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UNIVERSITY OF SOUTHAMPTON

FACULTY OF HEALTH SCIENCES

**Experiences and health care needs of older people with End Stage Renal
Disease managed without dialysis in Thailand during the last year of life**

by

Wanicha Pungchompoo

Thesis for the degree of Doctor in Clinical Practice

September 2013

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF HEALTH SCIENCES

Thesis for the degree of Doctor in Clinical Practice

**EXPERIENCES AND HEALTH CARE NEEDS OF OLDER PEOPLE WITH END
STAGE RENAL DISEASE MANAGED WITHOUT DIALYSIS IN THAILAND
DURING THE LAST YEAR OF LIFE**

By Wanicha Pungchompoo

There is a growing population of elderly patients with End Stage Renal Disease (ESRD) managed without dialysis in Thailand, and as yet services have not been developed to specifically respond to the needs of this group. As a consequence this population are likely to have unmet needs with respect to health care, and suffer from symptoms that could be better managed. In order to develop palliative care aimed at improving the quality of life of this group in Thailand research is required about patients' experiences, symptom burden and health care needs as the end of life approaches.

Objectives: Phase 1) to explore experiences and health care needs during the last year of life among older people with ESRD managed without dialysis from the perspective of bereaved carers; Phase 2) to develop/adapt the VOICES (View of Informal Carers – Evaluation of Service) questionnaire for use in Thailand; and Phase 3) to conduct a pilot survey to test and refine the VOICES questionnaire. A mixed-method exploratory design underpinned the approach to this study.

Phase 1: Retrospective, exploratory semi-structured interviews and purposive sampling were used to collect data from 12 bereaved relatives of patients who had attended two hospitals in one region in Thailand. Interviews were digitally recorded, transcribed and analysed using framework analysis, and results used to develop the VOICES Thai prototype. The experiences and health care needs of older people with ESRD managed without dialysis were explored under four main themes, including: 1) symptom experiences; 2) impacts; 3) symptom management; and 4) health care needs and utilisation. Findings confirmed patients' needs were not being met, and the need to develop approaches to symptom management (pain and breathlessness) at home, health education, and psychological and spiritual support at the end of life.

Phase 2: A cognitive interviewing technique was implemented, using two cycles of data collection with a sample of 10 bereaved carers and a prototype of the Thai VOICES questionnaire. These data were analysed using content analysis. A culturally specific questionnaire was generated during this second phase and issues with questionnaire design rectified.

Phase 3: A small-scale pilot survey of an interviewer-administered Thai-VOICES questionnaire with a sample of 20 bereaved carers was conducted. Two main factors affected response rate: method of recruitment and interview method. The telephone interview was considered to be the best choice for conducting a national survey in the Thai context. The resulting VOICES-ESRD questionnaire can now be used to generate evidence about the needs of patients with ESRD in Thailand and inform future policy and practice.

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DECLARATION OF AUTHORSHIP

I, Wanicha Pungchompoo declare that this thesis entitled

Experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life

and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Either none of this work has been published before submission, or parts of this work have been published as: [please list references]

Signed:

Date:.....

