose and cause a bad smell in the community until everyone cannot cope with it and hopefully they will take my body to the temple".

Evaluation; The researcher assessed her needs and ask about the level satisfaction of home based palliative care using the questionnaire. The researcher determined that she needed help in monitoring the CAPD process and support to learn to live with quality and without complications. She lived alone in a small rented house. The palliative care team set up home health care to follow up her case every month.

CAPD Case Study Exemplar 3: Uncle L :

Uncle L was 62 years old. He had been treated with CAPD 3 times per day at 6am, 2pm, 10 pm. and HD on Monday and Thursday. He got problems with infection. The water dialysis was not clear. He had problems with the water draining out less than the water drain into the body. He had many lung secretions which he could not adequately cough out. When he slept he needed to use two pillows to lie down. Basically, his habits related to the process of CAPD at home were not good. He usually did it himself but did not follow instructions for example following the recommended time to put on dialysis and the time to take out the dialysate fluid.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptom, uncertainty in illness, and quality of life to make relationships with those living with ESRD and their family. At the first visit, Uncle L had complications with extreme tiredness, discomfort in the stomach and secretions in his lungs and throat. His face looked ill. His wife had planned to send him to the hospital.

HBPC 2: Objective was to develop understanding

At the second visit, Uncle L had just come back from the hospital for treatment of progressive symptoms for one week. When the researcher saw him, he looked better after the hospital admission. The researcher talked about the progression of disease, how to observe the symptoms and their changes. After a discussion with his neighbor, the researcher realized he had a habit of lying to his doctor about his CAPD treatments and results at home. The researcher tried to assess his problems and analyzed why he had this problem. From the assessment, the researcher found that he had problems about his finances as well as with the relationships in his family. His wife was heard to say: “Ta L, you should die, I feel so bored with you both in from you using a lot of money and from the time taken from me”. The researcher gave instructions about progressive symptoms and the need to be careful because he will get complications from not doing the dialysis properly and was at risk for infection because of poor hygiene.

HBPC 3: Objective was to develop mindfulness (encourage mind)

When the researcher met him, he was uncomfortable from a choked feeling in the stomach. The research gave suggestions about the correct position after dialysis and also taught breathing exercise of SKT 1. When talking about the life cycle he said that “I know one day in the future I will die but at the moment I feel bored and I don’t know why I live?” At this visit, the researcher talked with him about how he could work around the house and help his wife to do things. By this visit, Uncle L was strong but experienced problems related to complications because he did not always follow instructions for peritoneal dialysis. The palliative care team supported him to do the correct procedure and encouraged him not to worry about the disease every day. He was instructed to change his position frequently and to walk around in his house more often. He felt better from talking with the team members and felt proud when talking about his job.

HBPC 4: Objective was to develop acceptance and Evaluation

During the fourth visit, Uncle L said in terms of symptoms, some days were good, and some days were bad. During his dialysis exchange for dialysis, most days he still had profit of about 100-200 cc. per cycle. He still had problems with a choking feeling in his throat during dialysis treatment. He always took Air-X when he got this problem. The researcher found that he had psychological and spiritual distress so the team discussed how to help him with these feelings.

Evaluation; The researcher assessed needs and asked about the level of satisfaction of home based palliative care using the questionnaire. After that the researcher determined that he would receive home health care as long as still had quality of life in his environment.

CAPD Case Study Exemplar 4: Aunt Jun :

Aunt Jun was 60 years old. She had been treated with CAPD for 2 years, 3 times per day at 6 am, 2 pm, and 10 pm. She had good practice and results from dialysis at home. Mostly her cycles had a profit from each cycle. She also had good health habits related to her precaution technique with dialysis and she exercised every day. She had problems with vision, she could not see clearly with her right eye.

Home based palliative care (HBPC):

HBPC 1: Objective was to develop relationship

The researcher and team explained about the objectives of home based palliative care, assessment of the symptom, uncertainty in illness, and quality of life. The team made recommendations to be careful to prevent accidents at home because of her vision problems. .

HBPC 2: Objective was to develop understanding

The researcher talked about the progression of her disease, how to observe the symptoms and their changes. At this time she looked good and appeared happy with her life. She was also content to demonstrate the methods she practiced during CAPD and to stay healthy. The researcher talked about SKT for healing exercise and Aunt Jun said she was interested.

HBPC 3: Objective was to develop mindfulness (encourage mind)

The researcher talked about the normal life cycle and Aunt Jun shared about her experience in dying. Before she started treatment with CAPD she had problems with uremia and had become unconscious. She was admitted to the ICU. The doctor told her relatives she had died. About one hour later she woke up. Everyone was quite surprised and she still survives. During this experience she said that she heard everything that everyone said but she could not respond. After experiencing death, she understood and tried to do the best things for her life. She worried that if she died now, she would not want to die alone. During the day she stayed alone, so if she died she might be alone.

HBPC 4: Objective was to develop acceptance and Evaluation

She said that I understand about life, what will happen, will happen. So I accept this. In her life she had experienced death and recovered again so she said that “I agree that everyone should prepare for death because we don’t know exactly what time we will die. For me, I had a problem with my waste products rising in my body until I went unconscious and was admitted in the ICU. The doctor told my relatives that he was sorry but that I died”. She said that “At that time I knew and I tried to say ‘I am here I do not die!’”. At the present, she tried to follow the instructions of her treatment and she did not have complications from CAPD.

Evaluation; The researcher assessed needs and asked about the level of satisfaction of home based palliative care using the standard questionnaire. After that the researcher determined that she would receive home health care as long as she still had quality of life in her environment.

Phenomena in End of Life care of ERSD:

As the time past, many people living with ESRD who still received treatment often changed their minds and realized the end of their life was coming. Figure 4.11 depicts the process noted among the study participants.

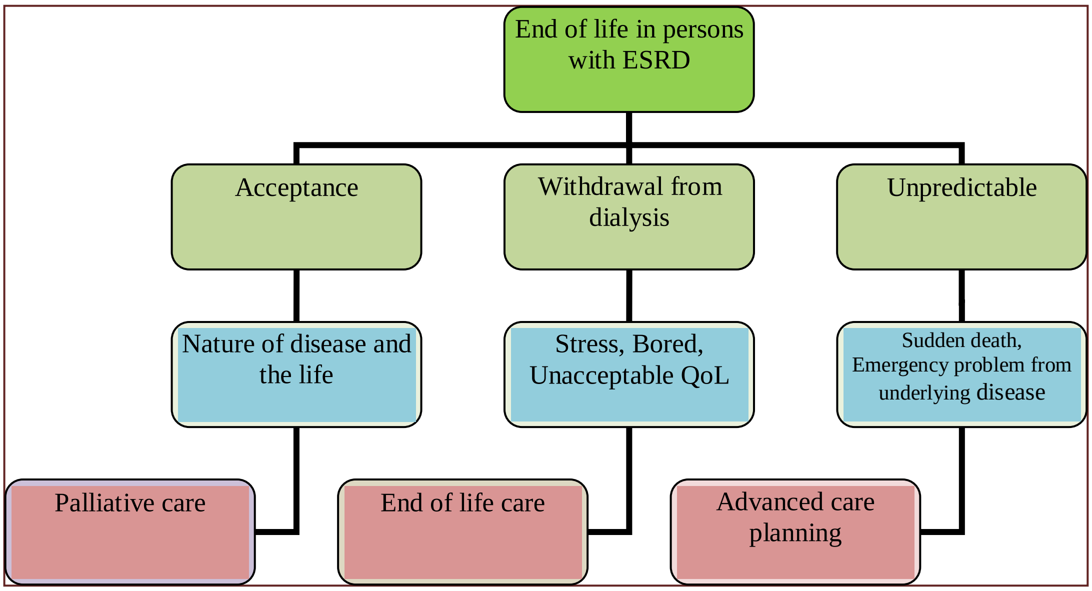


Figure 4.10 Phenomena of people living with ESRD in each type of care

During the course of this project, five study participants with ESRD died, 3 of them died at the hospital and 2 of them died at home.

Early signs and symptoms;

Anemia, Hypertension, Leg cramps, pitting edema, gains in weight with fluid retention, weakness and fatigue.

Late signs and symptoms;

Uremic pruritus, frequent headaches, heat or cold intolerance, ammonia or urine smell to breath, chest pain or palpitations , Dyspnea , easy bruising , purpura, bleeding, loss or gain in weight, nausea and vomiting , coma.

Hyperkalemia commonly occurs and can be the ultimate cause of death. Hyperkalemia first results in hyperreflexia and muscle fasciculation, eventually progressing to muscle weakness, paralysis, cardiotoxicity, and finally death as cells are no longer able to sustain normal electrical activity.

Uremic toxins on the brain causing mental and behavioral changes; Memory deficits including amnesia, accompanied by lethargy and drowsiness, are common early symptoms, gait disturbances, paresthesias, organic psychosis, and finally coma.

Dying trajectory:

The dying trajectory for persons with people living with ESRD was characterized by symptoms of uremia, which is the buildup of toxic waste products in the blood. Toxins that the kidney normally eliminates include urea, excess phosphorus, potassium, acids, hormonal and protein by products, sodium and water, begin to accumulate.

One of the study participants with ESRD complained of excessive itching two weeks before she died. The doctor adjusted her medicine but she still had severe itching in her arms, body and legs .The following week later, she came to hemodialysis as she normally did but her symptoms had changed. She was now extremely exhausted and had nausea and vomiting. Her son took her to the ICU ward and after that she soon died in ICU.

The reaction of this person could be characterized using Elizabeth Kubler Ross's steps as: Depression, bargaining, acceptance.

Another participant had changed symptoms at home after dialysis. Her relatives took her to the ICU ward where she was treated for two days and then she died.

The reaction of this person could be characterized using Elizabeth Kubler Ross's steps as simply: bargaining and death.

A third study participant had problems with infection (sepsis). He got a high temperature and his daughter took him to ICU. He died just after only one day in ICU.

The reaction of this person could be characterized using Elizabeth Kubler Ross's steps as: bargaining, acceptance, and death.

Another study participant who died had purpura, bruising and easy bleeding all over his body. His daughter-in-law took care him. He also had problems with his prostate gland and used a Foley catheter. He had signs of a urinary tract infection. For several weeks, he was extremely tired. He died at home with his family the day before his hemodialysis treatment was due.

The reaction of this person could be characterized using Elizabeth Kubler Ross's steps as: bargaining, acceptance, and death.

Another study participant felt uncomfortable after hemodialysis treatments. His desire was to stay at home because he had accepted the normal cycle of life and he thought that his time was coming. He chose to go without any further medication or treatment and died one day later at home.

The reaction of this person could be characterized using Elizabeth Kubler Ross's steps as: bargaining, acceptance, and death.

Near Death Experience

One study participant had problems with volume-overload and dyspnea until she lost consciousness. She shared her experience with "dying". Her story was that she had uremia, confusion and then lost consciousness. Her relatives brought her to the hospital at in a rural area in her hometown. Once there the doctor suggested treating her with CAPD she was then admitted to the ICU ward. The doctors tried treating her until she "died". They reported her cause of death was pleural effusion. Her body had started to turn a blue and green color her family told her afterwards. However during this time, she said "I heard everything that everyone said about me and felt the joss stick and flower on my hand but I couldn't respond". About one hour late after the doctor signed the death certificate "I died; I woke up and said I am still alive! Everyone was surprised. I woke up for about 1-2 hrs. but after that I went unconscious again for 2 hrs. Later I woke up again. It was not the time for my death". She talked with us and her daughter supported the truth of her story.

The meaning of dying for people living with ESRD:

The normal changes occur in the final stage of living, commonly called "dying". During this period, this study examined ways of caring. It was intended to help the dying and their loved ones to understand and be prepared for these changes. The study explored the meaning of death among in people living with ESRD and their families. This is often a time of self-examination, of questioning, of looking for the meaning of life. As the body's systems weaken, less oxygen is available to the muscles and more effort is needed to complete everyday tasks. At this time, one may become embarrassed, discouraged, ambivalent, depressed, and irritable and/or just naturally become more interested in matters that seem more important: matters of the mind, heart and spirit.

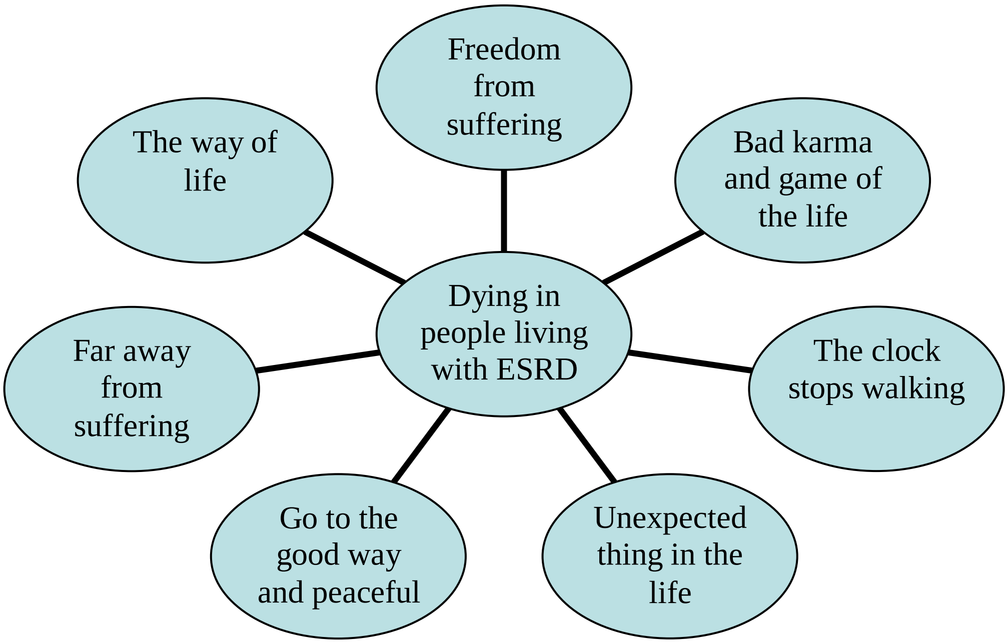


Figure 4.11 The meaning of dying for people living with ESRD

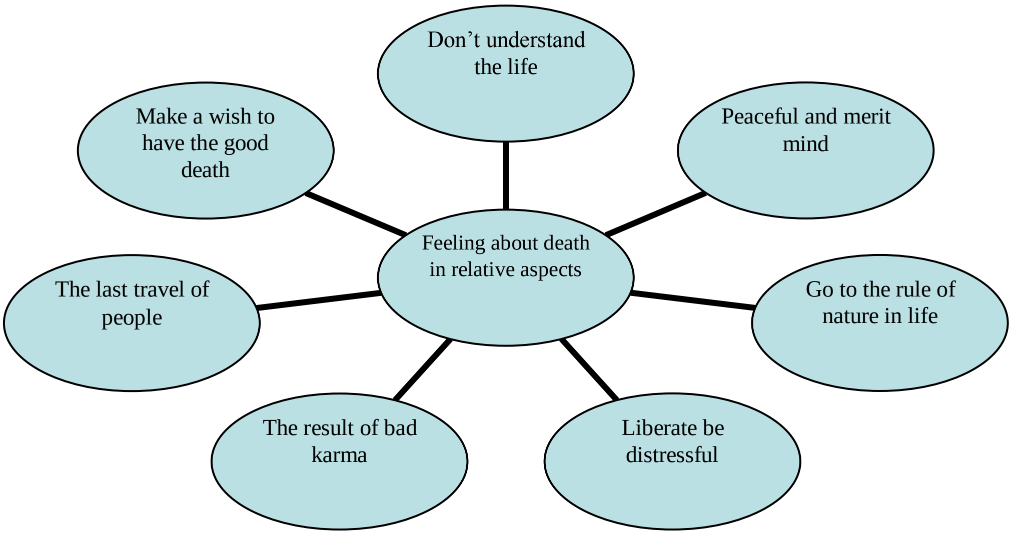


Figure 4.12 The meaning of dying from the perspective of families of people living with ESRD

The meaning of dying of people living with ESRD's families

Don't understand:

When asking about the meaning of death, one relative said about "I did not understand about birth and death especially in the progress of disease. Yesterday it was good but today it was bad, the life looks as fragile as the leaf".

Concern about how to care

Most of relatives in rich families provided good care and were concerned about the best care and outcome for their relative with ESRD, often their mother or father. On the other hand, some families had problems with their financial situation so they could not give attention to their family member with ESRD which led to sadness and a difficult living situation. One relative said that "Even though my happiness was gone, I still loved to care for her because I loved mom". Meanwhile one relative in the family said that "Whenever you will die? I hurt a lot from taking care you, go go! away from this world!". This reflects that this disease was so terrible at times for both families and the persons with ESRD. Whether the people living with ESRD had good or bad care depended on the economic status of the family and their concern about caring for their emotional state of mind. These differences were reflected in the relationships observed among the families in this study. Even though the nature of Thai culture is the concern for caring, if the situation was influenced by other factors, the caring style was at time changed.

Relationship between couple:

When the disease happened in one member of a couple it appeared that problems were worsened often if the wife was the one affected with the disease. But this was not always the case as in one couple; the wife ignored the husband with ESRD and let the duty of care fall to the daughter. Many married women with ESRD said that their husbands' behavior had changed toward them since they had the disease. One said "I did not care just only paid for treatment, I was still OK". When asking about the details of her life, she said she was so sad and understood the nature of her life. In contrast, one woman with ESRD said that she got good care from her husband who helped her with dialysis in the hospital even though their family was poor. Her husband sought to make money by working as fortune teller during his wife’s dialysis treatments. Rich families had fewer problems than poor families in many aspects.

Acceptance of the nature of life:

Many relatives said that acceptance was the best way because they did not have many other choices so acceptance of the life cycle made sense. One said that if we accepted that birth, aging, illness, and death were part of the normal life cycle, everything would be easier.

Make a wish to have peace at the end of life:

Many relatives said that they wished to let their loved one go to a peaceful place in the new life. Relatives reflected about death with peacefulness. In this study, contrary to the former era when talking about death was not acceptable among Thai people, the participants, including people living with ESRD and their families did accept talking about death. They engaged in discussions about how to prepare for death and expressed the need to know how to observe and care for persons at the end of life. The study suggested that observation of symptoms such as tiredness, itching and pain was important in the prediction of impending death.

Die with dignity and with a clear mind:

Many of relatives were concerned about dying with dignity and with a clear conscience. ? Many relatives waited for the time just before the people living with ESRD would die to try to allow them to speak their peace with the relatives.

The process in EOL of people living with ESRD

Caring for a dying loved one isn't easy, even when knowing the end of life is approaching. Understanding what to expect and what one can do to increase one's comfort that can help is essential. Death is a personal journey that each individual approaches in his/her own unique way. Nothing is concrete, nothing is set in stone. There are many paths one can take on this journey but all lead to the same destination. As one comes close to death, a process begins; a journey from the known life of this world to the unknown of what lies ahead. As that process begins, a person starts on a mental path of discovery; comprehending that death will indeed occur and believing in his/her own mortality. The journey ultimately leads to the physical departure from the body. In this study, the process of the end of life followed the cycles displayed in Figure 4.13.

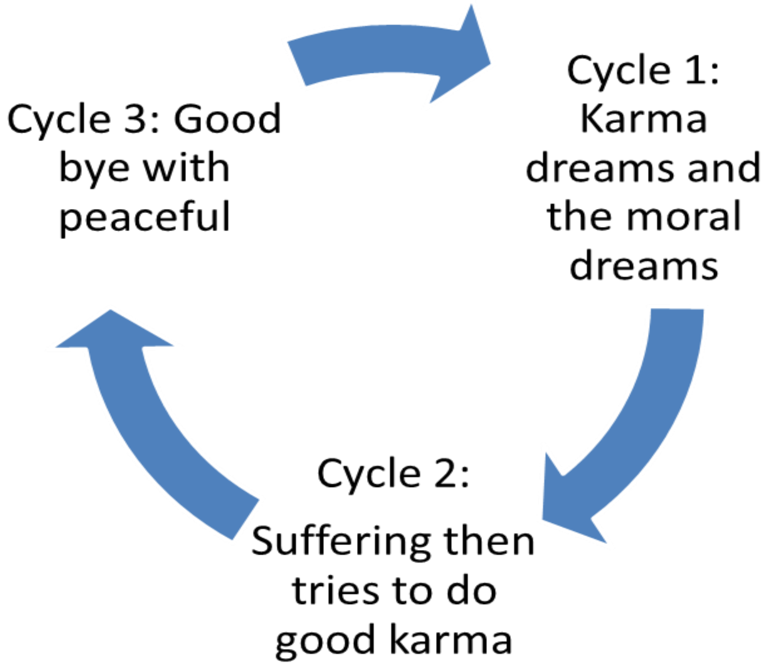


Figure 4.13: The process in end of life before dying of people living with ESRD

Cycle 1: Karma dreams and the moral dreams (กรรมนิมิต และคตินิมิต)

Plan:

When people living with ESRD were in the process of the end of life just before death, they often spoke about bad karma in life. They spoke about former actions when they were young and did such things as killing birds by elastic rings and getting pleasure from seeing the birds die. At the time of death in this case, the picture of bad karma appeared. Uncle L, who saw the birds which he killed them in his head at the time of his death so he tried to forgive them by doing the good karma. His sister said that “when he was young he liked to play this game and many friends encouraged him to kill the birds”.

Act:

The relatives provided support at the end of life. Good karma resulted from how people lived before they passed away.

Reflect:

This cycle reflects the way of life of people who do anything in the life, including good or bad things. The process teaches us to know that anyone is able to get the same way if they make up for bad karma in early life. In Buddhism, many people believe that is the law of doing .This law will reflect the result of doing things in either a good or bad way.

Cycle 2: Suffering from the uncomfortable symptoms and try to do good karma

Plan:

Many people living with ESRD had worsening symptoms especially being tired, fatigued, pruritus/itching or uremic symptoms. During this process most relatives were frightened and sent their relative with ESRD to the hospital .Some relatives chose to allow the people living with ESRD to die in the hospital. In the cases who received home based palliative care, relatives still initially sent their family member to the hospital and asked about the progressive symptoms. After that, the relatives would usually follow the living will of people living with ESRD about their requested place of death. One relative tried to move his mother to go back home to die.

Act:

This cycle tried to relieve suffering from the physical aspect and tried to make the living will of people living with ESRD and families so that they could choose the place to die. Moreover many relative tried to seek ways to support the person close to death and to help if he/she wanted to do anything more in life.

Reflect:

In home based palliative care, the health care providers should be well prepared in the knowledge and management of progressive symptoms .These is important to treat in crisis situation for families. They will accept the normal life cycle and accept the progressive symptoms which cannot be avoided but which can be managed to extend their time.

Cycle 3: Good bye with peace

Plan:

The researcher prepared one of the study participants at home by teaching how to send him to paradise or heaven to have a peaceful death. Basically, in

Buddhism it is believed that it is an important process to help someone in the last breath to heaven. If not this process does not occur, the last moral dreams will be about lead to that thing such as the animals and thus the next life after death will result in a rebirth in that animal. So this process of helping someone to the good next life is an important thing, the nurse or relative should know the way to do like this.

Act:

How do decorate the body after death?

How do prepare to set up the ritual?

Communication for relative and friends

Reflect:

This cycle will be reflected to quality of life and die with dignity and peace.

Think about good or bad karma; good karma leads to happiness and bad karma leads to suffering. This is the fact from people's beliefs.

The core component in developing palliative care model was communication, symptom management, psychosocial support and care for end of life because of uncertainty in illness and uncertainty in life of people living with ESRD.

Management in people living with ESRD should consider the timing of involvement. The timing involvement related to pre-dialysis, dialysis and withdrawal from dialysis until terminal stage of life.

4.3.3 Satisfaction, spiritual well-being aspects on home based palliative care

Quantitative data study:

In this study, the researcher evaluated the model of care by a questionnaire before and after in three aspects including satisfaction, well-being and psychological effect, Well-being and psychological effects. In the questionnaire the measurement of life satisfaction in home based palliative care of people living with ESRD was composed of 22 questions divided in 4 parts : part 1; 6 activities related to the development of the relationship and trust ,part 2; 6 activities to develop understanding ,part 3; 5 activities to develop mindfulness ,part 4 ; 5activities related to acceptance. The 3 responses to each question were composed of: very satisfied, satisfied, and not satisfied at all. The highest score for life satisfaction was 66 in people living with ESRD. The relative satisfaction questionnaire was composed of 17 questions .The highest attainable score was 51.The data were shown in Table 4.11.

Table 4.11: Satisfaction, well-being and Psychological & spiritual score before and after home based palliative care (HBPC) model

Variables	Before HBPC		After HBPC	
	Min/Max	$\overline{X}$ ±SD	Min/Max	$\overline{X}$ ±SD
Satisfaction persons with ESRD	26/54	38.05±7.49	55/66	62.93±3.38
Satisfaction of relative	27/42	36.84±3.73	40/51	47.86±6.32
Well- being	2/10	5.60±2.21	5/10	7.85±1.74
Psychological& spiritual	6.29/ 24.67	21.17±4.82	14.79/28.68	28.54±3.51
QoL	12.06/27.05	18.44±4.46	18.38/29.67	23.65±3.21

From table 4.11 the home based palliative care model increased satisfaction of people living with ESRD from 38.05 to 62.93 satisfactions. For relative of people living with ESRD increased satisfaction from 36.84 to 47.86.

For well-being of people living with ESRD before and after intervention with HBP model the average score increased from5.60 to 7.85. The psychological and spiritual of people living with ESRD before and after intervention with HBPC model the average score increased from 21.17 to 28.54.

4.3.4 Evaluation in the home based palliative care model

The home based palliative care model for people living with ESRD was developed by using the framework for program evaluation in public health following these steps:

4.3.4.1Steps in evaluation practice and standards for effective evaluation

Steps in Evaluation Practice

Step1. Engage stakeholders or participants

The participants were composed of doctors, nurses, social workers, health volunteers, families and people who are living with ESRD. They engaged in the program and followed the guidelines step by step. Stakeholders were engaged in the program and they reported an interest in palliative care. Therefore, evaluation findings are strengthened because they did address the stakeholders' concerns and values. After becoming involved, stakeholders helped to execute the other steps of the process. Those persons were involved in or affected by the program and they will be the primary users of the evaluation.

They include people who are living with ESRD, their families and health centers affected directly in the program who received services to enhanced community services.

Community nurses were primary users of the evaluation and the specific persons who are in a position to do or decide something regarding the program. In practice, community nurses would be a subset of all stakeholders identified. The evaluation addresses their values and satisfies their unique informational needs.

Step2. Describe the model

Need: This home based palliative care is important for active nurses in the community. The program followed the Thai nursing council policy about palliative care both in the hospital and community setting. This program was supported by national policy. Moreover, it included a willing group of community nurses who are interested in palliative care and end of life care in the community.

Expected effects: The researcher expects that this study will stimulate to people in the community to accept in a normal process of life cycle. It hopefully will ultimately change the attitude of people in society in terms of talking about death and dying. This will help people in community to prepare themselves for death as a natural cycle of life. .

Activities: The activities were set by the group and researcher by using the Buddhism concepts such as making relationships for encouragement, to develop understanding, develop mindfulness, and to develop acceptance.

Resources: Human resources in health centers, hospitals, health volunteers, willing minds

Stage of Development: using the method of mixed research in qualitative study to develop model: Pre planning, planning, situation analysis, model development.

Context: Descriptions of the program's context include the setting and environmental influences such as the policy of the Thai nursing council prepare to set up palliative care in the community, in the context of social and economic conditions of people living with ESRD. Understanding these environmental influences is required to design a context-sensitive evaluation and aid users in interpreting findings accurately and assessing the generalizability of the findings.

Activities: Set of needs addressed by the palliative care program; the researcher and team set SWOT analysis and assessed needs, desired, and assets of community members. Identify barriers and facilitators to service use. Learn how to describe and measure program activities and effects, listing specific expectations as goals, objectives, and criteria for success.

Clarifying the reason of model activities are believed to lead to expected changes. The researcher believed that this model would be a guide community nurses to set up palliative care following the Thai nursing council which has identified a need to set up palliative care in the community. Analyzing the context within which the program operates by conferencing with team members before and after the home based palliative care visits. Considering how the program was linked to other ongoing efforts by creating network with the team from two doctors and nurses at Chulalongkorn hospital was an important part of the process.

Step 3 Focus the evaluation design

Purpose: In the home based palliative care set the purpose with stakeholders from objective in set palliative care program to evaluation of the program.

Users: The community nurses agreed with the activities of home based palliative care and the activities were flexible for practice in community.

For the people living with ESRD who used the program, they were satisfied in the process of home based palliative care from qualitative data collection.

Activities : Meeting with stakeholders to clarify the intent or purpose of the evaluation; Learning which persons are in a position to actually use the findings, then orienting the plan to meet their needs; Understanding how the evaluation results are to be used; Writing explicit evaluation questions to be answered; Describing practical methods for sampling, data collection, data analysis, interpretation, and judgment; Revising parts or all of the evaluation plan when critical circumstances change.

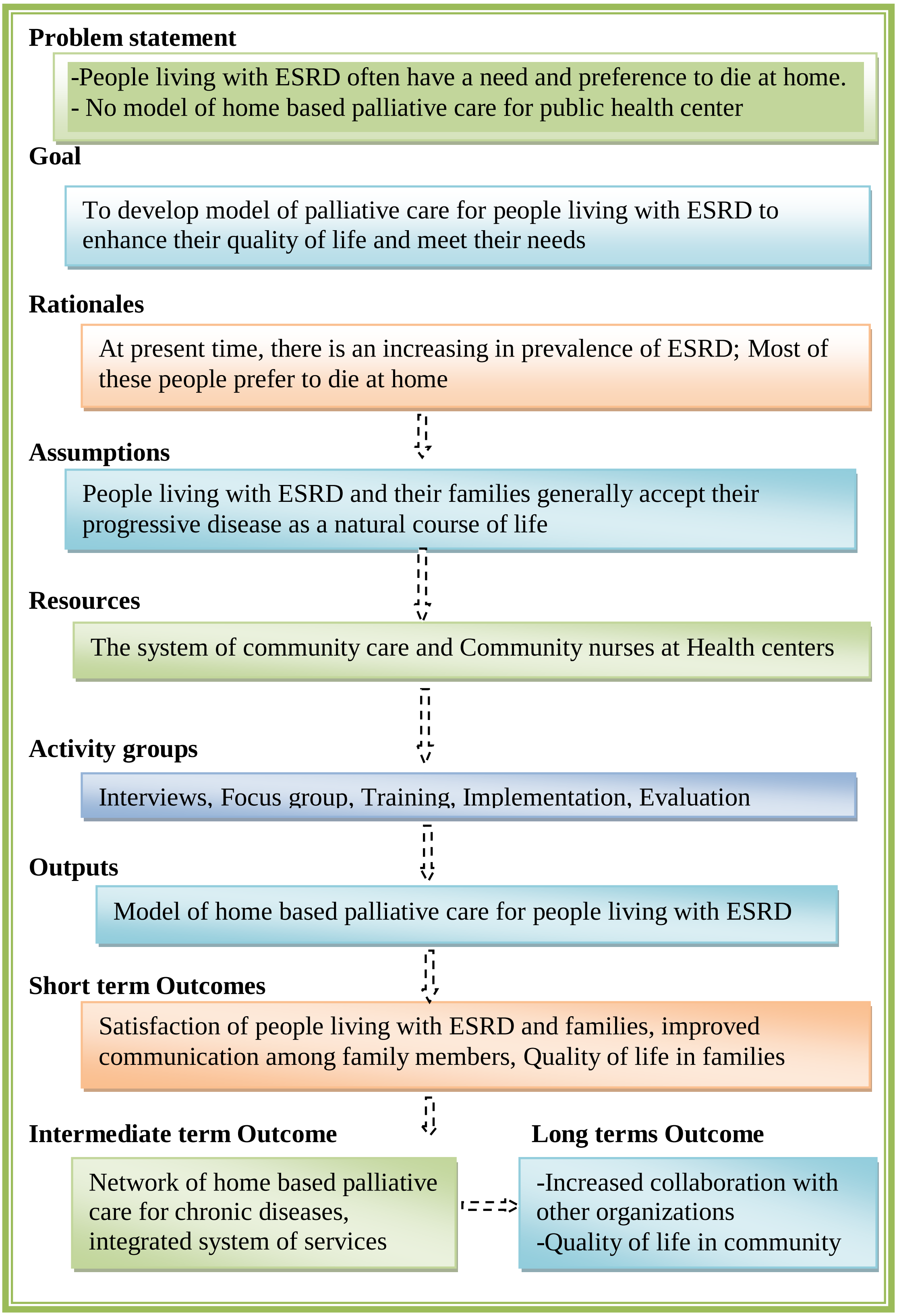
Step 4: Gather credible evidence.

Persons**;** Clients, model participants, nonparticipants; Staff, program managers, administrators; Key informants; Representatives of advocacy groups; Elected officials, legislators, policymakers

Documents; There were grant proposals, materials, asset and needs assessments; surveillance summaries; photographs.

Observations; There were meetings, special events/activities and direct service in community.

Drawing an explicit logic model to illustrate relationships between program elements and expected changes; the logic model showed in the following:



Problem statement

-People living with ESRD often have a need and preference to die at home.
- No model of home based palliative care for public health center

Goal

To develop model of palliative care for people living with ESRD to enhance their quality of life and meet their needs

Rationales

At present time, there is an increasing in prevalence of ESRD; Most of these people prefer to die at home

Assumptions

People living with ESRD and their families generally accept their progressive disease as a natural course of life

Resources

The system of community care and Community nurses at Health centers

Activity groups

Interviews, Focus group, Training, Implementation, Evaluation

Outputs

Model of home based palliative care for people living with ESRD

Short term Outcomes

Satisfaction of people living with ESRD and families, improved communication among family members, Quality of life in families

Intermediate term Outcome

Network of home based palliative care for chronic diseases, integrated system of services

Long terms Outcome

-Increased collaboration with other organizations
-Quality of life in community

Figure 4.14 Logic model for home based palliative care model

Table 4.12 The model's capacity to deliver services;

Characteristic	The result
Continue monitoring Training	There is palliative care training for health care providers both for hospital and community settings. This is an opportunity to monitor training for palliative care.
Qualitative needs assessment	Many data support the lack of knowledge in palliative care for community
Assess feasibility	Composed of 4 steps in home based palliative care by using the concept of karma in Buddhism.
Acceptability	99% of stakeholders accept the model
The participation rate	88%Health volunteers 90%Community nurses and team
Levels of people living with ESRD satisfaction	99% of people living with ESRD were satisfied in the caring model
Levels of families Satisfaction	97% of families were satisfied with the model
Quality of life for dialysis in people living with ESRD	The score of Quality of life was 14-29 /30 in dialysis compare with before started home based palliative care the score was 10-26. The quality of life of people living with ESRD was increased.

Step 5: Justify conclusions.

Standards: The home based palliative care practice followed the standard of Thai nursing council.

Analysis and Synthesis: analysis and synthesis of the program were useful for setting the home based palliative care in community because the process used more time in visiting, up to 4 times as many visits but it relieved the suffering of people living with ESRD who felt hopeless or tried to cope with many problems at home .Consequence, the system of caring should include home based palliative care. While initially it may require more visit time, over time the trend will include an improved quality of life for person in the community.

Interpretation: The researcher was aware of the interpretation in many aspects of the data collection and analysis.

Judgments are statements concerning the merit, worth, or significance of the program so the study results should support whether to continue the provision of home based palliative care services.

Recommendations are actions for consideration resulting from the evaluation. In this study, recommendations included the extension of palliative care services to cover all health centers in Bangkok but the study was restricted with the time, budget for extended service to all areas of Bangkok.

Step 6: Ensure use and share lessons learned

Lessons learned in the course of an evaluation do not automatically translate into informed decision-making and appropriate action. Deliberate effort is needed to ensure that the evaluation processes and findings are used and disseminated appropriately.

4.3.4.2 Standards for Effective Evaluation

Standard 1: Utility

The following utility standards ensure that an evaluation will serve the information needs of intended users:

Stakeholder identification: In the home based palliative care showed their needs.

Evaluator credibility: The researcher conducted the evaluation with trustworthiness and competence while performing the evaluation of findings to achieve maximum credibility and acceptance.

Information scope and selection: The researcher scoped the area of study around Saint Louis college and selected the case of people living with ESRD both who are treated with hemodialysis and peritoneal dialysis for development home based palliative care for people living with ESRD.

Values identification: The perspectives, procedures, and rationale used to interpret the findings were carefully described so that the bases for value judgments were clear.

Report clarity: Evaluation was reported clearly and described the model being evaluated, including its context and the purposes, procedures, and findings of the evaluation so that essential information is provided and easily understood.

Report timeliness and dissemination: Substantial interim findings and evaluation reports were disseminated to intended users so that they could be used in a timely fashion.

Evaluation impact: Evaluations have been planned, conducted, and reported in ways that encourage follow-through by stakeholders to increase the likelihood of the evaluation being used.

Standard 2: Feasibility

The following feasibility standards ensured that an evaluation was realistic, prudent, diplomatic, and frugal:

Practical procedures: Evaluation procedures were practical while necessary information was obtained to keep disruption to a minimum.

Political viability: During planning and conduct of the evaluation, consideration was given to the varied positions of interest groups so that their cooperation could be obtained and possible attempts by any group to curtail evaluation operations or to bias or misapply the results could be averted or counteracted.

Cost-effectiveness: The home based palliative care project required more time for one case with 4 times as many visits in comparison to home visits made 1 time per year. Home health care required 1 visit per month and home based palliative care required 1 visit per week. So when compared, the time it might take both different levels of care are related to the need for caring for physical, emotional and psychological symptoms.

Table 4.13 Satisfaction level of type of visiting

Type of visiting	**The time in service**	**The level of satisfaction**	**The benefit reduce cost of treatment**
Home visit (HV)	1 per year	Satisfied (60%)	Satisfied (33.33%)
Home health care (HHC)	1 per month	Satisfied (97.14%)	Satisfied (86.28%)
Home based palliative care (HBPC)model	1 per week	Very satisfied 97.14%)	Very satisfied (91.42%)

Standard 3: Propriety

The following propriety standards ensured that an evaluation was conducted legally, ethically, and with regard for the welfare of those involved in the evaluation as well as those affected by its results:

Service orientation: The evaluation was designed to assist organizations in addressing and serving effectively the needs of the targeted participants.

Formal agreements: All principal parties involved in the evaluation agreed in writing to their obligations.

Rights of human subjects: The evaluation was designed and conducted in a manner that respected and protected the rights and welfare of human subjects.

Human interactions: Evaluators interacted respectfully with other persons associated with an evaluation, so that participants were not threatened or harmed.

Complete and fair assessment: The evaluation was complete and fair in its examination and recording of strengths and weaknesses of the model so that strengths could be enhanced and problem areas addressed.

Disclosure of findings: The principal parties to an evaluation ensured that the full evaluation and findings with pertinent limitations were made accessible to the persons affected by the evaluation and any others with expressed legal rights to receive the results.

Conflict of interest: Conflict of interest was handled openly and honestly so that the evaluation processes and results were not compromised.

Fiscal responsibility: The evaluator's allocation and expenditure of resources reflected sound accountability procedures by being prudent and ethically responsible, so that expenditures were accountable and appropriate.

Standard 4: Accuracy

The following accuracy standards ensured that the evaluation conveyed technically adequate information regarding the determining features of merit of the model:

Program documentation: The program being evaluated was documented clearly and accurately.

Context analysis: The context in which the program existed was examined in enough detail to identify probable influences on the program.

Described purposes and procedures : The purposes and procedures of the evaluation were monitored and described in enough detail to identify and assess them.

Defensible information sources: Sources of information used in a model evaluation were described in enough detail to assess the adequacy of the information.

Valid information: Information-gathering procedures were developed and implemented to ensure a valid interpretation for the intended use.

Reliable information: Information-gathering procedures were developed and implemented to ensure sufficiently reliable information for the intended use.

Systematic information: Information collected, processed, and reported in an evaluation was systematically reviewed and any errors corrected.

Analysis of quantitative information: Quantitative information was analyzed appropriately and systematically so that evaluation questions were answered effectively.

Analysis of qualitative information: Qualitative information was analyzed appropriately and systematically to answer evaluation questions effectively.

Justified conclusions: Conclusions reached explicitly justified the stakeholders' assessment.

4. 4 The result of meditation healing exercise (SKT6) in people living with ESRD

This study used a quasi-experimental quantitative method. The study included the people living with ESRD who met the inclusion criteria totaling 74 people. The 74 people living with ESRD were divided in 2 groups with 35 people living with ESRD in the SKT intervention group and 39 people living with ESRD in the non SKT intervention group. The two groups were treated with hemodialysis but in different wards in the same hospital. In the SKT group, they practiced and listened in meditation healing exercise (SKT 6) during hemodialysis. The effect was measured by blood results including electrolytes, BUN, creatinine, hematocrit, albumin, calcium, phosphorus which were compared with the blood results with the non SKT group every month for 4 months. After the study was completed, the non SKT group was informed about the technique of SKT and the benefits from its practice.

4.4.1 The Descriptive of group study

4.4.1.1 The general characteristics of people living with ESRD in the study

The characteristic of the groups are displayed in Table 4.13. The minimum age of the SKT group was 51 years and the in the non SKT group, 45 years. The maximum age of SKT group was 85 years and for the non SKT group, it was 82 years. The mean of age in SKT group was 70 years and the age in non SKT group was 61 years.

The SKT group was predominantly male (54.29%) as was the non SKT group (51.28%). The method of health care payment among those in the SKT group was predominantly the out of pocket scheme (77.14%); in the non SKT group, social security was the most common payment mechanism (46.15%).

Table 4.14 displays the number of years on hemodialysis in the two groups. For the SKT group, 48.58 % of the cases had duration of hemodialysis of 1-3 years; similarly, in the non SKT group 46.15 % of the cases had duration of hemodialysis of 1-3 years.

Table 4.16 reveals the characteristics of relatives and care givers of the SKT non SKT groups. The age groups were predominantly between 31-40 years with the percentage of 37.14 and 51.28 respectively. Most of the relatives or care givers were female with 80%, in SKT group and 76.92% in the non SKT group. Most of them had single status with 54.29% and 43.59% in SKT and non SKT groups respectively.

Table 4.14 Description of sample in SKT group and non SKT group

Characteristic	**SKT Group**		**Non SKT Group**	
	Number	Percent	Number	Percent
Age(range/year)				
41-50	4	11.43	8	20.51
51-60	7	20.00	10	25.64
61-70	9	25.71	10	25.64
71-80+	15	42.86	11	28.21
Gender				
Male	19	54.29	20	51.28
Female	16	45.71	19	48.72
Marital status				
Married	14	40.00	21	53.84
Single	5	14.29	9	23.08
Divorced	4	11.43	3	7.69
Widowed	12	34.29	6	15.39
Education				
Primary school	12	34.29	10	25.64
Secondary /Technical	15	42.86	18	46.15
Bachelor degree	8	22.85	11	28.21
Employment				
Employed	10	28.57	26	66.67
Unemployed	25	71.43	13	33.33
The right in welfare				
Out of pocket scheme	27	77.14	14	35.89
Social security S.	3	8.57	18	46.15
Government servant	5	14.29	7	17.96
Total	**35**		**39**	

Table 4.15: The duration of cases in hemodialysis

	SKT group		Non SKT group	
Years on hemodialysis	Number	Percent	Number	Percent
<1	4	11.43	2	5.13
1-3	17	48.58	18	46.15
>3-5	8	22.86	13	33.34
>5-8	2	5.71	2	5.13
>8-11	2	5.71	1	2.56
>11	2	5.71	3	7.69
Total	35	100	39	100

Table 4.16 Description of relative /care giver in SKT group and non SKT group

Characteristic	**SKT group**		**Non SKT group**	
	Number	Percent	Number	Percent
Age(range/year)				
21-30	7	20	4	10.26
31-40	13	37.14	20	51.28
41-50	10	28.57	11	28.20
51-60	5	14.29	4	10.26
Gender				
Male	7	20.00	9	23.08
Female	28	80.00	30	76.92
Marital status				
Married	10	28.57	14	35.89
Single	19	54.29	17	43.59
Divorced	3	8.57	2	5.13
Widowed	3	8.57	6	15.39
Education				
Primary school	6	17.14	5	12.82
Secondary /Technical	22	62.86	19	48.72
Bachelor degree	**7**	20.00	15	38.46
Total	**35**	**100**	**39**	**100**

4. 4.1.2 The result of Physical assessment symptoms

The results showed that the main symptom among the non SKT group in the pre –test period was a problem with tiredness; mean score of 3.7, followed by drowsiness with a mean score of 3.05. For SKT group the problems were noted in the measure of well-being, with mean score of 3.17, tiredness with mean score 2.88, and drowsiness with mean score of2.31. The data are displayed in Table 4.17.

Table 4.17 Edmonton symptom assessment system score before intervention

Physical symptoms	**SKT group**	**Non SKT group**
	$\bar{x}$ ±SD	$\bar{x}$ ±SD
Pain	2.28±2.51	2.67±2.55
Tiredness	2.88±2.43	3.72±2.58
Drowsiness	2.31±2.24	3.05±2.22
Nausea	1.48±1.91	1.20±1.97
Lack of appetite	1.85±2.25	1.77±2.59
Shortness of breath	1.60±1.83	2.70±2.79
Depression	1.65±1.98	1.30±2.31
Anxiety	2.00±2.35	2.22±2.75
Well- being	3.17±2.92	2.40±2.63
Other symptom	1.60±2.36	1.60±2.04

Before the intervention, the researcher assessed the skin of the study participants with ESRD in both groups and found that most persons in both groups had dry skin (91.42% in SKT group and 94.87% in non SKT group

Table 4.18 The characteristics related to skin in people living with ESRD before-after intervention

Characteristics of skin	Dry skin	Numbness	Itching
	N(%)	N(%)	N(%)
SKT before	32 (91.42)	28(80)	17(48.57)
SKT after	28(80)	22(62.85)	12(34.28)
Non SKT before	37(94.87)	29(74.36)	13(33.33)
Non SKT after	36(92.30)	27(69.24)	11(28.21)

In addition Table 4.18 reveals other reported symptoms including numbness in the hand or leg, and itching. After the intervention ,the researcher assessed the skin of people living with ESRD in both group found again the majority of persons in both groups had dry skin., in addition to numbness in the hand or leg and less commonly, itching in both groups. Interestingly, both the intervention and the control groups had a reduction in all skin symptoms after the intervention however the percentage change was greater in the intervention group.

The Edmonton symptom assessment system for palliative care measured tiredness, anxiety, overall well-being and several other physical symptoms. The results are displayed in Table 4.19. In for the non SKT group at the post –test period, the major problems reported included tiredness with mean score of 5.33, well-being with mean score of 5.21, and anxiety with a mean score of 4.95. In the intervention group, the major reported symptoms included overall well-being with a mean score of 3.17, tiredness with a mean score of 2.88, and drowsiness with a mean score of 2.31. All mean symptom scores were lower in the SKT intervention group post-intervention as compared to the control group.