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Definitions

- End-stage renal disease (ESRD)** ESRD is defined as irreversible decline in a person's own kidney function, which is severe enough to be fatal in the absence of dialysis or transplantation. ESRD is included under stage 5, where it refers to individuals with an estimated glomerular filtration rate of less than 15 mL per minute per 1.73 m² body surface area, or those requiring dialysis (Levey 2003; Hunt *et al.* 2013).
- Conservative management (non-dialysis)** It refers to management without dialysis. It includes active management, such as, pain and symptom management, psychological care, social and family support, and practical help in order to optimize quality of life and relieve suffering (Murtagh *et al.* 2009a). In Thailand, the management without dialysis includes restricted fluid intake, high-dose bicarbonate, ferrous sulphate, blood transfusion, home visit and hospital admission, if required and available for ESRD patients who are unable, waiting or refuse to receive dialysis treatment or kidney transplantation (Teerawattananon *et al.* 2007).
- Older people** In this research the term older population or elderly is used to refer to persons age 60 and above. The definition adopted in age specific official policies and programs in Thailand. Moreover, age 60 is used by the United Nations and other key international organizations studying epidemiological aspects of older people and has been adopted by both the first and second World Assemblies on Aging as the starting point of the older age span (Knodel & Chayovan 2008).
- The VOICES (Views of Informal Carers- Evaluation of Services) questionnaire** The questionnaire was developed by Addington-Hall *et al.* (1995) VOICES is a survey questionnaire designed to be completed by bereaved informal carers and consists of eight sections including help at home, general practitioner care, district nursing care, symptoms and treatment, other health care received, care received in the last week and circumstances surrounding the patient's death (Burt *et al.* 2009).

Abbreviations

ESRD	End Stage Renal Disease
CKD	Chronic Kidney Disease
GFR	Glomerular Filtration Rate
HD	Haemodialysis
NHS	Nation Health Service
NHF	National Kidney Federation
PD	Peritoneal dialysis
RRT	Renal Replacement Therapy
KT	Kidney Transplantation
QOL	Quality of Life
TRT	Thailand Renal Replacement Therapy
TH	Thailand
UK	United Kingdom
VOICES	Views of Informal Carers-Evaluation of Services
WHO	World Health Organization
K/DOQI	Kidney Disease Outcome Quality
UC	Universal Coverage
CSMBS	Civil Servant Medical Benefit Scheme
SHI	The Social Health Insurance
NHSO	The National Health Security Office
MOPH	The Ministry of Public Health
QALY	Quality-adjusted life-year
CASP	The Critical Appraisal Skills Program
PDQ	Personal Data Questionnaire
IR-ESRD	Illness Representative of End Stage Renal Disease
HSMSEQ	Haemodialysis Self-management Self-efficacy Questionnaire
SF-36	The medical Outcome Short Form 36
SD	Standard Deviation
MDRD	The Modification of Diet in Renal Disease
NDT	Non-Dialysis Treatment

CCI	Charlson Comorbidity Index
SCG	The Stroke Comorbidity Grade
MSAS-SF	The Memorial Symptom Assessment Scale Short Form
FACIT-Sp	The Functional Assessment of Chronic Illness Therapy Spiritual Scale
DPCELQ	The Dialysis Patients Choices at the End of Life Questionnaire
GP	General Physician
IRB	Institutional Review Board of Faculty of Nursing
CMU	Chiang Mai University
DKD	Diabetic Kidney Disease
GPs	General Practitioners

Chapter 1: Introduction and rationale for the study

End-stage renal disease (ESRD) causes health problems for patients all over the world (Santos 2010), and the number of patients with this condition is increasing rapidly. In Thailand, the epidemiology of renal disease is poorly understood, and the health care workforce and treatment facilities are inadequate for the patient caseload (Sitprija 2003). In particular, elderly patients constitute the biggest ESRD population in Thailand. Curtin *et al.* (2004) stated that the elderly experience more complications than other age groups since their health is at continual risk of deterioration because of the presence of co-morbidities. An emerging issue is that dialysis may not be offered in the first place, or it may be withdrawn later as part of a conservative management strategy, which focuses on quality of life as the end of life approaches. Symptom burden and inadequate health service provision are important issues faced by patients in Thailand. However, there are few published studies related to the symptom experiences and health care needs of patients who are not receiving dialysis. Due to this inadequate evidence base, there is a lack of understanding about how much these patients might suffer whilst being managed without dialysis, and what kind of health services they might benefit from before death.