Table 4.19 Physical symptom (ESAS) in palliative care after intervention

Physical symptoms	**SKT group**	**Non SKT group**
	$\overline{X}$ ±SD	$\overline{X}$ ±SD
Pain	1.48±1.63	3.97±2.09
Tiredness	2.65±1.78	5.33±1.75
Drowsiness	2.02±1.82	4.05±1.97
Nausea	1.28±1.60	2.05±2.01
Lack of appetite	1.68±1.69	4.84±1.87
Shortness of breath	1.34±1.45	3.54±2.47
Depression	1.54±1.85	2.48±2.36
Anxiety	1.94±1.96	4.95±1.83
Well-being	2.42±2.06	5.21±1.64
Other symptom	1.31±1.93	2.23±2.24

4.4.1.3 The result of uncertainty in illness of group study

Uncertainty in illness was measured using Mishel’s uncertainty in illness scale–community in the SKT group and non SKT groups pre- and post-intervention. From the table 4.20, SKT group showed decreased mean score of uncertainty from 48.37 to 45.80. This suggests that the practice of SKT helped to decrease uncertainty in illness. In the non SKT control group, the measure of uncertainly increased at the second time period suggesting that those who did not receive the intervention had an increase in uncertainty over time.

Table 4.20 Uncertainty in illness of SKT and non SKT group before and after intervention

Uncertainty in illness	Before		After	
	$\overline{X}$ ±SD	Min/Max	$\overline{X}$ ±SD	Min/Max
SKT group	48.37±14.01	29/86	45.80±12.36	23/72
Non SKT group	53.17±7.12	38/69	59.38±6.32	49/75

4.4.1.4 Results of quality of life of people living with ESRD

In this study, quality of life of people living with ESRD was measured by quality of life index score of Ferrans and Powers dialysis version III. There were composed of 4 dimensions of quality of life in health and functioning, social and economic, psychological/ spiritual, family and measured quality of life both in SKT group and non SKT group to compare the mean difference of pre-test and post-test.

The results of the SKT group before the study intervention showed a total quality of life mean score of 19.65, SD 4.77. The minimum score was 9.48 and the maximum was 27.97. The 4 dimensions of quality of life in health and functioning scale had a mean score at 17.58, SD 5.74; the social and economic scale had a mean score of 19.79, SD 4.28. The psychological and spiritual scale had a mean score of 21.34, SD 5.72. The family scale had a mean score of 22.85, SD 5.47.

The results of the SKT group after the meditation intervention revealed a total quality of life score with a mean of 19.98, SD 3.19, The 4 dimensions of quality of life in health and functioning scale had a mean score of 21.28, SD 3.54. The social and economic scale had a mean score of 21.82, SD 3.49.The psychological and spiritual scale had a mean score of 23.88, SD 3.25, and the family scale had a mean score of 24.43, SD 4.31.

The results of SKT on this group showed a slight increase in the mean quality of life score. It suggests a slight increase in quality of life associated with SKT meditation. The details are shown in Table 4.21.

Table 4.21 Quality of life index scores in Ferrans and Powers Dialysis version-III of SKT group in before and after SKT practice

Variables	Before	SKT	After	SKT
	$\overline{x}$ ±SD	Min/Max	$\overline{x}$ ±SD	Min/Max
1.Health and Functioning	17.58±5.74	.71 / 27.64	21.28±3.54	9.96 / 26.21
2.Social and Economic	19.79±4.28	11.57 / 28.58	21.82±3.49	13.57 /27.42
3.Psychological /Spiritual	21.34±5.72	6.57 /30	23.88±3.25	16.07 /27.86
4.Family scale	22.85±5.47	7.20 /30	24.43±4.31	13.78/ 30
Total QoL	19.65±4.77	9.48 /27.97	19.98±3.19	15.12/26.66

The results of the non SKT group at the start of the study showed a total quality of life score with a mean of 19.14, SD 3.76, The 4 dimensions of quality of life in health and functioning scale had a mean score of 17.30, SD 4.19. The social and economic scale had a mean score of 19.62, SD 4.20. The psychological and spiritual scale had a mean score of 21.1, 7 SD 4.88. The family scale had a mean score of 20.87, SD 5.45.

The results of the non SKT control group after the intervention period showed a total quality of life score with a mean of 16.94, SD 2.15. The 4 dimensions of quality of life in health and functioning scale had a mean score of 15.1, SD 1.98. The social and economic scale had a mean score of 18.41, SD 2.86. The psychological and spiritual scale had a mean score of 18.54, SD 3.56. The family scale had a mean score of 17.80, SD 3.039.

The results revealed that the control group had a decreased quality of life from time period 1 to time period 2 without the intervention. In addition the other measures related to quality of life decreased in the non-intervention group over time. The details are displayed in Table 4.22.

Before the SKT intervention, the results showed physical symptoms in palliative care with a score between 0 and 53 and a mean of 21.08 with SD of 17.73. The uncertainty in illness score revealed a score between 29 and 86 with a mean of 47.37 and SD of 14.01. The last quality of life index showed a score between 9.48 and 27.97 with a mean of 19.64, SD, 4.76.

Table 4.22 Quality of life index scores in Ferrans and Powers Dialysis version-III in non SKT group before and after intervention

Variables	Before		After	
	$\overline{X}$ ±SD	Min/Max	$\overline{X}$ ±SD	Min/Max
1.Health and Functioning	17.30±4.19	4.57/26.21	15.15±1.98	9.89/19.54
2.Social and Economic	19.62±4.20	10.86/ 27.42	18.41±2.86	12.21/23.79
3.Psychological /Spiritual	21.17±4.88	4.29/ 30	18.54±3.56	5.79/25.64
4.Family scale	20.87±5.45	7.80/30	17.80±3.04	9.00/24
Total QoL	19.14±3.76	6.71/26.58	16.94±2.15	9.8/ 20.21

After the SKT intervention, the results showed physical symptoms in palliative care score between 0 and 45 with the mean of 17.65 and SD 13.88. The uncertainty in illness score was between 47 and 72 with a mean of 58.94 and SD, 6.61 the quality of life score range was between 15.67 and 28.79 with a mean of 22.82, SD, 3.98.

The physical symptom score results of the SKT group before intervention ranged from a score of 0 to 61 with the mean score of 22.65, SD 15.48. The range of scores for the uncertainty in illness measure was 38 to 69 with a mean of 53.31, SD 7.16 the quality of life scores ranged from 10.30 to 26.58 with a mean of 19.23, and SD of 3.48.

Thus after the SKT intervention the group reported an improved quality of life as well as decreased uncertainly and physical symptoms.

In contrast, Table 4.24 reveals that the non-SKT control group scores had an opposite pattern, with an increase in physical symptoms and uncertainty and a decrease in quality of life from Time Period 1 to Time Period 2.

Table 4.23 The result of before and after SKT intervention in physical symptoms (ESAS), uncertainty and quality of life in SKT group

Variables	Before		After	
	$\overline{X}$ ±SD	Min/Max	$\overline{X}$ ±SD	Min/Max
ESAS	21.08±17.73	0/53	17.65±13.88	0/45
Uncertainty	48.37±14.01	29/86	45.80±12.36	23/72
QoL	19.64±4.76	9.48/27.97	22.82±3.98	15.67/28.79

Table 4.24 The result of before and after SKT intervention in physical symptoms (ESAS), uncertainty and quality of life of non SKT group

Variables	Time period1		Time period 2	
	$\overline{X}$ ±SD	Min/Max	$\overline{X}$ ±SD	Min/Max
ESAS	22.65±15.48	0/61	38.66±12.69	18/76
Uncertainty	53.31±7.16	38/69	59.38±6.33	47/75
QoL	19.23±3.48	10.30/26.58	17.11±1.72	13.56/20.21

4.4.1.5The testing of variables in physical symptoms, uncertainty in illness, satisfaction and quality of life of group study

The testing before intervention of both groups

Before studying the effects of SKT, the researcher presented to the two groups the SKT meditation healing exercise practice. Both groups had similar baseline characteristics. The independent T test showed that there was no difference between the SKT group and the non SKT group at the beginning of the study with the following statistical test as noted in Table 4.25 and 4.26 with the exception of duration of time on hemodialysis.

In Table 4.25, Most of dependent variables were not significant different. That means two groups were similar for intervention testing.

Table 4.25 Group statistics of dependent variables in the beginning study

Variables	**SKT group**	**Non SKT group**
	$\bar{X}$ ±SD	$\bar{X}$ ±SD
Social & economic	19.79±4.28	19.62±4.19
Psychological &spiritual	21.34±5.72	21.38±4.41
Family	22.84±5.46	20.88±5.41
Health &function	17.89±5.04	17.44±3.82
QoL	19.64±4.76	19.23±3.48
ESAS	21.08±17.73	27.10±14.48
Uncertainty	48.37±14.01	53.31±7.16

Table 4.26 Independent samples test of dependent variables at the beginning of study

	Levene's Test for Equality of Variance		T-test For Equality of Means			
	F	p-value	t	df	p-value (2-tailed)	Mean Difference
S&E	.003	NS	.172	72	NS	.17
P&S	2.47	NS	.016	72	NS	.019
F	.003	NS	1.547	72	NS	1.95
H&F	3.19	NS	.437	72	NS	.45
QLI	4.137	NS	.430	72	NS	.41
ESAS	5.520	.022	-1.61	72	NS	-6.01
uncertainty	15.05	NS	-1.93	72	NS	-4.93

This study examined the differences before and after the SKT intervention for several dependent variables including of the quality of life in Health & Functioning (H&F), Social & Economic scores (S&E), Psychological & Spiritual scores (P&S), and Family functioning (F), Physical symptoms (ESAS), Uncertainty in illness The results are described in the next section.

SKT practice group

A paired-samples t-test was conducted to compare SKT meditation healing practice before and after SKT conditions. There was a significant difference (t (34) = -2.4, p = 0.02) in the psychological and spiritual scores for SKT before (M=21.34, SD=5.72) and after SKT (M=22.92, SD=5.04). These results suggest that

SKT practice improved the psychological and spiritual scores of persons with ESRD. Specifically, the results suggest that the practice of SKT increases the psychological and spiritual subscale scores.

There was also a significant difference (t (34) =2.37, p = 0.02) in the quality of life scores for SKT before (M=19.64, SD=4.76) and after SKT (M=20.71, SD=4.62). These results suggest that SKT practice improved the quality of life for persons with ESRD.

There was a significant difference (t (34) =-3.85, p <.001) in the ESAS symptoms in the SKT group before (M=21.08, SD=17.73) and after SKT (M=17.65, SD=13.88). These results suggest that SKT practice reduced symptoms in persons with ESRD.

And finally, there was a significant difference (t (34) =-5.85, p<.001) in the uncertainty in illness score for the intervention SKT group before (M=48.37, SD=14.02) and after SKT (M=58.94, SD=6.61).

These results suggest that SKT practice really does have a positive effect on uncertainty in illness by decreasing its score. Specifically, the results suggest that when the study participants practice the SKY intervention, the uncertainty in illness score decreased. These results are shown in Tables 4. 27

Table 4.27 Pair difference test of variables between before and after SKT intervention with SKT group

		Paired	Sample	Test	p-value
Factors	$\overline{x}$	SD	t	df	(2 tailed)
ESAS	3.42	5.26	3.85	34	<.001
Uncertainty in illness	2.57	4.62	3.29	34	<.001
Quality of life	-3.168	3.24	-5.77	34	<.001
Health &Functioning	-3.38	3.13	-6.39	34	<.001
Social& Economic	-2.03	1.95	-6.16	34	<.001
Psychological& spiritual	-2.54	3.26	-4.61	34	<.001
Family	-1.58	2.01	-4.67	34	.002

In the non SKT group: A paired-samples t-test was conducted to compare non SKT practice group conditions in different time of beginning to observe until the model over. There was a significant difference in all the dependent variables. There was a significant difference in the following scores in a different pattern from the SKT group: health & functioning; social and economic; psychological and spiritual; quality of life; family relations aspect of quality of life; total quality of life; physical symptoms (ESAS); and uncertainty in illness. The results showed that the non-SKT group had an increase in physical symptoms and uncertainty in illness scores but a decreased quality of life in all subscales.

The data are shown in Table 4.28.

Table4. 28 Paired sample test in non SKT group

Factor	$\overline{X}$	Paired SD	Sample t	Test df	p-value (2 tailed)
ESAS	1.15	8.83	8.17	38	<.001
Uncertainty in illness	-6.07	6.06	-6.25	38	<.001
Quality of life	2.12	2.25	5.89	38	<.001
Health &Functioning	2.29	2.64	5.41	38	<.001
Social& Economic	1.21	1.97	3.83	38	<.001
Psychological& spiritual	2.54	3.06	5.19	38	<.001
Family	2.11	4.98	2.65	38	.012

After the SKT intervention, the researcher compared the results of the SKT and non-SKT groups on several selected variables. The independent T test statistical test showed there was significant difference between the SKT group and the non SKT group after SKT intervention with the following statistical test:

Table 4.30 showed that there were significant differences in the outcomes between SKT group and non SKT group at the conclusion of the study.

Table4.29 Mean and standard deviation of variable of SKT practice (after)

Variables	**SKT group**	**Non SKT group**
	$\overline{X}$ ±SD	$\overline{X}$ ±SD
ESAS(Physical symptoms)	17.65±13.88	38.66±12.69
Uncertainty in illness	45.80±12.36	59.38±6.32
Health & functioning	21.28±4.58	15.15±1.98
Social &economic	21.82±4.02	18.41±2.86
Psychological &spiritual	23.88±4.95	18.77±2.88
Family	24.43±4.33	18.77±2.89
Quality of life	22.82±3.98	17.11±1.72

Table 4.30 Independent samples test of dependent variables at the end of study

	Levene's	test	T test		p-value
Variables After the program intervention	F	p-value	t	df	(2-tailed)
ESAS	2.01	NS	-6.80	72	<.001
Uncertainty	25.69	.05	-6.04	72	<.001
Health and functioning	45.01	.05	7.59	72	<.001
Social and economic	2.68	NS	4.23	72	<.001
Psychological	18.55	.05	5.49	72	<.001
Family	10.81	NS	6.66	72	<.001
Quality of life	43.88	NS	8.14	72	<.001

. **4.4.2 The study of relationship between dependent variables of group study.**

In the SKT group, an analysis of the correlations between quality of life and other dependent variables before SKT practice revealed that quality of life was a significance of the relationships between physical symptoms, the health & functioning subscale of the quality of life scale, the social & economic subscale of the quality of life scale, the psychological & spiritual subscale of the quality of life scale, and the family subscale of the quality of life scale (p<.05). That means the study participants with ESRD who had less physical symptoms would have an increase in the total quality of life and the quality of life subscales (Health & functioning, social & economic, psychological & spiritual, family).

When examining the relationship between ESAS scores and (physical symptoms in palliative care) and other dependent variables including the health & functioning, social & economic, psychological & spiritual subscales, the correlations were found to be negative and statistically significant (P<.01). That means that as physical symptoms increased the health & functioning, social & economic, psychological & spiritual subscales decreased.

An examination of the relationship between the health & functioning subscale with other variables including the social & economic, psychological & spiritual, and family subscales also found statistically significant positive correlations (p<.01). That means that as the health & functioning score increased the social & economic, psychological & spiritual, and family subscale scores also increased.

Similarly, the social & economic subscales were found to have a statistically significant positive correlation with the psychological &spiritual, family subscale (p< .01). That means that as the social & economic subscale increased, the psychological & spiritual, family subscale also increased.

And finally, the correlation analysis between the psychological & spiritual subscale and the family subscale was found to be positive and statistically significant (p<.01). That means that as the psychological & spiritual subscale increased the family subscale score also increased. These data are shown in Table 4.31.

Table 4.31 The correlation of variables in the study; pre test

	QoL	Uncertainty	ESAS	Duration	H&F	S&E	P&S	Family
QoL	1							
Uncertainty	-.259	1						
ESAS	-.588*	.295	1					
Duration	.188	-.046	-.25	1				
H&F	.931*	-.243	-63**	.207	1			
S&E	.909**	-.254	-61**	.163	.822**	1		
P&S	.922**	-.178	-62**	.237	.799**	.819**	1	
Family	.643**	-.199	-.26	.098	.489**	.560**	.602**	1

*. Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

In the same group (SKT group) after SKT practice, an analysis of the correlations between quality of life and other variables after SKT practice revealed that quality of life was significantly correlated with uncertainty in illness, physical symptoms, and the health & functioning, social & economic , psychological & spiritual and family subscales (p<.05). That means that the study participants with ESRD who had less physical symptoms in palliative care and uncertainty in illness, would have an increased total quality of life score as well as subscale scores.

When examining the ESAS (physical symptoms in palliative care) scores with other dependent variables such as health & functioning, social & economic, psychological & spiritual subscales, the correlations were found to be negative and statistically significant (P<.01). That means that as physical symptoms increased, the health & functioning, social & economic, and psychological & spiritual subscales decreased.

The correlations between the health & functioning subscale and other subscale scores related to quality of life were found to be positive and statistically significant (p<.01).That means that as health & functioning increased, the social & economic, psychological & spiritual, and family subscale scores also increased.

A similar significant correlational relationship was noted between the social & economic subscale and other subscales including the psychological & spiritual and family subscale (p< .01). As the social & economic subscale score increased, the psychological & spiritual, family subscales also increased.

Finally, the analysis of the positive correlation between the psychological & spiritual subscale and the family subscale was found to be statistically significant (p<.01). As the psychological & spiritual subscale increased, the family subscales score also increased.

The data shown in Table 4.32

Table 4.32 The correlation of variables in post test

	QoL	Uncertainty	ESAS	Duration	H&F	S&E	P&S	Family
QoL	1							
Uncertainty	-.375*	1						
ESAS	-.391*	.221	1					
Duration	.020	-.053	-.278	1				
H&F	.535**	-.271	-.614**	.139	1			
S&E	.501**	-.194	-.565**	.135	.566**	1		
P&S	.50**	-.124	-.562**	.003	.736**	.610**	1	
Family	.551**	.001	-.254	.137	.370*	.513**	.486**	1

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

For the non SKT group;

At first data collection period,

The relationship between uncertainty in illness and quality of life in the family subscale were found to be statistically significant r= (-.350), n= 39, p-value <.05. The results suggested that as the uncertainty in illness increases, the quality of life in family decreases. The data are shown in Table 4.33.

Table 4.33 Correlations of dependent variables of non SKT group; pretest

	QLI	uncertainty	ESAS	H&F	S&E	P&S	Family
QLI	1						
uncertainty	-.137	1					
ESAS	-.149	.100	1				
H&F	.830**	.106	-.160	1			
S&E	.868**	-.179	-.014	.620**	1		
P&S	.881**	-.223	-.064	.582**	.724**	1	
Family	.647**	-.350*	-.220	.198	.556**	.649**	1

Table4.33 reveals that in the pre-test (or first data collection period) the quality of life score was significant with health & functioning, social & economic, psychological & spiritual, and family subscales. Uncertainty in illness had a significant relationship with only the family subscale.

In the non-SKT group a significant correlation was noted between quality of life and health & functioning, social & economic, psychological & spiritual, family subscales. There was no significant relationship between quality of life and uncertainty in illness or physical symptoms. At this point however there was a significant negative correlation between physical symptoms and the health &

functioning subscales that means as the physical symptoms in palliative care increased, the quality of life in health & functioning score decreased.

Table 4.34 Correlation of dependent variables of non SKT group; posttest

	QLI	uncertainty	ESAS	H&F	S&E	P&S	Family
QLIpost	1						
Uncertainty	-.300	1					
ESAS	-.284	-.052	1				
H&F	.840**	-.269	-.436**	1			
S&E	.776**	-.102	-.046	.475**	1		
P&S	.840**	-.202	-.148	.641**	.654**	1	
Family	.835**	-.179	-.160	.649**	.650**	.998**	1

4.4.4 The result of SKT on biochemical substance in blood test, satisfaction, and quality of life

4.4.4.1 Biochemical substance test from SKT and non SKT group

Before examining the results of the laboratory tests, the researcher tested for assumption of repeated measured design to meet with the assumptions .These result showed that in some tests, as shown the table of equality of covariance, that the observed covariance matrices of the dependent variables were equal across groups.

The main analysis of repeated measured design, using the Mauchly's test, tests the hypothesis that the variances of the differences between conditions are equal. The Mauchly 's test in Table 35 shows that the Mauchly's test statistic is significant (p-value < .05). It means that there is significant difference between the variance of differences: the condition of sphericity was not met.

This study corrected for violations of sphericity by adjusting the degrees of freedom associated with the F- value. There are three different estimates of sphericity used to correct the degrees of freedom: Greenhouse and Geisser or Huynh-Feldt and the lower bound estimate. If the partial eta square (epsilon) > .75 then the Huynh- Feldht correction is used and when the partial eta square(epsilon)< 0.75 ,or nothing is known about sphericity at all, then the

Greenhouse-Geisser correction is used . To determine this one must look at the test of within subject effects (Tabachnick,2009).

Table 4.35 Mauchly's Test of Sphericity for biochemical substance in blood test

					Epsilon		
Within Subjects Effect	Mauchly's	Approx. Chi-Square	df	*p*-value	Greenhouse-Geisser	Huynh-Feldt	Lower-bound
Na	.440	58.024	5	<.001	.602	.690	.333
K	.821	13.908	5	.016	.874	.922	.333
HCO_3	.898	7.597	5	NS	.942	.998	.333
Cl	.764	19.070	5	.002	.878	.927	.333
BUN	.820	14.012	5	.016	.889	.940	.333
Creatinine	.572	39.470	5	<.001	.735	.770	.333
Albumin	.698	25.382	5	<.001	.838	.883	.333
Calcium	.752	20.140	5	<.001	.850	.897	.333
Phosphorus	.621	33.731	5	<.001	.803	.844	.333
Hct	.381	68.333	5	<.001	.617	.641	.333

Table 4.36 Biochemical substances in blood result of SKT practice in both groups

Biochemical substance in blood	SKT group $\bar{X}$ ±SD	Non SKT group $\bar{X}$ ±SD
Na1	134.03±2.95	135.79±6.44
Na2	134.23±3.34	136.39±3.95
Na3	135.43±3.21	137.31±3.27
Na4	135.29±3.15	137.31±3.78
K1	4.21±.57	4.77±.72
K2	4.30±.709	4.72±.80
K3	4.65±.63	4.65±.63
K4	4.45±.75	4.79±.65
HCO_3:1	24.14±4.03	23.54±2.08
HCO_3:2	24.69±3.66	23.62±2.44
HCO_3:3	26.48±3.54	24.71±2.30
HCO_3:4	24.72±3.48	25.37±2.66
Cl1	97.91±4.36	100.33±3.19
Cl2	98.31±4.09	99.64±3.32
Cl3	100.83±3.24	101.13±2.52
Cl4	100.46±2.58	100.92±2.49
BUN1	71.84±23.62	73.04±16.39
BUN2	70.33±22.98	76.83±16.88
BUN3	66.22±22.02	81.61±20.63
BUN4	64.52±19.71	84.73±18.77
Cr1	7.72±4.11	11.93±3.79
Cr2	8.19±4.36	11.82±3.24
Cr3	7.93±3.74	12.84±3.56
Cr4	7.29±3.56	12.45±3.90
Albumin1	3.13±.53	3.63±.45
Albumin2	3.08±.43	3.44±.43
Albumin3	3.02±.37	3.43±.38
Albumin4	3.34±.37	3.72±.32
Calcium1	8.77±.91	8.69±1.14
Calcium2	8.70±.87	8.63±1.3
Calcium3	8.83±.91	8.76±1.13
Calcium4	9.00±.67	8.98±1.25
Phosphorus1	4.75±2.04	6.33±2.2
Phosphorus2	4.67±1.86	6.24±2.14
Phosphorus3	5.08±1.94	6.22±1.84
Phosphorus4	5.09±1.78	6.31±1.82
Hematocrit1	32.41±7.07	31.43±4.22
Hematocrit2	32.06±4.39	31.26±4.05
Hematocrit3	31.87±4.91	30.07±3.22
Hematocrit4	32.80±4.79	31.22±3.01

Table 4.37 Tests of Within-Subjects Effects of biochemical substances in blood result

Source		Type III Sum of Squares	df	Mean Square	F	*p*-value
Na	Greenhouse-G	116.403	1.985	58.641	3.350	NS
Na& group	Greenhouse-G	1.725	1.985	.869	.050	NS
K	Huynh-Feldh	1.184	2.766	.428	1.543	NS
K& group	HuynhFeldh	.497	2.766	.180	.647	NS
HCO_3	Sphericity	143.170	3	47.723	9.172	<.001
HCO_3&grou	Sphericity	58.076	3	19.359	3.721	.012
Cl	Huynh Feldt	238.865	2.78	85.93	12.978	<.001
Cl&group	Huynh Feldt	51.973	2.78	18.698	2.824	NS
BUN	Huynh-Feldt	220.234	2.819	78.130	.829	NS
BUN&group	Huynh-Feldt	3880.790	2.819	1376.743	14.613	<.001
Creatinine	Greenhouse-G	14.360	2.206	6.509	1.489	NS
Creatinine&g	Greenhouse-G	26.72	2.206	12.111	2.770	.049
Hct.	Greenhouse-G	49.050	1.850	26.514	2.151	NS
Hct& group	Greenhouse-G	12.722	1.850	6.877	.558	NS
Albumin	Huynh-Feldt	4.691	2.649	1.771	20.059	<.001
Al& group	Huynh-Feldt	.132	2.649	.50	.563	NS
Calcium	Huynh-Feldt	4.307	2.690	1.601	2.024	NS
Ca &group	Huynh-Feldt	.038	2.690	.014	.018	NS
Phosphorus	Huynh-	2.667	2.53	1.053	.999	NS
P&gr.	Feldt	2.985	2.533	1.178	1.119	NS

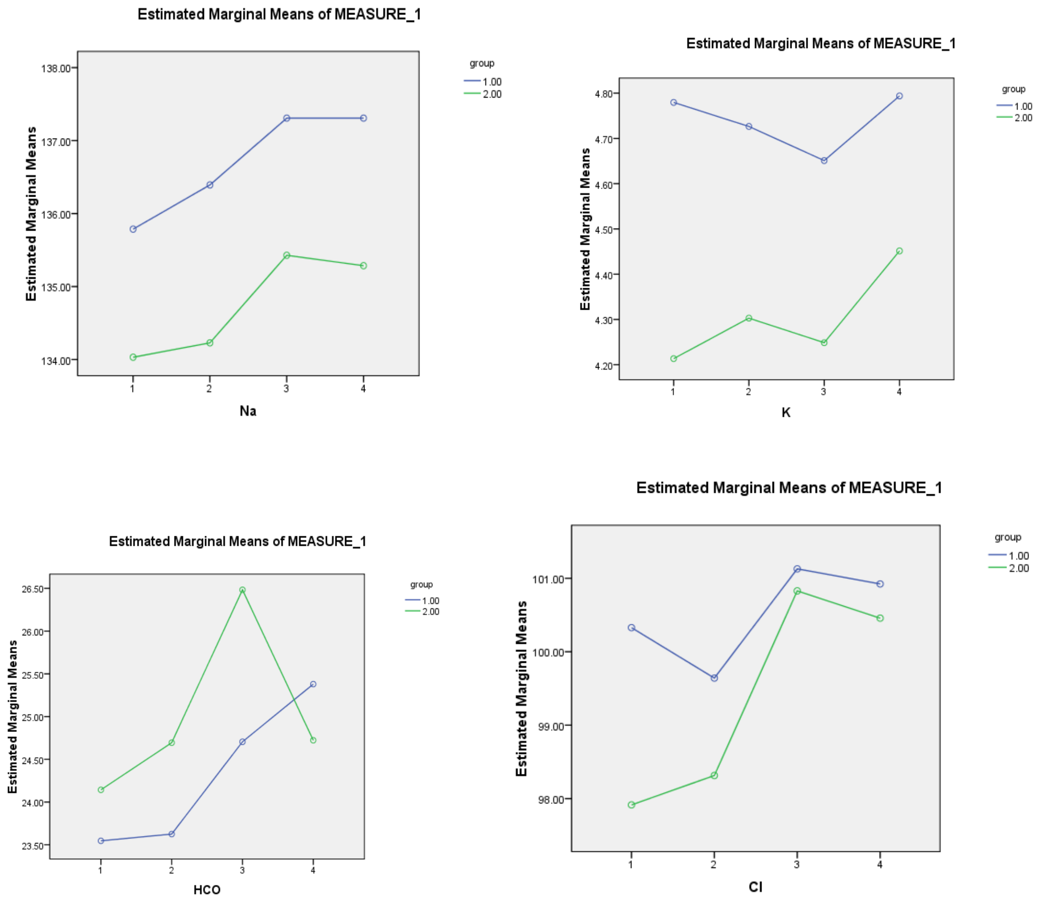
The main effect of the BUN blood tests within group revealed an F (2.82, 202.96) = .365, p-value >.05 The Huynh-Feldt test showed these corrected values using this correction. F is not significant because its p-value is .473 which is more than the normal criterion of .05. That means the SKT practice within group was not different but the main effect of BUN blood and groups were significantly different, F

(2.82, 202.96) = 14.61, p-value< .001.That means that the main effect of SKT was significantly different between SKT group and non-SKT group.

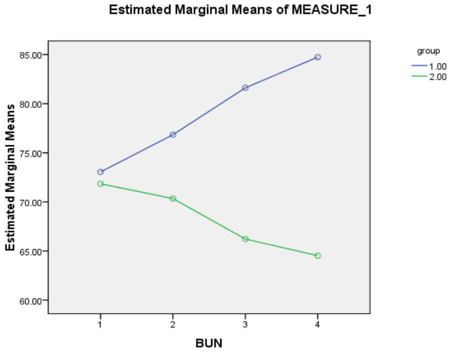
The main effect of the creatinine blood test within group resulted in F (14.36, 694.51) = 1.49, p-value = .227.Greenhouse-Geisser corrected values was used for this correction. So the creatinine blood test within group was not significantly different in the time taken. But the main effect of creatinine on SKT practice between the SKT group and non-SKT group was significantly different, F (6.49, 467.07) = 2.77, p-value < .05. That means that the creatinine results in SKT group and non-SKT group was significantly different.

The graph in figure 4.15 showed the electrolyte levels, including Na, K, HCO_3, and Chloride respectively at 4 time intervals in both the non-SKT and the SKT group.

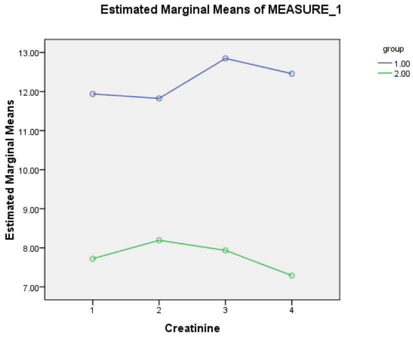
Figure 4.15 The results of biochemical substance in blood tests



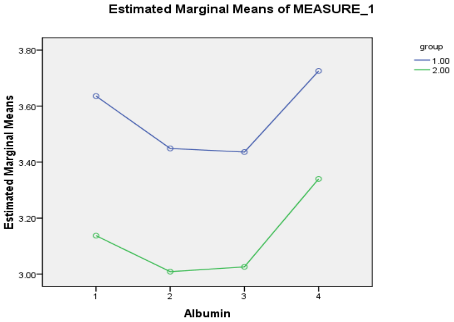
The graph of BUN blood



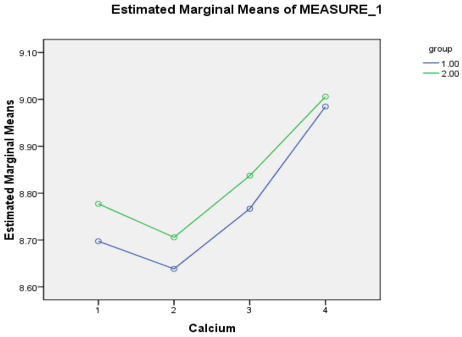
The graph of Creatinine



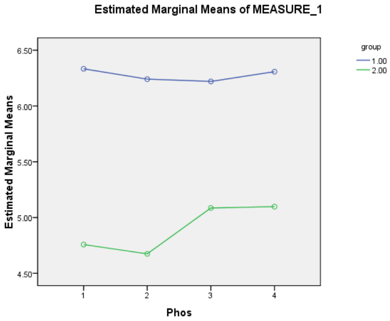
The graph of albumin



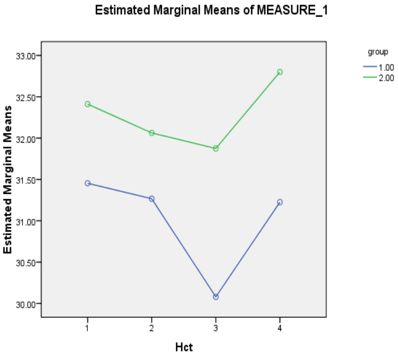
The graph of phosphorus blood



The graph of calcium blood



The graph of hematocrit blood in both groups



1= non SKT group
2= SKT group

4.4.5 The opinion of people living with ESRD in meditation healing exercise SKT6:

The results of both the quantitative and qualitative components of this study suggested that meditation healing exercise can help to decrease physical, emotional and psychological and spiritual problems associated with ESRD, improve symptoms and improve quality of life. This section will include vignettes that supported the positive effects of SKT 6 from the qualitative data in this study.

The aim of meditation healing exercise SKT6 was to bring inner peace within the self and the world in a positive and spiritual way. The world is not a peaceful place and within every soul there is some form of tension and stress. It is therefore essential to create positive and peaceful thoughts to bring peace to one's mind. SKT meditation healing practice is one of the best methods to bring about this transformation and nurture the natural qualities within. The positive discovery about meditation was that the people living with ESRD were able to focus within themselves and become free of negativity. Meditation techniques simply involve a process of transforming the self and one's thoughts, while recognizing the negative thoughts and changing them into positive and peaceful thoughts.

The best attitude towards meditation healing practice was to be very patient as the mind did not always want to focus. Having a sense of expectation towards positive results could create uncomfortable pressure and thus take away the enjoyment of the experience. By practicing meditation regularly, the person who meditates gains a wonderful sense of the self which was supported by the following qualitative data from the study participants with ESRD:

The participants of people living with ESRD

Participant Suy: She was 86 years old. Her daughter had retired from her job in order to take care of her. She had tracheotomy tube and also had coronary artery disease. Her daughter encouraged her to practice SKT every day. She hoped that her mother would feel better and the uncomfortable symptoms would be relieved. During the practice of SKT, her daughter observed her O_2 Saturation to be 100 %. Previously, her O_2 Levels would drop which is why she bought the machine.

Participant Am; She was 76 years old and lived alone in her apartment although one of her grandchildren stayed at the same apartment. Basically, she was a very impatient person but once she started practicing SKT, it made her calm down. She tried to practice it on her own. She said she liked to practice SKT 6 during the night before she went to bed and she practiced her breathing technique in the morning. She found that the SKT technique made her think about her life in the past and in the present time. She found that cause of her disease may have come from her unhealthy habits.

Participant Po; She was 59 years old. She said that she practiced SKT6 every day before bed. She enjoyed this practice of meditation. At the ward while she was on hemodialysis, she requested to move the CD player near her bed because she wanted to practice during her hemodialysis treatment. She had problems with high blood pressure during hemodialysis. Her blood pressure was as high as 180/120 mmHg. at times. The hemodialysis nurse reported these symptoms to doctor. During the practice of SKT6 in the ward she said that I like to practice SKT 6 because I feel good.

Participant Heng; She was 87 years old. Her daughter took care of her at home. She tried to understand even though she had problem with language. Her daughter told her about the process of SKT 1 and 6. She practiced and followed the steps. Her daughter reported that she had herpes simplex on her face. Her daughter wanted her mother to practice meditation. After she practiced SKT for one week, the herpes improved. She had problems with herpes for a long time and used antiviral to treat this but it was not improved from the medication but only after meditation.

Participant Bay; She was 80 years old. She had her son to take care of her. Her son resigned from work to care for her. She tried to practice SKT6 by listening. She said that sometime she did not practice because she slept early. In this case the researcher took a lot of time to teach her because she had problems with hearing.

Participant Wan; He was 63 years old. He had his wife to take care of him. His wife tried to stimulate him to practice meditation. He found it was easy to understand the technique of SKT after the researcher explained the concepts and benefit associated with this practice. He said that he practiced every day before bed.

Participant Ra; She was 66 years old. She said that she practiced at night before she went to bed. She liked it. The researcher observed that when she turned on the CD player in SKT she had a good intention to practice. She said that "I feel good and comfortable both in mind and physical". She said that she taught her brother at home about this technique.

Participant Dul; He was 65 years old. He was not interested in meditation healing exercises until he developed pain in his blood line access site on his arm. It had signs of swelling and pain which prevented him from resting and sleeping. His face looked terrible with pain and discomfort. The researcher talked with him about how relaxation could help his pain but at first he did not believe her. Then when his pain worsened, the researcher talked with him again so he decided to try the practice. He felt better and the pain in his arm was decreased and was grateful for the suggestion. He said that he would now use this technique at home.

Participant Chai; He was 84 years old. He felt that the technique was easy to practice and he liked to practice it because during the day when he stayed at home alone. He used the time alone to practice this technique. It made him calm down and sleeps better.

Participant Keang; He was 78 years old. He had problems with a weak left side of his body (hemiplegia). He said that this technique was good and easy for him because he could listen and think while following the CD. He practiced in the evening and before bedtime.

Participant Me ; He was 56 years old. He said that "I believed in the concept that the body can heal itself". So he liked to practice this procedure because it did not cause harm and it did not cost anything to practice. He had problems with back pain so the researcher suggested SKT 3 technique to reduce his back pain

Participant So; She was 61 years old. She said that "I would like to practice this easy action because the nature of people is to be lazy, so if it is difficult nobody would want to do it .For this procedure, I think that it is so easy".

Participant Sarn ; He was 79 years old. He said that "First I did not want to practice because in my daily activity of each day I was very busy". At night I wanted to sleep and I felt tired from each day. He went to Hong Kong for 4 days so he would not get his hemodialysis. The researcher talked with him and explained the mechanism of meditation healing exercise because he would not have the choice of doing dialysis while in Hong Kong and would have more free time. He decided to practice the meditation healing exercises.

Participant Su; He was 80 years old. At first, he was not interested in this technique until he listened to the reasons it could help. He had problems with insomnia and had a decreased appetite so he just tried the practice. One week later he felt better.

Participant Pra; He was 78 years old. He had problems with tiredness each day. He practiced meditation at the temple. The researcher explained about the mechanism of meditation and meditation healing exercises. He asked how it was different from concentration meditation. After that he decided to mix meditation healing exercises in his daily life.

Participant Da; She was 76 years old. She said that she likes to listen to the meditation exercises on the CD and practices it in the afternoon and sometimes at night. “It felt good” when she practiced she said.

Participant Wut ; He was 67 years old. He did not have a job to do anymore .His son paid for his hemodialysis treatments. During the day he turned on the CD to practice at home and he said that it helped him in the mind aspect. After he had practiced for 2 months he found that he felt more comfortable and fresher every day and had less insomnia.

Participant Wit; He was 61 years old. He felt that he suffered from his disease so he tried to practice meditation and SKT. He practiced everyday depending on his available time. He said that he felt better and he felt more calmed down and relaxed.

Participant Nong ; He was 76 years old. He had problems with ESRD and had a weak on his right side. His daughter-in-law cared for him and helped him to practice meditation exercises. He started to practice at home and he said that this technique helped him to calm down.

Participant Torn; He was 64 years old. Her daughter cared for him and brought him to the hospital and picked him up when the hemodialysis was done every week. He said that during the day he wanted to do something so he practiced SKT every day before bed and sometime he practiced SKT during the day.

Participant Som; She was 87 years old. She had problems related to a stroke. She could not walk. She had a caregiver from the center that took care of her and she practiced SKT by listening to the CD in the evening. She practiced SKT during the night before bed and she felt it helped her to sleep well.

Participant Huy; He was 76 years old. He always practiced SKT meditation at night. He said that at first when he practiced this technique he felt uncomfortable so he stopped. He tried it again and this time he felt better and it helped to calm him down.

Participant Boon; He was 72 years old. His son took care of him and he said that he practiced by turning on the CD but sometimes he slept instead of practicing. He had problems with cold symptoms but after he practiced for two months, the symptoms of the cold disappeared. He said that “I think that this technique is quite good if we have a good habit of practicing”.

Participant Leu; He was 84 years old. His daughter turned on the meditation CD every night to practice SKT. He felt good from the exercises which also helped his problem of insomnia disappear.

Participant Muy; She was 78 years old. Her daughter turned on the meditation CD for her every day and stimulated her to practice. Her daughter observed that her symptom of heavy secretions in the morning seemed to be reduced after practice so it felt good for her to continue practice.

Participant Geng; She was 74 years old. She had problems with herpes on her back but after meditation practice for about 1 week, she said that it was better. Basically, she had problems and had been treated for treatment for a long time but it was still painful so she decided to practice SKT which made her better.

Participant Sert; He was 57 years old. He had own business and tried to run his business by himself so he felt interested in alternative treatments. He like to practice and he believe that the body can heal itself so he usually practiced SKT 1, 3, 6 because he had problems with back pain. The results of practice were that his pain improved. He said that “I like to practice and thank you for suggesting this technique”

Participant Tong; She was 78 years old. She felt interested in meditation and SKT for healing exercise was easily to practice for her. She observed that her body felt good and her tiredness was decreased after meditation.

Participant Jae; He was 76 years old. He came to the hospital for dialysis by himself. His family was busy. He felt that this disease made him suffer a lot so he felt hopeless and signed off on his property to his wife and son. He said that "I am waiting for the death date if I stopped to treat; it means my life stopped too". At first, he didn't like to practice after the research suggested it. One day however he turned on the meditation exercise CD in the ward and he listened and then tried to practice. He said "It feels good and I feel relaxed".

Participant Bai ; He was 74 years old . Basically, he did not like to practice meditation except he was willing to try the breathing exercises in SKT. He then said that "I am OK to practice and I will test the results of SKT". After practicing 2-3 weeks, he said that he felt more comfortable and did not have headaches as a complication from dialysis anymore.

Participant Mud; He was 57 years old. He had respect for Islam initially and so he did not want to practice. But after speaking with the research one day, he said that "I will try to practice". After practicing for two months he said that he felt good and was satisfied with the practice; moreover, it made him calm down.

Participant Bun; He was 71 years old. He practiced at home during the night before bed so sometimes he fell asleep before finishing the practice. He said that it felt good.

Participant Kim; She was 78 years old. She had problems with herpes so she tried to practice and after that the frequency of infection in herpes got better. She liked to listen to the meditation CD and she said that it was easy to practice.

Participant Lert; He was 82 years old. He said that he practiced in the evening and sometimes at night .He felt better and relieved from headaches so he decided to continue to practice. When he first practiced SKT 6 following the steps in CD, he said that he felt uncomfortable. Then later he felt better, his problem of insomnia had disappeared and we were less itchy and tired.

Participant Pol; He was 30 years old. He had the intention to practice because he believed that it might help him get better so he practiced every day and every night. He was changed in that his itching was relieved and his face looked brighter and happier. Before SKT practice, he had problems with itching which disappeared 1-2 weeks after he started the meditation. He felt better and less tired compared with before the practice of this technique.

The limitation from intervention with meditation healing exercise SKT6 practice

At ward

- Sometimes there was the noise from the hemodialysis machine which disturbed concentration. Many people living with ESRD complained about the noise from this environment. So they agreed to practice at home.
- Some people living with ESRD complained that the noise was so loud for them that they got uncomfortable from this practice and did not like it. They did not like noises from any source.
- The environment was also a problem sometimes as the doctor, nurses and those who cared for the patients might disturb the practice.
- One of the people living with ESRD said that he did not believe in this SKT practice and he did not believe that it could help him. It was unbelievable for him. Moreover, he had the idea to resist SKT6 practice.

At home

- Some people living with ESRD did not have a CD player at home. In some cases they were rich but they did not want to buy the CD player.
- There were many poor people so it was difficult for them to buy the CD player.
- The time in practice was not available if they had many activities to do at home and some people spoke of their lack of the discipline in practice at home.

Meditation is one of the methods of relaxation. Both relaxation and meditation have a mental as well as physical dimension. They are believed not only to have beneficial effects on the mind, but also on the body itself. Meditation may be used as a treatment to help relieve stress in conditions such as coronary artery (heart) disease, essential hypertension, tension headache, insomnia, asthma, immune deficiency, panic and many others including meditation healing exercise or SKT6 will help to reorganize the body to balance system. It is the sense of imbalance in both body and mind that can be an important cause of illness and the spread of disease. The body is able to treat these diseases itself.

The meditation healing exercise SKT6 is a basic tool which used when determining to establish and develop a new set of beliefs until they become part of subconscious mind. The meditation healing exercise SKT6 combines meditation and visualization to use for releasing tension and attaining spiritual fulfillment, they can also be used as a first step to setting up changes in one's life and health, starting with the determination to change beliefs about illness and treatment, and about the ability of the body to cure and treat itself." Many people living with ESRD reported about meditation healing exercise SKT6 made them calm, peace and slept better. These are the direct effects of meditation in sleep pattern in sleep better, fall asleep easier and stay asleep to the night.

CHAPTER V

DISCUSSION

This study was a mixed methods research design which aimed to develop and evaluate a home based palliative care program for people living with ESRD in the community. The model was designed to be delivered by community nurses and included a meditation healing exercise SKT6 for relaxation of neurons and muscles which can affect the healing process.

The organization of this chapter is divided into 6 parts: (5.1) Suffering and needs of people living with ESRD and families; (5.2) Capacity of health care providers in preparing home based palliative care; (5.3) The development of home based palliative care; (5.4) Bodies of knowledge, which extend the application of uncertainty in illness; (5.5) Reflection of meditation healing exercise SKT6; and (5.6) The researcher's reflections.

5.1Suffering and needs of people living with ESRD and families

Chronic kidney disease is a public health problem for both developed and developing countries. At a certain level of renal function, the progression of kidney disease to ESRD is inevitable. From the result of the study, the suffering of people living with ESRD was found in many dimensions regarding physical, psychological, social, and spiritual dimensions. For many, the suffering of people living with ESRD started when they had accumulated waste products in the body when the kidney function failed. At this time, they would feel tired and uncomfortable which would bring them to the hospital where they would get the diagnosis of CKD and eventually ESRD which required treatment with dialysis. Hemodialysis is commonly performed twice a week for 4–5 hours per session in most people living with ESRD. Dialysis fluids are mostly bicarbonate based. Most of the dialysis units offer hemodialysis only. CAPD as an alternative dialysis therapy for ESRD is offered at home in the community, and requires 3–4 fluid exchanges per day.

Studies on the recently devised classification of CKD have facilitated prevalence estimates that have revealed an “iceberg” effect of CKD in the community, with dialysis and transplant people living with ESRD being the tip of the iceberg. Hypertension, smoking, obesity, and hypercholesterolemia, currently among the World Health Organization’s (WHO’s) top 10 global health risks, are strongly associated with CKD (World health organization, 2009). These factors, together with increasing diabetes prevalence and an aging population, will result in significant global increases in CKD and ESRD patients. Treatments now available effectively reduce the rate of progression of CKD and the extent of co-morbid conditions and complications. The challenges are (1) to intervene effectively to reduce the excess burden of cardiovascular morbidity and mortality associated with CKD, (2) to identify those at greatest risk for ESRD and intervene effectively to prevent progression of early CKD, and (3) to ultimately introduce cost-effective primary prevention to reduce the overall burden of CKD. The vast majority of the global CKD burden will be in developing countries, and policy responses must be both practical and sustainable in these settings (Zhang & Rothenbacher, 2008).