I am a clinical researcher and an experienced nurse working in renal services in Thailand. I am committed to improving the quality of patient care for patients who are managed without dialysis. Based on my experiences and evidence in Thailand, many of these patients suffer with unmanaged symptoms at home and need comprehensive health care provision. Hence, I was interested in exploring experiences and health care needs during the last year of life among older people with ESRD managed without dialysis in Thailand, from the perspective of their bereaved relatives. In this study I aimed to adapt a pre-existing questionnaire that was developed for use in the United Kingdom to capture the needs of patients at the end of life from proxy reports (the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire); (Addington-Hall *et al.* 1995; Addington-Hall & O'Callaghan 2009; Burt *et al.* 2010; Hunt *et*

al. 2011). I set out to adapt this instrument with a view to conducting a large scale survey with a Thai population.

The aims of the study were achieved using a mixed-method exploratory sequential design, specifically an instrument development model (Creswell & Plano Clark 2007) comprising three phases. The first phase involved a qualitative exploration of the experiences and health care needs of older people with ESRD being managed without dialysis, from the perspective of bereaved family carers. Framework analysis was applied to analyse the resulting qualitative data. From this initial exploration, the findings were used to develop a VOICES (View of Informal Carers – Evaluation of Service) – ESRD/Thai questionnaire. Two cycles of cognitive interviews (using a think-aloud technique) were conducted to develop the instrument during the second phase. Then, a small-scale pilot survey of the new instrument was undertaken in the third phase. The methods used and the findings from this study make up this Doctorate in Clinical Practice (DClinP) thesis, which is divided into eleven chapters as described below:

Chapters 1 and 2 provide the introduction, rationale and background. Chapter 3 provided a critical literature review as supporting evidence for the study.

Chapter 4 presents an argument for the choice of methodology and methods (a mixed-methods exploratory sequential design) used to pursue the research objectives.

Chapters 5 and 6 (Phase I) present the methods used in the qualitative study and the findings from the framework analysis of symptom experiences and health care needs among older ESRD patients managed without dialysis in Thailand.

Chapters 7 and 8 (Phase II) report the process of, and the findings from, the development of the VOICES-ESRD/Thai questionnaire by the application of a cognitive interview technique.

Chapters 9 and 10 (Phase III) are focused on the methodology of the small-scale pilot survey that was carried out in order to test the questionnaire. The results chapter (Chapter 10) reflects on the methods of recruitment and administration, examines response rates, classifies instances of missing data, and identifies redundant data items in order to inform further refinements to the VOICES-ESRD/Thai questionnaire for use in a larger survey.

Finally, the key outcomes of the research and some strengths and limitations in relation to the three phases of the study are discussed in Chapter 11. Specific clinical implications and research recommendations are also set out.

Chapter 2: Background of the study

2.1 Introduction

This chapter will discuss the prevalence of ESRD worldwide and in Thailand, the consequences of ESRD, palliative care in the context of ESRD, management approaches to ESRD, and finally the health care system and policy context for ESRD in Thailand. The last section is provided so an international audience can appreciate the backdrop to the study which was conducted in the Thai context.

2.2 Size of population with ESRD worldwide and in Thailand

According to US Renal Data System, the size of the population living with end-stage renal disease is growing steadily (Schieppati & Remuzzi 2005). A World Health Organisation report in 2002 stated kidney and urinary tract diseases contribute to the global burden of disease, with approximately 850,000 deaths every year and 15,010,167 disability-adjusted life years (World Health Organization. 2002; Schieppati & Remuzzi 2005). The number of cases of end-stage renal disease (ESRD) worldwide has increased by 20% from 970,436 in 1999 to 1,172,655 in 2004 (Chen *et al.* 2009). In the United Kingdom, the number of patients with renal disease will have increased from approximately 30,000 in 2000 to between 42,000 and 51,000 in 2010 (Noble *et al.* 2008). The report on 'Renal Replacement Therapy' in Thailand in 2007 estimated the total number of patients currently not receiving dialysis treatment or on a waiting list for treatment in Thailand was more than 79,371 cases (Praditpornsilpa 2007). The mean and medium age of ESRD patients in Thailand was 58 years and 59 years respectively and the proportion aged 60 years and above 48.9% (Praditpornsilpa 2007). As the population lives longer and the proportion of older people increases, so the prevalence of ESRD increases (Murtagh *et al.* 2008). ESRD disease is a common health problem in older people, which generally impacts upon their health and also their quality of life (Curtin *et al.* 2004). A study by Munshi *et al.* (2001a) showed that the older population is the largest growing group of ESRD patients and the very elderly who are managed

with Renal Replacement Therapy (RRT) have a very poor outcome leading to increased morbidity and mortality rates of ESRD older populations.