The people living with ESRD and their families in this study started to solve the problems in many aspects such as the cost of treatment. Some families that did not have health social insurance or health welfare, management for care people living with ESRD had to pay privately for care. Moreover, some families did not have someone to take care of their affected family member because all of the relatives were busy. The ESRD participants shared many problems with their symptoms progressed over time. They shared stories of tremendous suffering including severe bone pain due to poor circulation which led in some cases to gangrene and amputation of the toes. Some participants with ESRD shared stories which reflected their ability to adjust to the demands associated with ESRD over time. They attributed the dialysis as the cause of improvement in their symptoms to some degree that they felt. Most of them tried to cope with and manage this disease starting from the time of diagnosis until treatment. Many people living with ESRD suffered with the uremic symptom until admission in ICU when they finally had to agree to dialysis treatment. Most of them tried to delay dialysis, including both CAPD and hemodialysis. One of the participants with ESRD had the experience of a near-death experience during which the doctor signed her death certificate. She did regain consciousness and reported that she woke up again from the dying process. During that time she said she knew everything and heard every word but she could not respond and tried to tell everyone “I am here and I am not dying”. So the researcher recorded stories of suffering from the time of diagnosis until acceptance with dialysis. When treatment with dialysis began many of them felt better with less tiredness and fatigue but someone who still had signs of hopeless said that “It was not any better after treatment”.

The general description of group study participants included the average age of people who were living with ESRD was 65.63 years. Most of the persons with ESRD were men (52.71%), and married (47.29%). The age range of care givers or family members who card for the persons with ESRD was 31-40 years. In addition, the majority of care givers were female (78.38%) and single (48.65 %). Basically, when comparing men and women as caregivers, more women provided care than men and they provided better can than the men in this study. The median prevalence of CKD was 7.2% in persons aged 30 years or older. In persons aged 64 years or older the prevalence of CKD varied from 23.4% to 35.8%. Congruent with other studies, most of the affected persons were men (Zhang & Rothenbacher, 2008).

Physical suffering in the people living with ESRD in this study was related to inadequate dialysis in some, including symptoms such as dry skin, tiredness, and general uncomfortable feeling in the body. This suffering affected the quality of life. The data from this study revealed the highest mean score of symptoms was tiredness (85%). The second most common reported symptom was drowsiness (87%).The ESAS scale revealed that nausea was the lowest mean score (31%) of symptoms in this study. So this group of people living with ESRD suffered less from nausea. The study was congruent with other studies about the symptoms experienced by people living with ESRD including the following weighted mean prevalence figures (and ranges): fatigue/tiredness 71% (12% to 97%), pruritus 55% (10% to 77%), constipation 53% (8% to 57%), anorexia 49% (25% to 61%), pain 47% (8% to 82%), sleep disturbance 44% (20% to 83%), anxiety 38% (12% to 52%), dyspnea 35% (11% to 55%), nausea 33% (15% to 48%), restless legs 30% (8%to 52%), and depression 27% (5%to 58%) (Fine, 2010). The assessment of fatigue in the clinical setting, although advocated in the literature, was rarely practiced. Some community nurses may not know how to help alleviate fatigue and fail to explore the symptoms of people living with ESRD. It may also be assumed that fatigue is a normal part of the disease process or treatments. If nurses do not ask about fatigue, people livings with ESRD may not discuss it, and fatigue may go unrecognized until it results in poor equality of life.

Reported symptoms of palliative care in this study were congruent with Ferrans and Powers Quality of Life Index (QLI) which set possible ranges for the final scores (0 to 30). The possible range for the final scores is the same for all four subscales and for the overall (total) score. Consequently, the highest score was family scale (21.8) whereas the lowest score was total quality of life score (19.38). Some studies about patients' perceptions of their experiences with ESRD and hemodialysis treatment found that the emerging theory suggests that a "new sense of self" is an emotional/psychological state that fluctuates with the evolving meanings of illness and treatment and perceived quality of supports (Georges, Grypdonck, & De Casterle, 2002).

From the analysis of these families' experiences, health professionals are afforded an insight into the diversity of needs that encompass the essence of care being provided in the home. This opportunity allows health professionals to gain further insight into this significant life event, leading to an enhancement of their care practices and enabling them to be better equipped to meet the individual needs of family units. This study was congruent with the study by Noble and team (2010), a qualitative study which explored symptoms in patients managed without dialysis. They found that as the numbers of patients presenting with end-stage renal disease (ESRD) increases, more are opting to withdraw from dialysis, often due to increased suffering and poor prognosis related to other co morbidities. Meanwhile more people living with ESRD decide to withdraw from dialysis they enhanced approach to assessment and control of symptoms, as well as supportive management is required, including effective and high-quality palliative care (Noble, Meyer, Bridge, Johnson,& Kelly,1010).

Home based palliative care is important to support people living with ESRD at home. After treatment with hemodialysis at the hospital they still had some problems at home such as tiredness, dizziness, and headache. These symptoms led to an uncomfortable life and boredom during treatment. So home based palliative care supported these people to relieve suffering and to learn about the methods to control these symptoms. HBPC allows persons to have quality of life and to continue treatment with dialysis including hemodialysis and CAPD. Moreover, home based palliative care helped to follow up to provide support to enhance quality in their environment.

5.2 Capacity of health care providers in preparing home based palliative care model

The study identified a lack of knowledge among health care providers regarding the delivery of home based palliative care model. Physical, psychological, social and spiritual issues need to be considered to ensure the highest possible quality of life for people living with ESRD and their families. Progression of symptoms and response to interventions show a high degree of unpredictability, requiring regular review. Experienced palliative care practitioners were aware of the complexity of the issues within the discipline. They suggested that the research, both quantitative and qualitative, including narrative-based approaches, were important for developing evidence base and challenged us to develop these methodologies appropriately within the discipline of palliative care.

Congruent with the study was the importance of ‘knowing the people living with ESRD’: community nurses’ constructions of quality in providing palliative care included the importance of 'knowing the patient'. This link with a ‘new nursing’ emerges at an interesting time for community nurses. The past decade has seen many changes in the way that community nursing services have been configured in Thailand. The work of the community nursing service has been redefined, making the ideals of new nursing community, for example holism, less achievable than they were in a decade ago. This study reiterates the view that palliative care is one aspect of community nursing work that is universally valued as it lends itself to being an exemplar of excellence in terms of the potential for realizing the ideals of nursing practice in community. This is of increasing importance in the context of changes that militate against this ideal (Luker, Austin, & Caress, 2000).

This study showed that current supportive services in the community were not adequate. In addition, several noted that teamwork among clinical staff and home-based care services in the community was not effective which also resulted in a diminished capacity to care for their loved ones. Several people living with ESRD and their family members expressed the need for support and EOL care for them as they learned to navigate this disease in the home setting. This study identified barriers and facilitators to replicating an evidence-based palliative care model including the barriers and facilitators encountered by two managed care organizations while replicating an evidence-based end of life in-home palliative care model. Using diffusion of innovation theory as a theoretical framework, results from focus groups and interviews with the project's clinical, administrative and research teams are presented and recommendations made for improving translational efforts. These key elements include marketing and communication, leadership, organizational support and training and mentorship (Luker, Austin, & Caress, 2000).

Communication skills are paramount in the effective delivery of palliative care. The emphasis in much of the previous literature had been on physician communication and also has been focused on the singular topic of breaking bad news for relative or people. Much less emphasis has been placed on communication skill as a vital skill of community nurses and on the opportunities for nurses, as they were often the key professionals after "bad news" was shared. Basically, nurses are the primary, constant healthcare providers across clinical settings. Effective skills in communication are critical to community nursing practice and to ensure quality care in palliative. Education regarding communication skills is needed in basic and graduate nursing education programs as well as in continuing education for practicing nurses.

5.3 The development of home based palliative care model

In this study, applied mixed methods guided the development of home based palliative care model. The qualitative component of the study helped to develop the model. There were 3 cycles composed of 1: Current situation analysis, cycle2: improvement implemented and cycle3: review change in each cycle reported regarding plan, act, and reflect. This model was developed based on the interviews about the palliative care problems from the nurses, doctors, people living with ESRD, families, health volunteers, and social workers. The information was given to the community in order to declare the problems, barriers and determine how to set up palliative care in community. Then the group analyzed the situation using SWOT analysis and SWOT matrix. After that the model of home based palliative care was created. The first model was tested in the community and evaluated by focus groups.

The design of the home based palliative care model in palliative care focused on people living with ESRD’s participation. The model sought to achieve relief from fatigue and other distressing symptoms, affirm life and regard dying as a normal process, integrate psychological and spiritual aspects of care, offer a support system to help patients live as actively as possible until death and to help the family cope during the patient’s illness and in bereavement. In the process of development of the home based palliative care, communication skills were essential. The researcher used these skills especially for End-of-life (EOL) education for community nurses. This had been historically inadequate despite efforts in recent years and represented a significant barrier to the proliferation of palliative care. Although nurses have frequent contact with dying patients and their families, they are often unsure of their role in the palliative care referral process. Limited educational opportunities for nurses have resulted in negative attitudes toward the dying and limited knowledge about palliative care. Community nurses often do not see a clear, direct role for themselves in palliative care model for decision making, reported fear as a barrier to EOL nursing care, and may not feel confident in the practice of EOL care. Moreover, community nurses' ideas about palliative care are often limited to pain and symptom management. Improvements in knowledge about palliative care and practical competence in communication are needed in nursing education. The lack of attention to palliative care in nursing education only complicates the expectation that nurses will be competent communicators. Among clinical staff, nurses are viewed as accessible communicators and are expected to communicate well with people living with ESRD and families.

Experienced palliative care practitioners of community nurses are aware of the complexity of the issues within the discipline. Physical symptoms, psychological, social and spiritual well-being need to be considered to ensure the highest possible quality of life for people living with ESRD and their families. People living with ESRD need call for attention to detail when evaluating people living with ESRD and developing individual management plans. Progression of symptoms and response to interventions show a high degree of unpredictability, requiring regular review as well.

When the model was developed, the model was composed of nursing care that focused on developing relationships, developing understanding, developing acceptance and developing mindfulness to agree with the cycle of life. One study reported the a similar method to develop the components of a rural palliative care model based on the experiences of social work and health care professionals providing palliative care in rural Canada. The results of their focus groups outlined significant components of the participants' experiences of providing rural palliative care which led to a beginning model of palliative care in rural Canada(Wilson et al., 2006).

In the activities involved with palliative care training, knowledge has an important ingredient. Some studies have shown the importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care. The centrality of knowing the people living with ESRD and his/her family emerged as an essential antecedent to the provision of high quality palliative care. The factors enabling the formation of positive relationships were given in descriptions of ideal care so the strategies used to achieve this included establishing early contact with the patient and family, ensuring continuity of care, spending time with the patient and providing more than the physical aspects of palliative care. The characteristics described by the community nurses are similar to those advocated in 'new nursing' which identifies the uniqueness of people needs, and the nurse–patient relationship is objectified as the vehicle through which therapeutic nursing can be delivered as well.

The link with 'new nursing' emerges at an interesting time for community nurses (Karen, Austin,& Christine,2009).

To sustain the program development in this study, satisfaction of the people living with ESRD, families and health care providers was essential. . When the stakeholders were satisfied, this led to the development of continuing and sustainable services for those who live in the community. The study that showed satisfaction with community palliative care had been lacking and that information provision was deemed unsatisfactory by a large proportion of respondents. Basically, dissatisfaction with care received from hospital, the community nursing service and the general health care providers was common. Levels of satisfaction with care were clearly related to a range of service factors (Jan & Ann, 2008).

Moreover, the home based palliative care model required that help must be provided anytime as it was necessary to provide quick responses for help. The use of technology in care delivery suggests that use to connect hospital-based and palliative care clinicians with patients, families, and staff in skilled nursing facilities may enhance some aspects of end-of-life care for their people in community. In addition it could be a method to provide content related knowledge and training in core aspects of end-of-life care for interdisciplinary groups of staff or caregivers (Sean, Patricia, Gabriella, Clare, Sandy, Tia et al., 2008).

Berzoff , Swantkowski & Cohen (2008) supported the development of a renal supportive care team from the voices of patients, families, and palliative care staff and found that although half a million Americans suffer from end stage renal disease **(***ESRD*), their quality of end-of-life care has been woefully inadequate. Respondents in this study also agreed that there needed to be greater education of both patients and families regarding all aspects of the disease process, open communication, on-going support between patients, families, and the staff, continuity of care, pain control, and assistance with advance care planning. The significance of these results was that palliative and supportive care issues in ESRD need greater attention.

Moreover, the study by Dale , Petrova & Munday (2009) on a national facilitation project to improve primary palliative care examined the impact of the gold standards framework on process and self-ratings of quality. They found that implementation of the GSF seems to have resulted in substantial improvements in the process and quality of palliative care. The study by Kristina,Peter & Lynn (2010) focused on meeting the needs of family carers. In their evaluation of three home-based palliative care services in Australia, they found that while policy promotes comprehensive assessment of family carer needs and a plan to adequately meet family carer needs within palliative care, there is a lack of research in the Australian context which examines the current type of assessment and types of care provided to family carers. Teerawattananon , Mugford & Tangcharoensathien_(2007) studied the economic evaluation of palliative management versus peritoneal dialysis and hemodialysis for end-stage renal disease which provided evidence for coverage decisions in Thailand.

ESRD is associated with poor quality of life (Morsch, Goncalves, & Barros, 2006), depression (Kimmel & Peterson, 2006), reduced physical functioning ability (Cleary & Drennan 2005; O'Sullivan & McCarthy 2007), poor sleep quality (Elder et al., 2007), and fatigue (McCann & Boore, 2000; O'Sullivan & McCarthy, 2007). People living with ESRD and families reported emotional and spiritual suffering. Most of the ESRD participants talked about their difficulty in adjusting to their lives and coping with this disease. One man appeared sad, depressed and expressed suicidal ideation during the interview; therefore he was referred for counseling and treatment. Another ESRD participant shared that he knew his life would be coming to the end soon. He felt bad and sometimes did not want to do dialysis and had requested to die at home.

This study also identified the need of a discussion about kidney transplants; many of the older study participants with ESRD said they did not want to have new kidney because they thought that they were nearly dead until they heard about how they could survive with a kidney transplant so they decided to continue dialysis treatment. In contrast, the younger participants with ESRD shared that they had hope to get a kidney transplant and they expressed the desire to have a new kidney.

The home based palliative care model was set up by the study team in an effort to find the appropriate model. The first palliative care team meeting included many disciplines of healthcare providers as the researcher identified willing professionals to join the project. The palliative care team included doctors, nurses, social workers, health volunteers, physical therapists, psychiatrists, and pharmacists. The development of home based palliative care model was revised after evaluating the first model as it was noted to be too time consuming and not realistic. The researcher found that there were many activities that were the responsibility of the community nurses that took time so if the first model required too much time it would not be feasible in reality. In the first model, the researcher set the home based palliative care for 6 visits but some community nurses suggested that this visit schedule should be decreased because they had many other people to care for in the community in addition to those with chronic diseases other than ESRD. The researcher agreed to changing the model as it needed to fit with the user. So the next plan was composed of two models: the first included 4 home visits for people living with ESRD who were not at the end of life stage and the second model included 2-3 home visits times for assessing information and providing suggestions until the people living with ESRD passed away.

The people living with ESRD reported that they felt more comfortable in their home because of the familiarity of the environment and the surroundings. The home also provided a private atmosphere away from the hustle and bustle of the hospital. The people living with ESRD felt secure and believed that autonomy was retained in the home setting. In this setting, the presence of family and friends helped to take away the constant attention to the disease. The social bond between family members, especially in Thai culture, has a better impact on the overall health outcomes because of the participation of family and friends in the care.

In Bangkok, Thailand the health center has set trends to set up home based palliative care in the community. The evaluation by SWOT analysis led to the conclusion that there are keys to success such as no fee for service in community, continuing development of nursing care, willingness to develop new approaches to human caring by health care providers. There is multidisciplinary team involvement in home visiting for people living with ESRD. There are part time community nurses available to help deliver health care service in case of high case loads. The main ingredient in setting up home based palliative care is a willing mind and caring .When the team had willingness to develop the palliative care program, other facilitators and providers of care agreed to help establish palliative care in the community. The researcher found that positive thinking can do many things and many people on the team who had positive thinking joined together to do the best thing for their community at that time. The community health center should have a competent team and access to the basic infrastructure of palliative care. There is also a need for transport to visit people living with ESRD at homes as well as a means of communication, like a telephone to stay in touch with people living with ESRD and their families around the clock. These are likely to be region specific and dependent on local conditions for basic infrastructure of home based palliative care. In this study, the home based palliative care model increased the scores of satisfaction in caring of people living with ESRD from 38.05 to 62.93, wellbeing from 5.60 to 7.85, the psychological and spiritual from 21.17 to 28.54, and total quality of life from18.44 to 23.65.

The study showed people living with ESRD demonstrated increased satisfaction, well-being, psychological & spiritual subscales of quality of life after receiving home based palliative care. The components in the home based palliative program included psychological and physical care to promote comfort which led to satisfaction among many people living with ESRD. Meanwhile satisfaction with care led to improved quality of life, in people living with ESRD and both of these outcomes were important treatment goals for people living with end stage renal disease (ESRD) (Kutner, Brogan & Kutuer, 1986). If people living with ESRD felt bored with their life, it sometimes ended in withdrawal from dialysis which led to death.

5.4: Bodies of knowledge, which extends the application of uncertainty in illness

The findings of this study revealed the complexity of issues that people living with ESRD and their families face. By using Mishel’s theory of uncertainty in illness as a guide, themes emerged that were congruent with his stimuli frame concept including symptom patterns, event familiarity and congruence. The symptoms reported included not only a plethora of distressing physical symptoms but emotional and spiritual crises as well. Uncertainty had evident in the concerns for the future theme including the economic consequences theme. Uncertainty was ultimately associated with the general inconsistent and progressive pattern of symptoms experienced by the majority of people living with ESRD. In addition, Mishel's theoretical component of structure providers was reflected in the theme of inadequate community supports. Who will care for the people living with ESRD's family member as the disease progresses? Who will educate family providers to care for them? How can the providers themselves learn the principles of palliative care to provide this care?

The concept of cognitive capacity was not directly identified within the themes and stories of these participants in relation to the ESRD sufferers themselves. All participants were chosen based on their ability to understand and participate in this study in order to give informed consent; thus none currently experienced significant cognitive decline. However, knowledge deficits among family caretakers were identified in relation to being competent to care for their family member with ESRD. The study in participants clearly identified the need for community support for people living with ESRD including coordination of existing resources and additional resources from both governmental and nongovernmental sources of that community. They identified the need for community teams who can provide support to people living with ESRD and their families in the own home and community setting throughout the stages of the disease including death.

The study found that the people living with ESRD had complications both from dialysis and complications of disease itself. The complications during hemodialysis treatment were composed of itching, hypotension, and headache. On the other hand, complications of peritoneal dialysis included infection, a feel of discomfort after dialysis, and tiredness. Moreover, ESRD suffering at times included the person's vulnerability for cognitive deficits due to uremia or other medical parameters. Several studies demonstrated that hemodialysis and peritoneal dialysis have beneficial effects on attention, psychomotor speed, memory and several cognitive domains (Gamvrula, 2006).

Inadequate community supports: Another major finding from the interviews with ESRD participants and their family members was that supportive services in the community were not adequate. In addition, several noted that teamwork among clinical staff and home-based care services in the community was not effective which also resulted in a diminished capacity to care for their loved ones.

Several people living with ESRD and family members expressed the need for support and EOL care for them as they learned to navigate this disease in the home setting. Over half of the family members thought that there was not enough emotional support for them especially in the community where existing palliative care networks or resources to service end of life care are scare or nonexistent.

Most of people living with ESRD felt that life with this disease was so terrible and they were led to despair. Many people living with ESRD have the attitude about the death that it is not terrible for them if they will leave from this world. The attitude toward life was that it was not important to them. The illness uncertainty concept emerged from the qualitative and quantitative data as had been described in the literature as a cognitive stressor, a sense of loss of control, and a perceptual state of doubt that changes over time. Illness uncertainty is associated with poor illness adjustment, but often needs to be appraised as a threat which has its own deleterious effect. In populations experiencing pain, illness uncertainty is related to heightened sensitivity to pain and reduced tolerance of painful stimuli. Illness uncertainty also has been related to maladaptive coping, higher psychological distress, and reduced quality of life. The illness uncertainty literature in relation to pain is somewhat limited but clearly suggests the potential negative impact on the perception of and adjustment to pain.

The study participants identified the need for community support for people living with ESRD including coordination of existing resources and additional resources from both governmental and nongovernmental sources. They identified the need for community teams who can provide support to people living with ESRD and their families in the own home and community setting throughout the stages of the disease including death.

For many families, the diagnosis of a life-threatening illness of a family member is their first major confrontation with death. The researcher noted that although most of the participants with ESRD shared stories that revealed an increased familiarity with their disease over time, they also shared many unexpected things that occurred in their lives that concerned them. The impact on the families of people living with ESRD who were caring for their loved ones with ESRD was also difficult in many cases.

The heart of palliative care is communication. If the health care providers give the right information, it will create understanding and help to set the stage for the delivery of palliative care. The important thing is that the families must understand the concept of palliative care which reduces unnecessary treatment to prolong and suffering both patients and families. The communication in this study at first included making relationships with families which included an explanation of the whole concept. This was essential for families to make an informed choice to receive palliative care. The main components of this communication included truth telling, breaking bad news, and addressing confidentiality issue.

5.5: Reflection of meditation healing exercise SKT6

The results of this study provide rich data to support the development of a multifaceted palliative care intervention for people living at home with ESRD. The study integrated meditation healing practice SKT6 to develop a quasi-experimental intervention study in the dialysis unit in the hospital. The intervention group received a specified series of interventions related to physical, psychological and spiritual needs. Supportive care included education, symptom management and home based meditation/relaxation exercises SKT6 developed by Kantraradusadee TS. The non SKT group received the usual care for ESRD people in the hospital and community. Before the intervention, the researcher assessed the skin of participants with ESRD in both groups and found that most persons both groups with ESRD had dry skin. After SKT6 practice, the results in the SKT group revealed a decrease in dry skin, numbness, and itching, in comparison to the non-SKT practice group. This result supported the conclusion that this meditation had a positive effect on skin condition.

The result of this study showed that the SKT practice group had an increased quality of life in comparison to the non-SKT group. The trend in the quality of life in the SKT group was that each subscale had increased in comparison to the decrease in all subscales among the non-SKT group. This result is congruent with the study of Phattaya (1992) who had also done research on 'the effect of learning mindfulness of breathing meditation techniques on anxiety and depression in patients who have had chronic kidney failure and received a kidney transplant.' That study concluded the experimental group who was taught mindfulness of breathing meditation techniques suffered less anxiety and depression and their level of stress and anxiety were clearly lower than those of the control group.

In the SKT group the relationship between of their quality of life and physical symptoms indicated a negative correlation. The direction the relationship of quality of life and physical symptoms were found to be statistically significant
r= -.59, n=35, p-value <.001. That meant that as the physical symptoms increase, the quality of life decreases. The other relationships in the study such as uncertainty in illness and quality of life or physical symptom were found to be non-significant.

When examining the relationship of variables such as physical symptoms, quality of life in 4 dimensions, and uncertainty, the results revealed that physical symptoms in palliative care indicated the a negative correlation with the health functioning subscales in quality of life. Physical symptoms in palliative care and social and economic subscales were found to be statistically significantly correlated. Physical symptoms in palliative care and psychological and spiritual subscale were also found to be statistically significantly negatively correlated r= (-.562), n= 35, p-value <.001.

Consequently, as physical symptoms in palliative care increase, the health functioning subscale, social and economic subscale, psychological and spiritual subscale decreases. These results are congruent with the Sammarco (2001) study that found the same significant positive correlation between perceived social support and quality of life, a significant negative correlation between uncertainty and quality of life. For the social and economic subscale, the correlation with quality of life was r=.909 which is congruent with the result of the impact of socioeconomic status on the quality of life of ESRD patients. Socioeconomic status was an important factor associated with QOL in patients with ESRD. Further studies are needed to determine optimum interventions and measures in groups with lower SES which may be important to improve QOL outcomes and reduce their morbidity (Sesso, Rodrigues-Neto, & Ferraz, 2003).

The results of biochemical substance tests:

In this study both the intervention and control group were examined in terms of several laboratory values including: BUN, and creatinine in addition to other renal laboratory indicators.