2.3 ESRD definition, incidence and treatment

End-stage renal disease (ESRD) is defined as an irreversible decline in a person's own kidney function, which is severe enough to be fatal in the absence of dialysis or transplantation (Levey 2003). ESRD is included under stage 5 of the National Kidney Foundation Kidney Disease Outcomes Quality Initiative classification (NKF/K/DOQI) of chronic kidney disease (CKD), where it refers to individuals with an estimated glomerular filtration rate less than 15 ml per minute per 1.73 m² body surface area, or those requiring dialysis irrespective of glomerular filtration rate (National Kidney Foundation/ Kidney Disease Outcome Quality Initiative ((NKF/K/DOQI)) (NKF 2003) (Table 1). In this study, stage 5 or End-Stage Renal Disease (ESRD) was to be studied. According to Johnson *et al.* (2004), risk factors for chronic kidney disease include diabetes mellitus, hypertension, family history of CKD, age older than 60 years and diabetic kidney disease (DKD). These are the major causes of end-stage renal disease (ESRD) (Narenpitak & Narenpitak 2008). In addition, the causes of death among older patients with ESRD include infection (peritonitis, pneumonia, septicaemia) and cardiovascular disease (CVD) (pulmonary oedema, right heart failure, and pulmonary artery hypertension, myocardial infarction, complete heart block, and arterial emboli) (Munshi *et al.* 2001a). In Thailand, the most common cause of end-stage renal disease is diabetic nephropathy, which relates to high blood pressure (hypertensive nephropathy) (Pradipornsipa 2007). In Thailand diabetic nephropathy accounted for 40.3% of the deaths among ESRD patients in 2007, and this aetiology of ESRD reflects the poor survival of those with diabetic nephropathy compared with other aetiologies (Pradipornsipa 2007).

Table 1 Classification for stages of Chronic Kidney Disease

Stages	Description	GFR (ml/min per 1.73 m ²)	Actions
1	Kidney damage with normal or increased GFR	≥ 90	Diagnosis and treatment of comorbid conditions
2	Kidney damage with mild decreased GFR	60–89	Estimating progression
3	Moderately decreased GFR	30–59	Evaluating and treating complications
4	Severely decreased GFR	15–29	Preparation for kidney replacement therapy
5	Kidney failure	< 15	Kidney replacement

(National Kidney Foundation/Kidney Disease Outcome Quality Initiative (NKF/K/DOQI 2002, cited in (Levey 2003))

According to Gilbar *et al.* (2005), ESRD is a chronic life-threatening condition. The disease is progressive, and people can develop a variety of physical, psychological and social problems at any point during the illness (Zalai *et al.* 2012). Feature characteristics of ESRD are similar to both end-stage cardiac and respiratory disease, except for the difference in terms of life-sustaining treatment, namely dialysis (Kane *et al.* 2013). Ormandy (2008) stated that the only way to survive with ESRD is to have renal replacement therapy (RRT) since ESRD patients should be started on RRT when they reach stage 4 or when uraemic symptoms are severe (Levey 2003; Ansell *et al.* 2007). RRT is an essential treatment including peritoneal dialysis (PD), haemodialysis (HD) or kidney transplantation (KT) (Kotanko *et al.* 2007). In Thailand, PD is available at home, but it is not appropriate for all patients, especially the elderly. HD is used for those who have specific medical conditions (Yodchai *et al.* 2011). KT has been found to be the most cost-effective treatment, but the number of kidney

donors is insufficient to meet patient demand in Thailand (Teerawattananon *et al.* 2007). There are estimated to be only around 200 donated kidneys available, but 10,000 new ESRD patients are diagnosed each year in Thailand (Teerawattananon *et al.* 2007).