The main effect within group of the SKT and non SKT groups was not significantly different but there were significant difference between the SKT group and non SKT group in the BUN results. For the discussion this result, first of all, BUN is a protein waste product. It changes every time in each cycle depend on the eating behavior of persons with ESRD and their control in food selection. The results revealed that the BUN was not different when examined within the group. When considering the impact of the intervention, there were significant difference in between group studies in the SKT and non- SKT groups. SKT6 mindfulness meditation also helped the body to heal itself if people living with ESRD continued its practice. The data supported that the practice provided reinforcement of the body’s inclination toward homeostasis and therefore toward optimal use of all its functions and potential. What ‘special abilities’ or ‘psychic powers’ as they were sometimes called developed in SKT practice are simply the product of the natural capacity of the refined human state. The result showed significant differences in SKT group and non-SKT group.

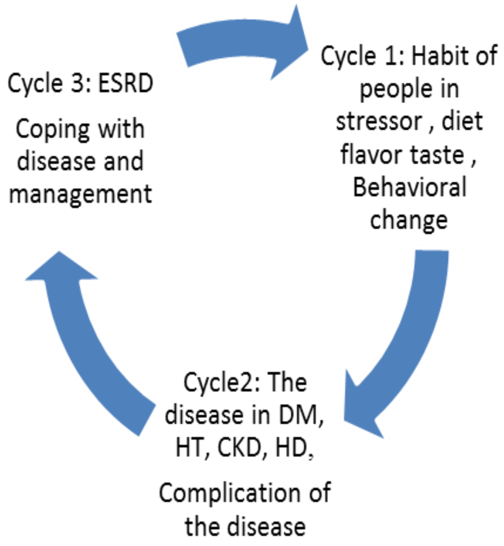
The main effect of creatinine blood levels within group revealed an F statistic of (14.36, 694.51) = 1.49, p-value = .227. So the creatinine level within group was not significantly different in terms of the time taken. The main effect of creatinine on SKT practice between groups was significant difference, F (6.49, 467.07) = 2.77, p-value < .05. That means that the creatinine levels in the SKT group and non SKT group were significantly different. For a discussion this result, creatinine is a waste product in the blood that results from energy metabolism of the muscle, which is transported in the bloodstream to the kidneys where it is then filtered and excreted from the body in urine. This chemical by-product of muscle metabolism is produced by creatinine from the real situation in dialysis, the creatinine result would be changed in each cycle of dialysis depend on the waste product and renal function in the body. It is true that when statistical testing was analyzed in within both groups, there was not a significant difference because the creatinine levels changed in both groups. However, when looking between SKT group and non SKT group, the researcher noted a difference in between groups. This result suggested that in the effect mindfulness meditation had an effect on blood flow based on creatinine level changes. Meditation can physiologically increase blood flow so that the cells in the body have more ability in function.

5.6 The researcher's reflection

After completion of this study n home based palliative care of people living with ESRD, the researcher reflected on several constructs and methods used:

5.6.1 Reflections on the way of life of people living with ESRD

The researcher examined the phenomena that lead to the development of home based palliative care model for people living with ESRD which starts with health behaviors. These begin with behaviors which make them at high risk for DM, HT, and CKD until finally they develop ESRD. Asking about life behaviors and past history and ways of coping with illness led to the following cycle.



Reflections on the acceptance of using Buddhism concepts

When a crisis occurs in life such as the diagnosis of ESRD, treatment with hemodialysis or peritoneal dialysis may require many questions to understand where the person is and how he/she can manage with the crisis. Reflecting on the loss, where he/she is in terms of the grieving process and identifying the coping mechanism of each person is essential. Some persons may not be able to cope with this disease and may decide to deny treatment which will lead to death. Many others however, learned to accept this disease by using the Buddhism concepts including acceptance of the disease as a result of bad karma. In this case, they must learn to cope with the disease and develop a high threshold to treat the disease. The researcher found benefits from the integration of Buddhism concepts including helping the people to survive while trying to do something good in preparation for the next life. In the meantime, they learned to live with ESRD in their environment.

From the Four Noble Truths, to use wording of 'Noble' because they ennoble one who understands them and they are called 'Truths' because, corresponding with reality, they are true. The First Noble Truth is talking about life is suffering. People living with ESRD live and therefore they must suffer. It is impossible to live without experiencing some kind of suffering. By nature, all people have to endure physical suffering such as sickness, injury, tiredness, old age and eventually the same destination in death. So this concept of suffering helps people living with ESRD to accept the suffering with their disease. The researcher found that suffering was part of the natural cycle of life especially in people living with ESRD who were treated with dialysis. That why people are born and what will be the last part of their life? These existential questions made the reminded the researcher in the Buddha’s teachings which included that happiness in life is nirvana, which is the way that is far from suffering.

5.6.2 Reflections on the good karma that leads to good things in life

From this study, the researcher found that someone got good karma by helping other people when they needed some help, one relative said that “I believe that he is a good man so someone will help him before he will die and when he needs help”. The researcher understood this meaning. Many others also shared situations that reflected the concept of a good karma which leads to good things in life. Moreover, positive thinking can lead someone to something and ones who have positive thinking will be drawn together.

5.6.3 Reflections on the opened mind as being useful for solving problems or disease

The researcher identified the phenomenon of an open mind in some people who which helped them with to cope with their disease which gave them a good life. In comparison, some cases had a closed mind which meant that they did not accept their disease and would not change their behavior which led them to encounter more problems. In these cases, they complained a lot but did not follow instructions for disease.

5.6.4 Reflections of the process in the study of mixed design

In this study using mixed design was very useful to examine the problems by using qualitative study and to test the relationships quantitatively among variables including pre-posttests to compare mean differences of groups study. The researcher found many benefits in the chosen study design and learned a lot in the process of mixed design. The limitations of the study included the constraints of time and the limited budget of the researcher. Yet the researcher was able to set up home based care in the community with community support because the coping while dying is an important part of the life process in the home environment. Even though the researcher had limited time to conduct the study, the researcher noted data saturation in the qualitative component of the study which suggested that collection of new data would not shed any further light on the issue under investigation.

5.6.5 Reflections on the process of home based palliative care model

The process of home based palliative care in the community stresses the psychological and spiritual aspects more than physical aspects. So when preparing home based palliative care in community, one should consider the cost effectiveness because the community nurses have much responsibility in the community, including in the schools and making home visits to persons with chronic disease living in the community. The researcher considered this aspect and tried to set up a quality and cost-effective approach to deliver home based palliative care for chronic disease in community. This study revealed much suffering from chronic diseases such ESRD and their needs for home based palliative care. The researcher found the benefits in helping many people to improve their quality of life while remaining in their home environment. In reality, many poor people get ESRD; it is not only the wealthy. This presents many problems even though the Thai government has a gold card for everyone. This card provides the right to some health care but it is not enough for poor people in community to treat complications and travel to the hospital frequently for treatments.

Home based palliative care model help people living with ESRD in supporting their mind to cope with disease. It is important to support them because ESRD requires many complex treatments and necessitates a collaborative management treatment plan involving the medical provider, the patient and his/her family, professional community health care providers and volunteers. Many people living with ESRD have died due to a lack of dialysis access or from the inability to tolerate it mentally or physically. They can develop hopelessness as they go through this process. The process of home based palliative care should include time to communicate with the person and his/her family as well as a demonstration using an easy way to practice care and mediation techniques. Many people living with ESRD said that “it is very useful to set up this care for me”. They expressed feeling better as a result of the care, they understood their treatment better and also felt less uncertain about the preparations in life that they needed to make.

5.6.6 Reflections on uncertainty in life

The real situation is that life is uncertain. Many people living with ESRD just came to dialysis one day and the next day later they had died from many reasons. Some of them died from complication of heart disease, or from progressive renal disease. The study reflected uncertainty in illness and uncertainty in life so the palliative care program taught about preparing for the time of death which is very useful for everyone because everyone does not know the exactly date of his/her death. If everyone is concerned about the not being careless in one’s life, it can help people to have good thoughts and to do good things always. This is one of the processes to prepare them to die with peace and dignity. This is the last feeling which affects the new life. If a person dies with a bad last feeling, it will make him/her go to a bad next life when he or she is born to the new life.

CHAPTER VI

CONCLUSION AND RECOMMENDATIONS

The purpose of this embedded mixed methods study was to better understand a research problem by simultaneously implemented but qualitative was mainly used to develop and evaluate a home based palliative care (HBPC) model for people living with ESRD and quantitative was embedded in order to answer different research questions to measure the relationship between SKT6 and quality of life, uncertainty in illness, physical symptoms, and biochemical substances in blood testing.

The lack of research focusing specifically on community nursing in palliative care represents an important gap in current knowledge of the model. Home based palliative care should be structured around specific person problems experienced at the end of life and not simply as care for persons at home living with a chronic disease. Although palliative care is provided in hospitals and some communities, it lacks the provision of follow-up home based palliative care and bereavement services in the community. Families, health care staffs and volunteers have inadequate continuing care for people living with ESRD. So the objective of the study was to develop and evaluate a home based palliative care model for people living with ESRD. Five specific objectives were identified: 1. To explore the palliative care needs of home based palliative care for people living with end stage renal disease, 2. to explore barriers or facilitators influencing home based palliative care for end stage renal disease, 3. to develop a model of home based palliative care for people living with end stage renal disease, 4. to evaluate the relationship between physical symptoms, uncertainty, and quality of life in people living with end stage renal disease and 5.to evaluate the effect of meditation healing exercise SKT6 on quality of life and biochemical substances in people living with end stage renal disease. The first, second and third objectives were examined using qualitative methodology. The fourth and the fifth objectives were examined using quantitative methods.

The total number of the study was 194 were divided into two groups. The first group 120 participants including 54 people who depicted the needs, barriers or facilitators and 66 people who consulted about the home based palliative care development. The second group was 74 people living with ESRD for quantitative study from two outpatient dialysis wards in one hospital. Each ward was assigned to be an intervention and a control group. The intervention group included 35 people living with ESRD who received training for SKT6 practice. The control group consisted of 39 people living with ESRD who did not receive SKT6 practice training (non-SKT group). The general characteristics of study participants including people living with ESRD and their families were described, Participants with ESRD completed at two times periods: an assessment of their symptoms using the Edmonton symptom assessment (ESAS-r), the uncertainty in illness scale of Mishel, and the quality of life index by Ferrans and Powers, dialysis version III. The researcher examined the changes in these scales in relation to exposure to the SKT6 meditation healing exercise in the intervention.

6.1Conclusions on the qualitative results

6.1.1 Suffering and needs of people living with ESRD

The suffering of 87 people living with ESRD was found in many dimensions regarding physical, psychological, social, economic and spiritual dimensions. The suffering of people living with ESRD began when they first got the diagnosis of ESRD and needed to start treatment with dialysis. Hemodialysis is commonly performed twice a week for 4–5 hours per session in most people living with ESRD. Most of the dialysis units offer hemodialysis only. CAPD as an alternative dialysis therapy for ESRD is offered at home in community, and requires 3–4 fluid exchanges per day. For those being treated with CAPD at home, the hospital would sometimes provide workers to come and provide care at home and also at times community nurses from the health centers visited these cases. Those receiving dialysis at home coped with many problems such as how to perform the procedure, how to maintain aseptic technique and how to avoid complications from the dialysate.

ESRD is a growing concern in Thailand as well as the rest of the world. Palliative care is focus on patient center and approach concerned with physical, psychosocial, and spiritual care in a progressive disease. In Thailand, an identified need to address the challenges experienced by people living with ESRD in the community has been identified and was supported in this study. The Uncertainty in Illness Theory provided a useful framework from which to assess the complex needs of people living with ESRD and how living with chronic illness brings a wide range of uncertainties in one's life. The study found that people living with ESRD and their families' experience great suffering from physical symptoms as well as emotional, spiritual, and economic stress. In addition their concerns include a current lack of community services and worry about the uncertainty of the future. To achieve high quality palliative care, states of the art of symptom management as well as family and community supports were necessary along with a strong health provider structure. This research demonstrated a successful, culturally competent palliative care model that addressed the complex needs of people living with ESRD and their families in Thailand. The ultimate goal was to improve the quality of life for people living with ESRD and support them in a manner that acknowledges their unique values and social norms during the end stages of their life.

In this study, the researcher identified the following themes related to suffering:

Four themes related with palliative care concept:

Physical themes

1. Tremendous suffering including stress and exhaustion
2. Hemodialysis for survival
3. Tolerate with dietary restriction and fluid restriction
4. Life must be tolerated

Spiritual themes

1 .Hope to have a new life with new kidney

2. Confusion about life
3. Bad karma from the former life

4. Loss of happiness that was experienced earlier in life

Emotional themes

1. Fear related to having access line implanted for treatment
2. Live for the day
3. Wish to die at home
4. High level of responsibility and emotional strength needed to cure the disease

Social themes

1. Concern for the future including management of disease
2. Economic consequences
3. Social restrictions
4. Loss of the job

The researcher of this study found that there were many people living with ESRD suffering from this disease. Most of them tried to cope and manage this disease starting from the point of diagnosis and through the treatment stages. The people living with ESRD shared many problems such as their symptoms progressed over time. They shared stories of tremendous suffering including severe bone pain due to poor circulation which led to gangrene and amputation of the toes. Some participants with ESRD shared stories which reflected their ability to adjust to the demands associated with ESRD over time. At times they attributed the dialysis itself as the cause of improvement in their symptoms to some degree.

ESRD has become a major health problem because it is a devastating medical condition, and the cost of treatment in dialysis is a huge economic burden as well. The people living with ESRD and families tried to solve the many faceted problems they encountered such as the cost of treatment. Some families did not have health social insurance or health welfare coverage for ESRD care. Moreover, some people living with ESRD did not have someone to take care of them because all of their relatives were too busy. Some relatives tried to help with the transportation from the home to the hospital for hemodialysis treatments and other people living with ESRD had to support themselves to get to the hospital treatments using a taxi.

Physical suffering among people living with ESRD was at times related to inadequate dialysis and often included dry skin, tiredness, and a feeling of general discomfort in the body. This suffering affected their quality of life. Treatments now available can effectively reduce the rate of progression of renal disease and the extent of complications. The challenges of present to prevent ESRD include: (1) to intervene effectively to reduce the excess burden of cardiovascular morbidity and mortality associated with renal disease, (2) to identify those at greatest risk for ESRD and intervene effectively to prevent progression of early renal disease, and (3) to introduce cost-effective primary prevention to reduce the overall burden of renal disease. The vast majority of the global renal disease burden is now in many countries, and policy responses should be both practical and sustainable in these settings.

In this study, many participants with ESRD who had delayed dialysis developed uremic symptoms which required admission in an ICU where they then had to start dialysis treatment. Most of the participants on CAPD and hemodialysis recalled that they had tried to delay the start of dialysis. One participant who had delayed treatment even recalled a near death experience after which she finally acknowledged the need for dialysis. While most shared that they felt better and were less fatigued once the treatments began, a few acknowledged hopelessness as one participant stated: “Dialysis has not made anything better since I started the treatment”.

From the analysis of this family’s experience, health professionals were afforded an insight into the diversity of needs that encompass the essence of care being provided in the home. This opportunity allowed health professionals to gain further insight into this significant life event, leading to an enhancement of their practice and enabling them to be better equipped to meet the individual needs of family units.

6.1.2 Knowledge level of health care providers about home based palliative care model

This study revealed about a lack of knowledge among health care providers related to the development of a home based palliative care model. The experienced palliative care providers were aware of the complexity of the issues within the discipline. Physical, psychological, social and spiritual issues need to be considered to ensure the highest possible quality of life for people living with ESRD and their families. Progression of symptoms and response of people living with ESRD to interventions showed high degree of unpredictability also.

Communication skills are paramount in effective delivery of palliative care model. The emphasis in much of the previous literature has been on physician communication and also has been largely focused on the singular topic of breaking bad news of people including relative. Much less emphasis has been placed on communication as a vital skill of community nurses as they are often the key professionals after "bad news" is shared. Nurses are the primary, constant healthcare providers across clinical settings, and effective skills in communication are critical to nursing practice and to ensure quality care in patients. Education regarding communication skills is needed in basic and graduate nursing education programs as well as in continuing education for practicing nurses as well.

6.1.3 The development of home based palliative care model

This model was developed based on the individual interviews and focus group meetings with the nurses, doctors, people living with ESRD, families, health volunteers, and social workers. The information was given to the community in order to identify the problems, barriers and how to set up palliative care in community. Then the group analyzed the situation using SWOT analysis and SWOT matrix. After several meetings, the model of home based palliative care was created. The first model was tested in the community and evaluated by a focus group. There were 3 cycles in developing the model which were composed of cycle 1: Current situation analysis, cycle 2: improvement implemented, and cycle 3: review change reported regarding the planning, actions taken, and reflections. The activities in home based palliative care included; 1. Develop relationships; explaining objectives, assessment of symptoms, including physical, psychological and spiritual. This process facilitated communication among families, persons with ESRD and health care providers. 2. Develop understanding; treatment and support from symptoms, suggestions for palliative care needs at home. The aim of this process was to determine symptom management for people living with ESRD.3.Develop mindfulness; explain more in detail the process of palliative care and assess acceptance of relatives and patients. This aim of this process was to determine psychosocial support needs and processes of care. 4. Develop acceptance; provide follow up to assess psychological need of people, uncertainty of life, satisfaction, and quality of life at home. The aim of this process was to support the dying at home. Moreover, the process of the end of life before death in people living with ESRD was composed of 3 cycles: cycle 1: Karma dreams and the moral dreams, cycle 2: Suffering from the uncomfortable symptoms and trying to do good karma, and cycle3: a peaceful death

The study supported the importance of 'knowing the people living with ESRD' and community nurses' constructions of quality in providing palliative care. The centrality of knowing the people living with ESRD and his/her family emerged as an essential antecedent to the provision of high quality palliative care. This factor was enabling the formation of positive relationships in given prominence of ideal care. Strategies used to achieve this included establishing early contact with the people living with ESRD and family, ensuring continuity of care, spending time with the people living with ESRD and providing more than the physical aspects of care. The characteristics described by the community nurses are similar to those advocated in 'new nursing' which identifies the uniqueness of people living with ESRD needs. Meanwhile the nurse–people living with ESRD relationship is objectified as the vehicle through which therapeutic nursing can be delivered.

The design of a home based palliative care service in palliative care that focuses on people living with ESRD’s participation can provide support and relief from fatigue and other distressing symptoms. This model can affirm life as it regards dying as a normal process while integrating psychological and spiritual aspects of patient care. The home based palliative care model offers a support system to help people living with ESRD live as actively as possible until death. It also can help the family cope during their loved ones illness and during the bereavement period. The home based palliative care team must build a network of support with other organizations/institutions that can offer further care to their patients, such as hospices, hospitals,and community service organizations. Characteristics of palliative caregivers are important to understand because palliative caregivers need a willing and open mind to care. The activities of home based palliative care should have specific purposes and concise concepts because in reality, time is limited and the quantity and quality of providers' work lives must be also considered.

The satisfaction of people living with ESRD, families and health care providers is essential for the program's sustainability. When the participants are satisfied, continuing services are more likely to occur within the community. By definition, palliative care is the provision of support to those who are at the end stages of life at any time they are in need. Thus it is necessary to build in a quick response time in the program. Because of the cost of in-person home care with 24 hour coverage this may require alternative such as the use of real time to connect community-based committees and palliative care clinicians, health centers and families in the community. The people living with ESRD, families, and staff should have access to skilled nursing facilities where they can be trained in aspects related to end-of-life care in their community. This knowledge and training can lead to improvements in the quality of life of people living with end stage disease living in the community.

This study utilized the Ferrans and Powers Quality of Life Index (QLI) which had a possible range of scores from 0 to 30. The results of this study included the finding that the highest scores was in the family quality of life subscale (24.43) and the lowest score was the total quality of life score (19.98). The lowest score in the quality of life was the health and functioning subscale and the highest score was in the family subscale. This reflects the culture of Thai people in which families tend to take good care of their loved ones when they are sick. Participants with ESRD and their families reported emotional and spiritual suffering. Most of the participants with ESRD talked about their difficulty in adjusting their life and coping with this disease. One ESRD participant shared that he knew his life would be coming to the end soon. He felt bad and sometimes did not want to do dialysis and had requested to die at home.

6.1.4 Uncertainty in illness

The findings of this study revealed the complexity of issues that people living with ESRD and their families face. By using Mishel's theory of uncertainty in illness as a guide, themes emerged that were congruent with his stimuli frame concept including symptom patterns, event familiarity and congruence. The symptoms reported that including not only a plethora of distressing physical symptoms but emotional and spiritual crises as well. Uncertainty was evident in the concern for the future theme as well as the economic consequences theme. Uncertainty in illness was ultimately associated with the general inconsistent and progressive pattern of symptoms experienced by the majority of people living with ESRD.

Stimuli frame: the study showed the minimum of the duration on hemodialysis was 3 months and the maximum on hemodialysis was 12 years. The average duration on hemodialysis was 2.91 years (SD 2.38). The people living with ESRD had complications both from dialysis and from the disease. The complications from hemodialysis treatment were composed of itching, hypotension, and tiredness. Complications of peritoneal dialysis included infection, feeling of discomfort from dialysis, and tiredness.

Structure provider: Inadequate community supports: Another major finding from the interviews with ESRD participants and their family members was that supportive services in the community were not adequate. In addition, several noted that teamwork among clinical staff and home-based care services in the community was not effective which also resulted in a diminished capacity to care for their loved ones. Several people living with ESRD and their family members expressed the need for support and EOL care for them as they learned to navigate this disease in the home setting. Over half of the family members thought that there was not enough emotional support for them especially in the community where existing palliative care networks or resources to service end of life care are scare or nonexistent.

Most of people living with ESRD felt that the life with this disease was so terrible and they felt despair. Some of them however had an attitude about the death that it would not be terrible for them if they left this world. The attitude about life for these study participants was that it was not important to them. The concept of cognitive capacity was not directly identified within the themes and stories of these participants in relation to the ESRD sufferers themselves. However, knowledge deficits among family caretakers were identified in relation to being competent to care for their family member with ESRD.

The study participants clearly identified the need for community support for persons with ESRD including coordination of existing resources and additional resources from both governmental and nongovernmental sources. They identified the need for community teams who can provide support to people living with ESRD and their families in the own home and community setting throughout the stages of the disease including death.

For many families, the diagnosis of a life-threatening illness of a family member was their first major confrontation with death. The researcher noted that although most of the participants with ESRD shared stories that revealed an increased familiarity with their disease over time, they also shared many unexpected happenings that occurred in their lives that concerned them. The impact on the families who were caring for their loved ones with ESRD was also difficult in many cases.

The heart of palliative care model is communication. If the health care provider gives the right information, it will create understanding and help to prepare for the delivery of palliative care model. The important thing is that the families must understand the concept of palliative care model in order to reduce unnecessary treatments to extend life which would increase the suffering both patients and families. The communication in this study started with the process of developing relationships with the people living with ESRD and the families. At this time, the whole concept as explained to ensure that everyone understood prior to agreeing to palliative care. The main concepts of this communication in palliative care included truth telling, breaking the bad news, and ensuring confidentiality.

Palliative care for people living with ESRD is comprehensive, interdisciplinary care focusing on symptom management, advance-care planning, communication, and psychosocial and spiritual support in the model. End-of-life care is one aspect of palliative care and incorporates all of the previously mentioned components including bereavement care in the model. People living with ESRD and their families were appropriate candidates for palliative care because of their high symptom burden, shortened survival, and significant comorbidity as well. The home based palliative care model increased satisfaction both in people living with ESRD and families.

The study supported the development of a palliative care program using a public health approach which incorporates government policy such as the Thai nursing council which regulates standards of care for holistic care models. This model of program development is important to stimulate and support groups working in the community and to ensure the integration of palliative care services. Moreover, educational policy is also important to provide support for training of health care professional volunteers in palliative care model. When implementing home based palliative care model, one should consider all aspects including of the holistic, physical, social, emotional, economic, spiritual, and community needs of persons who would benefit from palliative care who live in the community.