2.4 Consequence of ESRD in Thailand and worldwide

As a consequence, the biggest group of ESRD patients is older people who may decline dialysis, discontinue dialysis or not be offered it in the first place although it would be clinically indicated, with an associated impact on their health-related quality of life (Munshi *et al.* 2001b). Moreover, it has been argued patients managed without dialysis have been particularly neglected (Murtagh *et al.* 2009a). According to Noble *et al.* (2008) the voice of patients managed without dialysis is generally silent in the literature. In addition, patients are often more focused on living than dying, so that it is a difficult task for health care teams to approach the issue of end of life care (Noble *et al.* 2008; Noble *et al.* 2010). In Thailand, patients often have to suffer with the symptoms and complications of ESRD at home. In particular, dialysis is not provided as the end of life approaches. This is because the management of ESRD in Thailand is costly, and more than half ESRD patients cannot access dialysis because the cost is prohibitive. Furthermore, access to this form of management is limited since it is only available in specialist institutions (Narenpitak & Narenpitak 2008). Murtagh *et al.* (2007a) reported that ESRD patients managed without dialysis suffer from symptoms including lack of energy or fatigue, pruritus, dyspnoea, leg oedema, drowsiness, pain, dry mouth, muscle cramps, difficulty concentrating, insomnia, constipation, dizziness nausea and muscle pain. Depressive and anxiety disorders are the most common mental health problems among the ESRD population (Zalai *et al.* 2012). Noble *et al.* (2012) suggested that ESRD patients who are not treated with dialysis may have psychological (depressive) and social symptoms as a consequence. Therefore, symptom burdens and unmet health care needs are an important issue of concern. However, there has only been a small amount of research directed at how patients manage without dialysis in order to explore how they die and what their needs are at the end of life.

2.5 Palliative care in the context of ESRD

2.5.1 What is known internationally?

World Health Organization (2004) stated that “palliative care can improve the quality of life of patients and families who face life-threatening illness, by providing pain and symptom relief, spiritual and psychosocial support from diagnosis to the end of life and bereavement by using a team approach to address the needs of patients and their families” (p. 7-8). The concept of palliative care as applied to renal disease translates into an agreed management plan to optimize the quality of life and relieve suffering (pain and symptom management). It can be offered simultaneously with other appropriate medical therapies. The concept is not synonymous with the end-of-life and is not defined by the absence of dialysis provision, but it is appropriate for all patients with a life-limiting serious illness. The concept of palliative care includes general palliative care, which can be defined as the care provided by the patient’s and their family’s usual professional carers as a vital and integral part of their routine clinical practice. In contrast, specialist palliative care is defined as the care provided by health and social care professionals who specialise in palliative care and work within a multi-professional specialist palliative care team (O’Connor & Pearson 2003). Moreover, Swidler (2009) clarified the process of renal palliative care as incorporating geriatric principles and involving the multidisciplinary team in offering a holistic approach to care. Active medical treatment of renal complications when appropriate (for example, treatment of fluid/electrolyte disorders, renal anaemia, fluid overload, mineral bone disease) is continued simultaneously with evaluation and treatment of geriatric syndromes and symptoms that accompany the condition (for instance, pain, depression, fatigue, insomnia, pruritus, constipation) to maximize function and QOL, avoid unnecessary hospitalization, and enable a dignified death (Murtagh *et al.* 2007b).

2.5.2 What is known about the situation in Thailand?

ESRD patients in Thailand would probably benefit from an offer of palliative care. Unfortunately, palliative care for patients with end-stage renal disease (ESRD) is a neglected aspect of nephrology in Thailand. Currently, palliative care is only developed in the context of advanced cancer, HIV/AIDS and gynaecology (Wright

et al. 2008b). According to Fitzsimons *et al.* (2007) a major difference between chronic illness and cancer patients is that individuals with chronic illness often have a more prolonged and less certain illness trajectory than cancer patients. This may lead to different palliative care needs. Patients dying from chronic illness, including ESRD, have been reported to have many concerns and unmet care needs (Fitzsimons *et al.* 2007). Murtagh *et al.* (2007a) suggested that end-stage renal disease patients should receive a palliative care approach in the final stage of their illness. In the only study to be located on this topic in a Thai population, Teerawattananon *et al.* (2007) sought to compare a group of dialysis patients (haemodialysis and peritoneal dialysis) with a group of ESRD patients managed without dialysis. The study revealed the types of treatment and care options being provided for Thai ESRD patients managed without dialysis. These included restricted fluid intake, high-dose bicarbonate, ferrous sulphate, blood transfusion, and hospital admission if required (Teerawattananon *et al.* 2007). Palliative care was recommended as the best course of action to provide the most cost-effective treatment for all age groups in Thailand (Teerawattananon *et al.* 2007). However, this study failed to mention or focus on patients' experiences and health care needs, which are key to developing health care services that are responsive to patients' needs.

2.6 Management without dialysis in Thailand and worldwide

2.6.1 Conservative management in Thailand and worldwide

Conservative management for ESRD patients is medically active and aimed at delaying and controlling the disease and its associated symptoms, without the use of renal replacement therapy (Braithwaite 2012). It is holistic in nature and includes coordinated medical and emotional support for patients and families across the disease trajectory. It is most appropriate for patients for whom dialysis proves the greatest burden with the least benefit to quality of life, comfort, and survival (Braithwaite 2012). In European countries, the ESRD population is generally characterised as around 80 years of age, with a limited prognosis due to age and high comorbidity scores. The incidence and severity of end-stage renal symptoms are comparable to other advanced conditions

such as cancer, CHF and COPD, and they are managed in a similar manner. The conservative management of ESRD patients may allow them to survive for months and even years, but death inevitably occurs once GFR falls below 5 ml/min. However, those who opt for less aggressive management may enjoy improved quality life since they avoid the arduous burden of routine dialysis, repeat hospitalisations, and the sense of “suspended living” in a drawn-out decline. The trend toward conservative management is increasing as the limitations of kidney replacement therapy become better understood.

According to Sitprija (2003) and Narenpitak & Narenpitak (2008) Sitprija (2003); (Narenpitak & Narenpitak 2008) renal replacement therapy (RRT) is both a clinical and an economic problem in Thailand. Patients with end-stage renal disease (ESRD) require dialysis or a kidney transplant to extend life, which are expensive treatments (Chittinandana *et al.* 2006). Although dialysis is a life-sustaining therapy it may also create, increase, or prolong suffering while not restoring or maintaining function and QOL in selected subgroups of geriatric patients. Some studies suggest that dialysis may not offer a survival advantage in patients over the age of 75 who have multiple comorbidities and cardiac ischaemia (Murtagh *et al.* 2007a; Swidler 2009). Fewer hospitalizations and more patient deaths at home may be possible in those patients who are treated medically using a multidisciplinary team approach, since this may provide a more humane and dignified end-of-life experience for frail geriatric patients and their families (Swidler 2009). Moreover, it could be argued that patients at the end stage of their life need spiritual and emotional support and full supportive care rather than dialysis. This is important because these patients have particular care needs, some of which relate to the fact that they are approaching the end of their lives. Palliative care or supportive services need to be developed (Murtagh *et al.* 2009a). However, that being said, most of the palliative care research has been conducted in European countries, for example, UK, France, Germany, Italy, and Spain, as well as in the United States. There is no evidence about the experiences, needs and care provided for older people with ESRD in Thailand, despite the fact that more than three quarters of the ESRD population are managed without dialysis.