Finally, the home based palliative care model was developed using the following template:

Model	Home based Palliative care model	Objective	Activity in home based palliative care (HBPC)model
1 ESRD	HBPC 1	Develop relationship,	1.explain objective ,assessment symptom, psychological and spiritual
	HBPC2	Develop understanding	2. Treatment and support from symptom, suggest palliative care at home
	HBPC3:	Develop mindfulness	3.Explain more in detail the process of palliative care and assess acceptance of relative and people living with ESRD
	HBPC4	Develop acceptance	4.Follow up ,assess psychological needs of people and uncertainty of life how to prepare and evaluation of satisfaction ,quality of life at home
2 ESRD & EOL	HBPC 1	Develop relationship& understanding	**Develop relationship and understanding** ;explain objective, assessment of symptoms, psychological and spiritual well-being
	HBPC 2	Develop mindfulness& acceptation	**Develop mindfulness** ;Treatment and support from symptom ,suggest palliative care at home, assess acceptance of relatives and patients, Do not attempt resuscitation, medical futility, assess the needs of people ,religious practice , **Develop acceptance** ; Follow up , assessment of acceptance or coping with uncertainty life, give suggestions for preparing documents or for a good death with dignity at home

Model	Home based Palliative care model	Objective	Activity in home based palliative care (HBPC)model
	HBPC 3	Evaluation& Bereavement care	Evaluation satisfaction, quality of life of people and family. After people living with ESRD die ,visit to support grief of relatives

6.2 Conclusion of quantitative results

Meditation healing exercise SKT6

The results of this study provided rich data that supported the development of a multifaceted palliative care intervention for people living at home with ESRD which included a specialized meditation technique. The intervention group in this study received a specified series of evidence-based meditation/relaxation of meditation healing exercise SKT6 developed by T.S. Kantharadussadee that have been shown to impact physical, psychological and spiritual needs. Supportive care to both the intervention and control groups included home visits focused on education and symptom management The non SKT group received the usual care. The SKT6 group received instructions on the technique of meditation healing exercises for both the hospital (during dialysis) and home setting.

The results in the SKT6 practice group after the implementation of the meditation exercises, showed an increase in the total quality of life score, the quality of life in health and functioning scale, the social and economic scale, the psychological and spiritual scale and the family scale. These results suggested that the SKT6 meditation healing exercises positively impacted their quality of life on many dimensions. A paired-sample t-test was conducted to compare the SKT6 meditation healing exercise before and after SKT6 implementation and the increased scores were noted to be significantly different. In addition there was a statistically significant reduction in the reported number of symptoms and level of uncertainty.

In contrast, the non-SKT practice control group scores decreased from the first time period to the second time period (during which time they received support palliative care but not the SKT6 intervention. Specifically these groups'score decreased in the total quality of life, the health and functioning subscale, the social and economic scale, the psychological and spiritual scale, and the family subscale. These results suggested that provision of usual care alone does not impact quality of life positively in people suffering with ESRD.

Other relationships noted among the study variables included a negative correlation between quality of life and physical symptoms. Not surprisingly, as physical symptoms increased, the quality of life decreased. This also held true for the relationship between physical symptoms, the social and economic subscale as well as the psychological and spiritual subscale, with both were having a statistically significant negative correlation.

Biochemical substance test for blood results after intervention with SKT6; the main effects of SKT6 on blood tests revealed that the BUN and creatinine levels, both indicators of kidney function improved in the study participants who practiced SKT6. This finding suggests that while SKT6 is a mindfulness meditation that was originally imbedded in a spiritual framework which focused on the enhancement of personal well-being, it can be applied to positively affect physiological processes in the context of disease.

Limitations of this study

This study was limited in terms of the time duration of the study and the level of financial support. In addition, since this was a quasi-experimental design, it was not possible to control for other factors that might impact the study outcomes among the intervention group. It would not have been ethical to develop a strict experimental protocol for persons living with a terminal illness and thus while this posed limitations to the interpretations the findings, the results strongly suggested a positive impact of SKT6 as the control group did not have similar improvements. Also caution must be made when interpreting the laboratory results as there was no control over medical treatment decisions which were made by the doctors which also could have impacted blood values. In addition, there was no control over other health behaviors and practices that also could have impacted the study outcomes.

6.3 Recommendations

The recommendations from this study of home based palliative care model for people living with ESRD are as follows:

6.3.1 Recommendations for nursing education

Nursing students also have the opportunity to significantly build their base of knowledge, best practice and the firsthand experience gives students more credibility and expertise in clinical practice. This research is necessary to prove which nursing practices work effectively and which don't in each dimension. Without research, a nursing education would not be based on concrete evidence in improving nursing practice. So this study palliative care can serve as a guide to learn about the steps in developing palliative care to community.

For extending of the knowledge management, communication among this issue in palliative care and clinicians around the world should expand the ability to share ideas about common areas of interest and to propose problems related to research implementation both in education and practice realms in palliative care model. Palliative care training methods, access to care strategies and solutions related to sustainable for palliative care model. Expanding the conversation to include an international perspective can help to identify strategies secure access to create networking, as well as develop relevant national palliative care programs. Dissemination of research related to palliative care model is a first step**.** Nursing curricula should also incorporate established principles and standards of palliative care practice and consider training in meditation relaxation techniques which this study suggested can improve the quality of life for persons with a terminal illness.

Consequence, for undergraduate level should prepare fundamental of palliative care and for graduate level should learn more in pharmacological and pathophysiological change in palliative and end of life care and also have short course training in palliative care for community.

6.3.2Recommendations for public health nursing service

The researcher found that home visiting in the community is an important component of home based palliative care. In the community, there are already established home health care agencies which have the responsibility of making home visits to sick persons with chronic diseases in the community. These caregivers need to be engaged in the development and implementation of a palliative care program in the community which may be a different focus for them. This study revealed that people living with ESRD who live with their family can be actively involved with family activities. And yet some expressed many complaints and felt hopeless and suicidal. Both the engaged and the hopeless ones benefitted from palliative care home visits. As one people living with ESRD stated: "It is very important to visit me at home and I feel happy if I have someone to talk that I need". This phenomena of need for home visits occurred both in the poor and the rich. Money did not take away the need for home visiting as they may be resistant to behavioral change based on their former high self-esteem related to their status in the community. However, in this study people from all economic circumstances benefitted from education to change behavior in order to avoid disease complications.

When applying this model, the community nurses should assess the symptoms and consider the c individual condition of people living with ESRD in order to determine which model of care identified in this study would be appropriate (Model 1 or 2).

A workshop involving key stakeholders from governmental departments, including drug regulators, legislators, policy makers, non-government organizations, academic faculty, medical doctors, nurses, pharmacists and representatives from other professional associations, is recommended. This could provide an interdisciplinary forum to raise awareness about palliative care, to define it, determine the need for it and identify opportunities and barriers to its expansion. Ultimately it is recommended that community stakeholders must become involved in a palliative care task force to lead the process of development of palliative care.

The palliative care task force should develop an agenda of tasks as a result of the recommendations of the workshop and then work towards achieving the development of a local and/or national palliative care strategy. The goal is to integrate existing community-based care with palliative care skills, knowledge and access to essential palliative care treatments and drugs.

Moreover, community nurses who are willing to reflect on and change aspects of the client-nurse relationship will ultimately be successful in the health promotion of people living with ESRD in home-based palliative care. It should be recognized that community nurses work within a specific health system context and, therefore, their practice is influenced by policies and funding models implemented at various levels of the health care system as well. Finally home based palliative care will lead to an improvement in the quality of life to people living with ESRD.

6.3.3 Recommendation for further nursing research

At the present time in Thailand, the research in home based palliative care is limited to the community and urban hospital settings. No research has been conducted on a model of home based palliative care for people living with ESRD in community. Home based palliative care provides psychological and spiritual support as well as physical symptom control. Consequently, it is a very useful setting in which to apply innovative techniques such as meditation healing exercises. The results from the practice of SKT meditation healing exercises in this study revealed that many persons at home demonstrated a high level of discipline in relation to practicing at home. Thus it is an intervention which can be easily learned and then implemented in the home setting. The positive impact of SKT6 was tested and supported in this study in terms of quality of life, satisfaction, physical symptoms and selected laboratory values.

Further research is recommended to confirm the positive impact of SKT6 in a home based palliative care model with people living with ESRD and other chronic diseases. Additional research studies should include a longer time frame in which the sustainability of the program and its economic effectiveness can also be evaluated. Ongoing research is needed to validate the model of palliative care developed in this study. It would be helpful to conduct quasi experimental designs studies in which the groups were assigned and other confounding variables could be controlled. For example, this might entail highly sophisticated analytic techniques to control for the timing of lab values and their relation to other disease markers.

Further nursing studies should include evidence-based nursing (EBN) of the palliative care model as it applies in the community. EBN is a process that founded on the process of the collection, interpretation, and integration of valid, important, and applicable research as well. In order to practice evidence based in nursing, health care providers must understand the concept of research and know how to accurately evaluate in this research. These skills are taught in nursing education and also as part of professional training as well. Research can play an important role in identifying the services in which supply matches demand but does not necessarily reflect the health needs of the population.

The last for the current situation regarding flooding in Thailand, it should also include this factors in terms of how this situation effect on people living with ESRD such as in the study of phenomenological study. A longitudinal study should be conducted to access the sustainability of HBPC model.

6.3.4 Recommendations for health policy

The serious illness of people living with ESRD underscores the need for accurate information about prognosis and treatment options for them and their families. In Thailand, public health nursing is one part of the nursing system which depends on Thai Nursing council. Palliative care is provided in the university hospitals and community hospitals in each province of Thailand. But at the community level, palliative care programs in the health centers or community level in home based palliative care of Thailand had not been developed before this study. Health policy needs to be developed to ensure that holistic palliative care is available in the community. It will be very useful if Thai nursing council becomes involved with the development of such a policy to extend palliative care to the community level.

In Thailand, there are currently health coverage reforms that are being reappraised by Thai policymakers. These policy reforms should support the development of palliative care programs but supporting the capacity and structure for providers and other community stakeholders. These policies should be incorporated by the government into all levels of health care systems and particularly at the community level. This strategy will be most effective if it involves the society through collective and social action. It will require facilitating the work of willing community nurses who currently do not have the support to develop model with current limited resources.

In conclusion, this study provided a unique contribution to the literature. It was the first intervention study in Thailand which developed and evaluated a home based palliative care program in the setting of Bangkok for people living with ESRD. The quasi-experimental study compared two groups who received home based palliative care using Mishel's framework of uncertainly as a guide. The results suggested significant improvements associated with a palliative care program which incorporated meditation healing exercises. The meditation program improved overall quality of life as well as several subscales related to quality of life and reduced symptoms and reported uncertainty among people living with ESRD. People living with ESRD and their families had experience great suffering and identified aspects of uncertainty in illness of their lives that supported the uncertainty in illness constructs. 4 steps was used to development of HBPC model; Develop relationship, understanding, mindfulness, and acceptance. Meditation healing exercise SKT6 affected to BUN, creatinine level, and quality of life. There were relationship between quality of life and Sodium, Chloride, BUN(r=-.400,-.446, p<.05) and there were relationship between BUN and physical symptom(r=.516, P<.05).

This study can provide a model for the process of the development of a community-based palliative care. It was limited in terms of the length of follow up time and the necessity of using a quasi-experimental design. Further research is needed to validate the results of a similar palliative care model in other sections of Thailand and among people living with ESRD with other chronic diseases. The ultimate goal is to improve quality of life of people suffering with terminal illness such as ESRD and to provide a home based care support for their families during this journey.

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APPENDICES

APPENDIX A

LIST OF EXPERTS

1. **ผศ.ดร. ชมพนุช โสภาจารีย์ คณะพยาบาลศาสตร์ มหาวิทยาลัยแม่ฟ้าหลวง**

2. **รศ.ดร. สิทธิชัย เอกอรมัยผล ประธานหลักสูตรศิลปศาสตรมหาบัณฑิต บัณฑิตวิทยาลัย มหาวิทยาลัยราชภัฏสวนดุสิต**

3. **พันโทหญิง ดร. วาสนา นัยพัฒน์ วิทยาลัยพยาบาลกองทัพบก**

4. **อาจารย์ สุภสิทธิ์ ศรศรี ภาควิชาการตลาด คณะบริหารธุรกิจ มหาวิทยาลัยอัสสัมชัญ**

APPENDIX B

INFORM CONSENT SHEET

หนังสือยินยอมตนให้ทำการวิจัย

โครงการวิจัยเรื่อง การพัฒนารูปแบบการพยาบาลแบบประคับประคองที่บ้านสำหรับผู้ที่อยู่กับภาวะไตวายเรื้อรัง
วันที่ให้คำยินยอม วันที่…….. เดือน ………………………… พ.ศ. 2554
ข้าพเจ้า (นาย/นาง/นางสาว) ……………………………ขอทำหนังสือนี้ไว้ต่อหัวหน้าโครงการเพื่อเป็นหลักฐานแสดงว่า

ข้อ 1. ก่อนลงนามในใบยินยอมตนให้ทำการวิจัยนี้ ข้าพเจ้าได้รับการอธิบายจากผู้วิจัยให้ทราบถึงวัตถุประสงค์ของการวิจัย วิธีการวิจัย อันตราย หรืออาการที่อาจเกิดขึ้นจากการวิจัย รวมทั้งประโยชน์ที่จะเกิดขึ้นจากการวิจัยอย่างละเอียด และมีความเข้าใจดีแล้ว

ข้อ 2. ผู้วิจัยรับรองว่าจะตอบคำถามต่างๆ ที่ข้าพเจ้าสงสัยด้วยความเต็มใจ ไม่ปิดบัง ซ่อนเร้น จนข้าพเจ้าพอใจ

ข้อ 3. ข้าพเจ้าเข้าร่วมโครงการวิจัยนี้โดยสมัครใจ และข้าพเจ้ามีสิทธิที่จะบอกเลิกการเข้าร่วมในโครงการวิจัยนี้เมื่อใดก็ได้ และการบอกเลิกการเข้าร่วมวิจัยนี้จะไม่มีผลต่อการรักษาโรคที่ข้าพเจ้าจะพึงได้รับต่อไป หรือการปฏิบัติงานของข้าพเจ้า

ข้อ 4. ผู้วิจัยรับรองว่า จะเก็บข้อมูลเฉพาะเกี่ยวกับตัวข้าพเจ้าเป็นความลับ และจะเปิดเผยได้เฉพาะในรูปที่เป็นสรุปผลการวิจัย การเปิดเผยข้อมูลเกี่ยวกับตัวข้าพเจ้าต่อหน่วยงานต่างๆที่เกี่ยวข้อง กระทำได้เฉพาะกรณีจำเป็นด้วยเหตุผลทางวิชาการเท่านั้น

ข้อ 5. ผู้วิจัยรับรองว่า หากมีข้อมูลเพิ่มเติมที่ส่งผลกระทบต่อการวิจัย ข้าพเจ้าจะได้รับการแจ้งให้ทราบทันทีโดยไม่ปิดบัง ซ่อนเร้น

ข้าพเจ้าได้อ่านข้อความข้างต้นแล้วมีความเข้าใจดีทุกประการ และได้ลงนามในใบยินยอมนี้ด้วยความเต็มใจ

ลงชื่อ …………………………………………… ผู้ยินยอม
(…………………………………………..)
ลงชื่อ …………………………………….……..… พยาน
(…………………………………………..)
ลงชื่อ ……………………………………..…..… พยาน
(…………………………………………..)

APPENDIX C

INSTRUMENT IN RESEARCH AND PERMISSION

Questionnaire

1. The Edmonton Symptom Assessment System (ESAS) for progressive symptom
2. Ferrans and Powers quality of life index ©Dialysis version– III
3. Uncertainty in illness of Mishel

Reliability Test of Instrument in this study

1. Reliability test of The Edmonton system assessment system –Revise version (ESAS-R) for progressive symptom in palliative care

Cronbach's Alpha	.87

2. Ferrans and Powers QUALITY OF LIFE INDEX©DIALYSIS VERSION – III

   2.1 Health and functioning subscale

Cronbach's Alpha	.81

   2.2 Social and economic subscale

Cronbach's Alpha	.89

   2.3 Psychological /spiritual subscale

Cronbach's Alpha	.87

   2.4 Family subscale

Cronbach's Alpha	.74

3. Uncertainty in illness

Cronbach's Alpha	.79

1. The Edmonton Symptom Assessment System (ESAS) for progressive symptom -r (Edmonton Symptom Assessment System: revised version) ฉบับภาษาไทย

โปรดวงกลมหมายเลขที่ตรงกับระดับความรู้สึกของท่านมากที่สุด ณ ขณะนี้

ไม่มีอาการปวด **มีอาการปวดรุนแรงที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่มีอาการอ่อนเพลีย/ไม่มีแรง **มีอาการอ่อนเพลีย/ไม่มีแรงมากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่มีอาการง่วงซึม/สะลึมสะลือ **มีอาการง่วงซึม/สะลึมสะลือมากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่มีอาการคลื่นไส้ **มีอาการคลื่นไส้รุนแรงที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่เบื่ออาหาร **เบื่ออาหารมากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่มีอาการเหนื่อยหอบ **มีอาการเหนื่อยหอบมากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่มีอาการซึมเศร้า **มีอาการซึมเศร้ามากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

ไม่วิตกกังวล **วิตกกังวลมากที่สุด**

0 1 2 3 4 5 6 7 8 9 10

สบายดีทั้งกายและใจ **ไม่สบายกายและใจเลย**

0 1 2 3 4 5 6 7 8 9 10

ปัญหาอื่นๆ ได้แก่ ____

0 1 2 3 4 5 6 7 8 9 10

ชื่อผู้ป่วย ______________________________ **ทำโดย** ☐ **ผู้ป่วย**
วันที่ ______________ **เวลา** ________________ ☐ **ผู้ดูแลผู้ป่วย**
☐ **อื่นๆ ได้แก่** __________

Thai version translated by Darin Jaturapatporn, MD, Montarat Chinda, MD and teame-mail: drdarinj@yahoo.com

2. Ferrans and Powers Quality of life index :Dialysis version

แบบสอบถามดัชนีคุณภาพชีวิตสำหรับการฟอกเลือด รูปแบบที่ 3 ของ เฟอร์แลนด์และเพาว์เวอร์ (Ferrans and Powers ; Dialysis version III) (ตัวอย่าง)

ส่วนที่1 : โปรดเลือกคำตอบที่บอกความพึงพอใจที่ตรงกับท่านมากที่สุดจากตัวเลือกที่ให้มาโดยวงกลมหมายเลขที่ท่านเลือก คำตอบของท่านไม่มีถูกหรือผิดใดๆทั้งสิ้น

ท่านพึงพอใจอย่างไรกับเรื่องต่อไปนี้	**ไม่พึงพอใจอย่างมาก**	**ไม่พึงพอใจปานกลาง**	**ไม่พึงพอใจ เล็กน้อย**	**พึงพอใจเล็กน้อย**	**พึงพอใจปานกลาง**	**พึงพอใจอย่างมาก**
1. สุขภาพของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
2. การดูแลสุขภาพของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
3.กำลังหรือพลังงานที่ใช้ในการทำกิจวัตรประจำวัน	**1**	**2**	**3**	**4**	**5**	**6**
4.ความสามารถในการดูแลตนเองโดยไม่ต้องอาศัยความช่วยเหลือจากผู้อื่น	**1**	**2**	**3**	**4**	**5**	**6**
5. ความเป็นไปได้ในการได้รับการเปลี่ยนไต	**1**	**2**	**3**	**4**	**5**	**6**
6.การเปลี่ยนแปลงในชีวิตหลังจากมีภาวะไตล้มเหลวหรือไตวายเช่นการควบคุมอาหาร หรือการจัดเวลาในการฟอกไต	**1**	**2**	**3**	**4**	**5**	**6**
7.ความสามารถในการควบคุมการดำเนินชีวิตของตนเองระยะนี้	**1**	**2**	**3**	**4**	**5**	**6**
8.โอกาสในการมีชีวิตอยู่นานเท่าที่ท่านต้องการ	**1**	**2**	**3**	**4**	**5**	**6**
9.สุขภาพของคนในครอบครัว	**1**	**2**	**3**	**4**	**5**	**6**
10.บุตรของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
11ความสุขของครอบครัวของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
12.ความสุขทางเพศของท่าน	**1**	**2**	**3**	**4**	**5**	**6**

ท่านพึงพอใจอย่างไรกับเรื่องต่อไปนี้	**ไม่พึงพอใจอย่างมาก**	**ไม่พึงพอใจปานกลาง**	**ไม่พึงพอใจ เล็ กน้อย**	**พึงพอใจเล็กน้อย**	**พึงพอใจปานกลาง**	**พึงพอใจอย่างมาก**
30.ความสำเร็จในชีวิตส่วนตัวตามเป้าหมายของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
31.ความสุขในชีวิตของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
32.ภาพรวมของชีวิตของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
33.ภาพลักษณ์ หรือลักษณะร่างกายของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
34.ความพึงพอใจตนเองในภาพรวม	**1**	**2**	**3**	**4**	**5**	**6**

ส่วนที่ 2 : โปรดเลือกคำตอบที่บอกความพึงพอใจที่อธิบายถึงความสำคัญต่อท่าน ที่ตรงมากที่สุดจากตัวเลือกที่ให้มาโดยวงกลมหมายเลขที่ท่านเลือก คำตอบของท่านไม่มีถูกหรือผิดใดๆทั้งสิ้น (ตัวอย่าง)

เรื่องต่อไปนี้มีความสำคัญต่อท่านอย่างไร	**ไม่มีความสำคัญ**	**ไม่มีความสำคัญ**	**ไม่ค่อยมี**	**สำคัญเล็กน้อย**	**สำคัญปานกลาง**	**สำคัญมาก**
1. สุขภาพของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
2. การดูแลสุขภาพของท่าน	**1**	**2**	**3**	**4**	**5**	**6**
3.ได้รับกำลังหรือพลังงานเพียงพอในการทำกิจวัตรประจำวัน	**1**	**2**	**3**	**4**	**5**	**6**
4.ความสามารถในการดูแลตนเองโดยไม่ต้องอาศัยความช่วยเหลือจากผู้อื่น	**1**	**2**	**3**	**4**	**5**	**6**
5. ความเป็นไปได้ในการได้รับการเปลี่ยนไต	**1**	**2**	**3**	**4**	**5**	**6**
17.ความสามารถของท่านในการรับผิดชอบครอบครัว	**1**	**2**	**3**	**4**	**5**	**6**
18.การเป็นประโยชน์หรือสามารถทำประโยชน์ต่อผู้อื่น	**1**	**2**	**3**	**4**	**5**	**6**
19.ความกังวลในชีวิตของท่าน	**1**	**2**	**3**	**4**	**5**	**6**

3. MISHEL UNCERTAINTY IN ILLNESS SCALE – COMMUNITY FORM

INSTRUCTIONS: example of the questions

Please read each statement. Take your time and think about what each statement says. Then place a "X" under the column that most closely measures how you are feeling TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel, then mark under "Undecided" for that statement. Please respond to every statement**.**

1. I don't know what is wrong with me.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
_______	_______	_______	_______	_______

2. I have a lot of questions without answers.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
_______	_______	_______	_______	_______

3. I am unsure if my illness is getting better or worse.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
_______	_______	_______	_______	_______

4. It is unclear how bad my pain will be.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
_______	_______	_______	_______	_______

5. **The explanations they give about my condition seem hazy to me.**

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree

23.The doctors and nurses use everyday language so I can understand what they are saying.

Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
(5)	(4)	(3)	(2)	(1)
_______	_______	_______	_______	_______

ตัวอย่างแบบสอบถามความรู้สึกไม่แน่นอนในความเจ็บป่วย

คำชี้แจง : โปรดพิจารณาข้อความต่อไปนี้แต่ละข้อ แล้วทำเครื่องหมาย × ลงในช่องที่ตรงกับความรู้สึกที่แท้จริงของท่านมากที่สุด**ในช่วงสัปดาห์ที่ผ่านมารวมทั้งวันนี้** โดยขอให้ท่านเลือกตอบเพียงคำตอบเดียวและกรุณาตอบทุกข้อ

ข้อคำถาม	ตรงกับความรู้สึกมากที่สุด	ตรงกับความรู้สึกมาก	ไม่แน่ใจ	ไม่ตรงกับความรู้สึกมาก	ไม่ตรงกับความรู้สึกมากที่สุด
1. ฉันไม่รู้ว่าฉันป่วยเป็นอะไร					
2. ฉันมีคำถามมากมายที่หาคำตอบไม่ได้					
3. ฉันไม่แน่ใจว่า อาการเจ็บป่วยของฉันจะดีขึ้นหรือแย่ลง					
4. ฉันไม่แน่ใจว่า ฉันจะต้องเจ็บป่วยอีกมากน้อยเพียงใด					
5. ฉันเข้าใจคำอธิบายของหมอและพยาบาลในเรื่องความเจ็บป่วยของฉัน					
6. ฉันเข้าใจจุดมุ่งหมายของการรักษาที่ได้รับอย่างชัดเจน					
7. อาการของฉันยังคงเปลี่ยนแปลงตลอดเวลาจนไม่สามารถคาดการณ์อะไรได้					

……………….23.

ตัวอย่าง ตารางฝึกปฏิบัติ สมาธิเพื่อการเยียวยา ด้วยเทคนิคที่1 และ 6

ชื่อ- สกุล………………………………………………………………………………..

เริ่มฝึกวันที่………เดือน………………….พ.ศ.2554 ถึงวันที่ ……..เดือน…………..พ.ศ. 2554

ในช่องเวลาที่ฝึกโปรดทำเครื่องหมายในเวลาที่ท่านฝึก

เดือนที่/สัปดาห์ที่	วัน/วันที่	เวลาที่ฝึก	ระยะเวลาที่ฝึก ชั่วโมง/นาที	หมายเหตุ
…./1	จันทร์ที่…	เช้า, กลางวัน, เย็น, ก่อนนอน		
	อังคารที่….	เช้า, กลางวัน, เย็น, ก่อนนอน		
	พุธที่…..	เช้า, กลางวัน, เย็น, ก่อนนอน		
	พฤหัสที่…	เช้า, กลางวัน, เย็น, ก่อนนอน		
	ศุกร์ที่…	เช้า, กลางวัน, เย็น, ก่อนนอน ………….. …………		

Permission of Instruments

1. Permission to use the Quality of Life Index

From: **Carol Ferrans** (cferrans@uic.edu)

Sent: Sat 9/25/10 4:09 AM

To: jintana artsuntea (jintasun@hotmail.com)

Dear Jintana Artsanthia,

Thank you for your email and your interest in the QLI. I am happy to grant you permission to use the Quality of Life Index for your study. I wish you every success with your doctoral dissertation.

Sincerely,

Carol Ferrans

Carol Estwing Ferrans, PhD, RN, FAAN

Professor and Associate Dean for Research

Co-Director, Center for Excellence in Eliminating Health Disparities

Co-Director, Community Engagement and Outreach Core, CCTS

College of Nursing (M/C 802), Room 606

845 S. Damen Avenue

Chicago, IL 60612

phone 312-996-8445

fax 312-996-4979

email cferrans@uic.edu<mailto:cferrans@uic.edu>

QLI website www.uic.edu/orgs/qli<http://www.uic.edu/orgs/qli>

2. Permission to use ESAS in Thai language From Dr.Darin Jaturapatporn

To jintana artsuntea From: **Darin Jaturapatporn** (drdarinj@yahoo.com)

Sent: Mon 10/18/10 6:51 AM

To: jintana artsuntea (jintasun@hotmail.com)

สวัสดีค่ะคุณจินตนา

ด้วยความยินดีค่ะ แต่อนุญาตได้เฉพาะฉบับภาษาไทย เพราะฉบับภาษาอังกฤษไม่ได้เป็นเจ้าของค่ะส่งฉบับ final มาให้ใช้ด้วยค่ะขอให้ทำ dissertation สำเร็จด้วยดีนะคะ

หมอเป้ (พญ ดาริน จตุรภัทรพร)

Permission in ESAS in English language

To jintana artsuntea, Sharon Watanabe, 'Cheryl Nekolaichuk'

From: **Cheryl Nekolaichuk** (Cheryl.Nekolaichuk@covenanthealth.ca)

Sent: Wed 10/20/10 4:52 AM

To: jintana artsuntea (jintasun@hotmail.com)

Cc: Sharon Watanabe (Sharon.Watanabe2@albertahealthservices.ca); 'Cheryl Nekolaichuk' (cln1@ualberta.ca)

Dear Jintana,

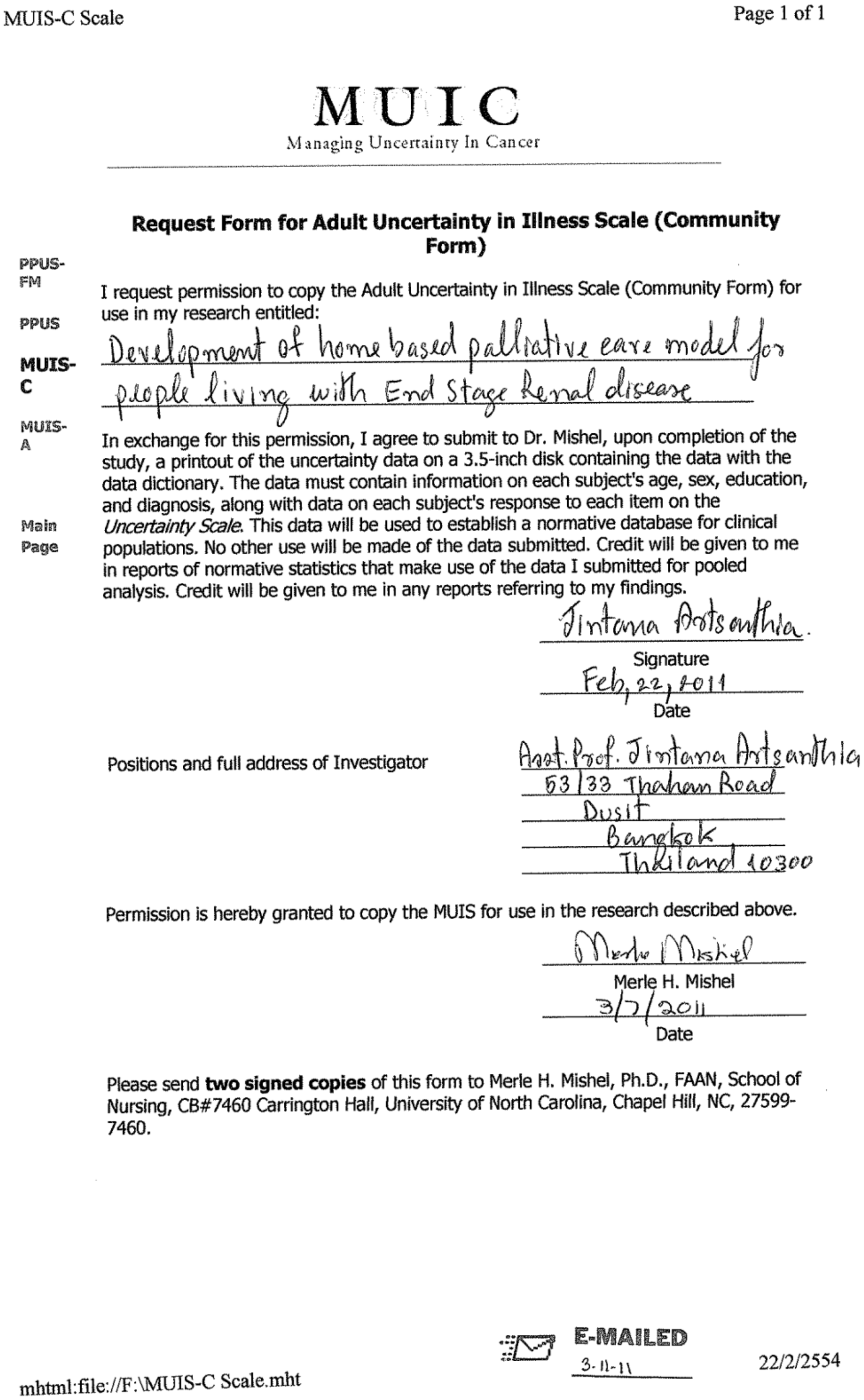
Thank you for your message and your interest in using the ESAS in your research. It is fine for you to use the tool, as long as you reference the source. I have also attached a copy of a recent manuscript (in press) introducing a revised version of the ESAS, the ESAS-r. We are planning to replace the ESAS with the ESAS-r in our clinical programs in January, 2011. I have copied Dr. Watanabe on this correspondence as we have been working together on developing the ESAS-r. You may want to consider using this revised version in your research.

Good luck with your doctoral study,

Best wishes,

Cheryl

3. Uncertainty in Illness of Mishel



MUIS-C Scale Page 1 of 1

MUIC
Managing Uncertainty In Cancer

PPUS-FM

PPUS

MUIS-C

MUIS-A

Main Page

Request Form for Adult Uncertainty in Illness Scale (Community Form)

I request permission to copy the Adult Uncertainty in Illness Scale (Community Form) for use in my research entitled:

Development of home based palliative care model for people living with End Stage Renal disease

In exchange for this permission, I agree to submit to Dr. Mishel, upon completion of the study, a printout of the uncertainty data on a 3.5-inch disk containing the data with the data dictionary. The data must contain information on each subject's age, sex, education, and diagnosis, along with data on each subject's response to each item on the *Uncertainty Scale*. This data will be used to establish a normative database for clinical populations. No other use will be made of the data submitted. Credit will be given to me in reports of normative statistics that make use of the data I submitted for pooled analysis. Credit will be given to me in any reports referring to my findings.

Jintana Artsanthia.
Signature

Feb, 22, 2011
Date

Positions and full address of Investigator

Asst. Prof. Jintana Artsanthia
53/33 Thahan Road
Dusit
Bangkok,
Thailand 10300

Permission is hereby granted to copy the MUIS for use in the research described above.

Merle Mishel
Merle H. Mishel

3/7/2011
Date

Please send **two signed copies** of this form to Merle H. Mishel, Ph.D., FAAN, School of Nursing, CB#7460 Carrington Hall, University of North Carolina, Chapel Hill, NC, 27599-7460.

E-MAILED
3-11-11

mhtml:file://F:\MUIS-C Scale.mht 22/2/2554

APPENDIX D

MANUAL OF PRACTICE IN HOME BASED PALLIATIVE CARE AND EVALUATION IN SATISFACTION OF HOME BASED PALLIATIVE CARE

คู่มือปฏิบัติการดูแลแบบประคับประคองที่บ้าน

โดย

ศูนย์บริการสาธารณสุขที่ 23,55 และนักศึกษาปริญญาเอก
ภาควิชาการพยาบาลสาธารณสุข มหาวิทยาลัยมหิดล

คำนำ

ในการจัดทำคู่มือการดูแลแบบประคับประคองที่บ้านฉบับนี้เพื่อเป็นแนวทางในการให้การดูแลแบบประคับประคองในชุมชนสำหรับผู้ที่มีภาวะไตวายเรื้อรังระยะสุดท้าย(End stage renal disease) และโรคเรื้อรังที่รักษาไม่หายขาดอื่นๆ การได้มาซึ่งคู่มือฉบับนี้ได้จัดการประชุมกลุ่ม(Focus group)จากผู้ป่วย ญาติ เจ้าหน้าที่สาธารณสุข แพทย์ พยาบาล ให้ทราบปัญหา ความต้องการ ปัญหา อุปสรรค ความเป็นไปได้ในการจัดการดูแลแบบประคับประคอง ฝึกอบรมการดูแลแบบประคับประคอง และจัดทำคู่มือการดูแลแบบประคับประคองนี้ขึ้น

คู่มือฉบับนี้ได้ให้รายละเอียดถึงบทบาทของทีมสหสาขาวิชาชีพในงานการดูแลแบบประคับประคองที่บ้านโดยกำหนดการดูแลที่เป็นส่วนหนึ่งของกิจกรรมการเยี่ยมบ้าน ที่การดูแลมีรูปแบบเฉพาะกับผู้ป่วยที่อยู่ในภาวะคุกคามจากโรคและความทุกข์จากโรคจนถึงระยะสุดท้ายของชีวิต

จึงหวังว่าคู่มือนี้จะมีประโยชน์เป็นแนวทางในการให้บริการการดูแลแบบประคับประคองที่บ้านได้จนเกิดประโยชน์กับผู้ป่วย ครอบครัว ชุมชน หน่วยงานทางสาธารณสุข

ทีมการดูแลแบบประคับประคองศูนย์บริการ
สาธารณสุขที่23, 55 และนักศึกษาปริญญาเอกสาขา
การพยาบาลสาธารณสุข คณะสาธารณสุขศาสตร์
มหาวิทยาลัยมหิดล

สารบัญ

ตัวอย่าง

คู่มือการพยาบาลแบบประคับประคองที่บ้านสำหรับผู้ป่วยโรคเรื้อรัง(โรคไตวายเรื้อรังระยะสุดท้าย)

การดูแลผู้ป่วยแบบประคับประคอง (Palliative Care) หมายถึง แนวทางปฏิบัติในการดูแลแบบประคับประคอง ที่มุ่งให้ผู้ป่วยมีความสุขสบาย โดยให้ความสำคัญต่อศักดิ์ศรีของความเป็นมนุษย์ ไม่พยายามเร่งรัดหรือเหนี่ยวรั้งการตาย พัฒนาคุณภาพชีวิตของผู้ป่วยและญาติเพื่อเผชิญกับปัญหา อันเกี่ยวเนื่องกับความเจ็บป่วยที่คุกคามชีวิต ผ่านกระบวนการป้องกันและบรรเทาความทุกข์ทรมาน โดยใช้การตรวจพบแต่เนิ่น ๆ การประเมินและการรักษาอาการเจ็บป่วยครอบคลุมทั้งด้านร่างกาย จิตใจ สังคมและจิตวิญญาณ

เกณฑ์การคัดเลือกผู้ป่วยเข้ารับการดูแลแบบประคับประคองที่บ้าน

การจัดประเภทการดูแลแบบประคับประคองที่บ้าน

รูปแบบที่1 ผู้ป่วยไตวายเรื้อรังระยะสุดท้าย(ระยะโรคไม่อยู่ในภาวะวิกฤตของชีวิต)

เกณฑ์การคัดเลือก

1. เป็นผู้ป่วยไตวายเรื้อรังระยะสุดท้ายได้รับการรักษาโดยการฟอกเลือดด้วยเครื่องไตเทียม หรือ ผ่านทางหน้าท้อง (peritonium dialysis)หรือ
2. ผู้ป่วยโรคเรื้อรังรักษาไม่หายขาด หรือโรคเรื้อรังอื่นและยังช่วยเหลือตนเองได้ สามารถรับรู้และสื่อสารได้
3. เป็นผู้ป่วยที่เคยได้รับการดูแลรักษาจากแพทย์เฉพาะทางอย่างต่อเนื่องมาเป็นเวลานานจากการบำบัดรักษาโรคให้หายขาด มาเป็นเพียงการดูแลรักษาตามอาการ เพื่อให้สามารถใช้ชีวิตที่เหลืออย่างมีคุณภาพชีวิตที่ดี ทั้งนี้เนื่องมาจากโรคที่ป่วยอยู่ (เช่นมะเร็ง) ได้ลุกลามไปมากแล้วให้สามารถกลับไปใช้ชีวิตช่วงสุดท้ายที่บ้าน
4. ผู้ป่วย ครอบครัว และคนใกล้ชิด เข้าใจถึงสภาพของโรคที่ป่วยอยู่และต้องการกลับไปใช้ชีวิตที่บ้าน โดยครอบครัวมีความพร้อมที่จะให้การดูแลผู้ป่วยได้ตลอดเวลา
5. ผู้ป่วยที่ได้รับการส่งต่อจากสถาบันการแพทย์อื่น โดยโรคที่เป็นอยู่ได้ลุกลามไปเกินกว่าจะให้การบำบัดใดๆได้เป็นการเฉพาะ

การดูแลแบบประคับประคองที่บ้านรูปแบบที่1ระยะโรคไม่อยู่ในภาวะวิกฤตของชีวิต

กิจกรรมการดูแลแบบประคับประคอง

ความถี่ในการเยี่ยมติดตามดูแล 1 ครั้งต่อสัปดาห์

การเยี่ยมบ้านHBP ครั้งที่1 : สร้างสัมพันธภาพกับผู้ป่วยครอบครัวและชุมชน อธิบายวัตถุประสงค์การดูแลแบบประคับประคองเพื่อให้ผู้ป่วยมีคุณภาพชีวิตที่ดีที่บ้านและวัดความพึงพอใจของผู้ป่วยและครอบครัวโดยแบบสอบถามก่อนการเริ่มการดูแลแบบประคับประคองที่บ้าน……………………..

ตัวอย่างแบบประเมินความพึงพอใจของผู้ป่วยต่อการดูแลผู้ป่วยแบบประคับประคองที่บ้าน

กิจกรรม	มาก	ปานกลาง	น้อย
1.ด้านการทำให้เกิดความอุ่นใจ 1.1.ท่านได้รับทราบวัตถุประสงค์ของการรักษา ดูแลแบบประคับประคอง อาการเปลี่ยนแปลงของตนเองจากทีมที่ให้การดูแล 1.2. ท่านได้มีส่วนร่วมในการวางแผนและตัดสินใจในการดูแลตนเอง 1.3. ท่านพึงพอใจในการดูแลด้านร่างกายอย่างเหมาะสม 1.4.ทีมรักษาพยาบาลที่บ้านทำให้ท่านรู้สึกอบอุ่นใจและไว้วางใจ 1.5. ท่านได้รับความสะดวกและความพึงพอใจในการรับคำแนะนำด้านต่างๆที่ทำให้สุขสบายขึ้นจากอาการของโรค 1.6 ท่านได้รับการตอบสนองด้านจิตใจตรงกับความต้องการ			
2.ด้านที่ทำให้เกิดความเข้าใจ 2.1 ท่านมีความเข้าใจในเรื่องโรคที่เป็นอย่างดี 2.2 ท่านเข้าใจการเปลี่ยนแปลงและความรุกรานของโรค 2.3 ท่านเข้าใจในวัตถุประสงค์การดูแลแบบประคับประคองที่บ้าน 2.4 ท่านเข้าใจในธรรมชาติของชีวิต 2.5 ท่านเข้าใจในสิ่งที่ควรทำเพื่ออนาคตของตนเองในการเตรียมสิ่งต่างๆถ้าวันข้างหน้าต้องจากลา 2.6ท่านมีโอกาสซักถาม ระบาย ได้เป็นอย่างดี			
3.ด้านการทำใจ 3.1 ท่านมีการทำใจเพื่อเตรียมรับกับเหตุการณ์ที่ไม่คาดคิด 3.2 ท่านรู้สึกไม่กังวลกับชีวิตข้างหน้ารู้สึกปล่อยวาง 3.3 ท่านเตรียมตัวของท่านเสมอ และมีการทำในสิ่งที่อยากทำในชีวิตของท่าน 3.4ท่านได้ทำใจเกี่ยวกับธรรมชาติของชีวิต ของโรคที่เป็นจนถึงการเตรียมตัวในวาระท้ายของชีวิต 3.5 ท่านได้รับคำแนะนำในการผ่อนคลายและจิตใจสงบ			

APPENDIX E

LIVING WILL

หนังสือแสดงเจตนาไม่ประสงค์จะรับบริการทางสุขภาพ(รูปแบบที่1)

วันที่ ……………………………………………

ข้าพเจ้า (ชื่อ-นามสกุล) ....อายุ........ปี

บัตรประชาชนเลขที่ ....ที่อยู่ที่ติดต่อได้...

เบอร์โทรศัพท์ .... เบอร์ที่ทำงาน..

ขณะทำหนังสือฉบับนี้ ข้าพเจ้ามีสติสัมปชัญญะบริบูรณ์ และมีความประสงค์ที่จะแสดงเจตนาที่จะขอให้วาระสุดท้ายของชีวิตเป็นไปอย่างสงบตามธรรมชาติ ไม่ต้องการให้มีการใช้เครื่องมือใดๆ กับข้าพเจ้า เพื่อยืดการมีชีวิตออกไปโดยไม่จำเป็นและเป็นการสูญเปล่า

○ เมื่อข้าพเจ้าตกอยู่ในวาระสุดท้ายของชีวิต หรือ

○ เมื่อข้าพเจ้าได้รับทุกข์ทรมานจากการบาดเจ็บหรือโรคที่ไม่อาจรักษาให้หายได้

ข้าพเจ้าขอปฏิเสธการรักษาดังต่อไปนี้ (เลือกได้มากกว่า 1 ข้อ)

○ 1. การเจาะคอเพื่อใส่ท่อช่วยหายใจ รวมทั้งการถอดท่อช่วยหายใจ

○ 2. การให้สารอาหารและน้ำทางสายยาง รวมทั้งถอดสายยาง

○ 3. การเข้ารักษาในห้องไอ.ซี.ยู (I.C.U.)

○ 4. การกระตุ้นระบบไหลเวียน และ ขบวนการฟื้นชีพเมื่อหัวใจหยุด

○ 5.การรักษาโรคแทรกซ้อนด้วยยาหรือวิธีการรักษาใดๆ

○ 6. อื่นๆที่ต้องการระบุ ....

ทั้งนี้ ข้าพเจ้า ขอเลือกสถานที่ ในการรักษาพยาบาลแบบประคับประคอง จนถึงวาระสุดท้ายของชีวิต

○ ที่บ้าน ○ ที่โรงพยาบาล

ลงชื่อ ………………………………………….ผู้แสดงเจตนา

( )

ลงชื่อ. ……………………………………….. พยาน ลงชื่อ……………………….พยาน

( ) ( )

APPENDIX F

EXAMPLE OF PHOTOS IN DATA COLLECTION

These photos received permission from participants

Activities: Focus group and in-depth interviews

Situation analysis: Focus group, Community nurse and health volunteer in the project of home based palliative care model

Some of palliative care nurses in home
Based palliative care model

Health center

Training meditation healing exercise SKT in palliative care model

Training palliative care and meditation healing exercise for health volunteers

Assessment from questionnaires

Discussion in cases with medical doctor

Symptom management

Clapping for draining secretion of people living with ESRD

Suction at home

Join with health volunteer in Community

Taught at home in preparing gauze for dressing wound

Demonstrate of exercise to reduce Complication of people living with ESRD

Medical doctor and palliative care team visited the cases

Home based palliative care

Home based palliative care

Finally, people living with ESRD still have quality of life in their environment with grandchild

In qualitative study; Intervention in hemodialysis ward

End of life care:

When the end of life was coming

BIOGRAPHY

NAME	Jintana Artsanthia
DATE OF BIRTH	January, 28, 1967
PLACE OF BIRTH	Prachinburi
INSTITUTIONS ATTENED	Bachelor Degree in Nursing Mahidol University ,1987-1990 Master Degree in Public Health , Mahidol University,1994-1996
RESEARCH GRANTS	Saint Louis College
HOME ADDRESS	53/33 Thahan Road , Dusit ,Bangkok 10300 E-mail:Jintasun@hotmail.com
EMPLOYMENT ADDRESS	215/4 Sathorn Road , Yannawa ,Bangkok ,10120
PUBLICATION/ PRESENTATION	
	Poster Presentation at Austin, USA. Comparison of study tracheostomy wound dressing between povidone-iodine and acetic acid.
	Oral Presentation at Singapore : Asia pacific nurses convention globalization ; Efficiency of self-care by using natural health program for health promotion of controlling blood sugar in diabetic patients.