2.7 The experiences of relatives of patients with end stage renal disease

Within the hospice model, palliative care is initially focused on the patient and their family, a focus that is supported by the definition of World Health Organization (2004) and which is used to guide all aspects of care at the end of life (Emanuel & Librach 2007). Patients are typically part of a family, and when care is provided, the patient and family are treated as a unit. All aspects of care are provided in a manner that is sensitive to the patient's and family's personal, cultural, and religious values, beliefs, and practices, their developmental state, and their preparedness to deal with the dying process (Emanuel & Librach 2007) (p. 5). Providing care for a person who is terminally ill requires an ongoing balancing act between the care burden and the ability of the carer to cope with the situation (Proot *et al.* 2003; Noble *et al.* 2012). As a consequence of end-stage renal disease (ESRD) and living with chronic illness, family members who live with the ESRD patients will experience a change in their life with a responsibility to provide care for patients (White & Grenyer 1999). There are a multitude of reasons why caregivers take on their role, including the simple explanation that it is a social expectation (Currow *et al.* 2011). Moreover, important responsibilities of patients will be transferred to their partner or other family members when the patient is at the end stage of their disease and planning to die at home (White & Grenyer 1999). This can affect the caregivers' health status and reduce their quality of life. There are reported unmet needs, including poor preparation for the role, and there are a lack of evidence-based strategies to support carers who care for their dying relatives (Hudson & Payne 2011). Noble *et al.* (2012) also summarised many reasons for the poor experiences of family caregivers of renal patients who receive dialysis, including unmet needs, financial hardship, social isolation, changed relationships with the patient and limited experiences of death and dying. Those needs are likely to be different for carers who care for ESRD patients who are managed without dialysis (Noble *et al.* 2010).

2.7.1 The experiences of relatives of patients with end-stage renal disease who are managed with conservative care

According to Kidney care by NHS (National Health Service 2004; Department of Health 2005; National Health Service 2012) there is a noticeable impairment of the quality of life among carers who care for people with ESRD who are managed without dialysis. The carer will experience a greater burden if their relatives have a worse prognosis (Sharpe *et al.* 2005). Phillips *et al.* (2005a) found that family members experienced increased pathological grief after the death of a relative who had discontinued dialysis. However, 5 years after the discontinuation of dialysis families reported low levels of distress, and the findings suggest that families successfully adapt to the impact of dialysis withdrawal (Phillips *et al.* 2005b). Noble *et al.* (2012) studied the experiences of carers supporting dying renal patients who were managed without dialysis: 'Caring from diagnosis to death emerged as an overarching theme underpinned by three sub-themes: 1) the caregiver's plight – making sense of the disease and potential deterioration, 2) having to care indefinitely, and 3) avoiding talk of death (p. 4-5).

Noble *et al.* (2012) also concluded that there is a need for the development of holistic, integrated care pathways based on carer perspectives, including the identification of information needs related to the original diagnosis, associated comorbidities, treatment options, prognosis, and assistance in developing strategies to manage communication with patients as the end of life approaches. In the UK, Noble *et al.* (2007) highlighted issues associated with care delivered to patients who decide not to undergo dialysis, suggesting that the key attributes of renal supportive care should include availability from diagnosis to death, with an emphasis on prognosis and the impact of advanced disease, an interdisciplinary approach to care, restorative care including active disease management and palliative care in tandem, effective, lucid communication to ensure informed decision making, and family and carer support. In Thailand the presence of family strongly impacts on the provision of end-of-life care for their relatives, and they have a vital role in making decisions and providing care for the terminally ill in hospital or in the home (Kongsuwan & Locsin 2011). The perspective of this group regarding the unmet needs of patients is thus very important. Furthermore, because of the challenges of collecting first-hand accounts as people approach death, proxy reports are recognised as a valid

method of collecting data capturing patients' experiences and needs at the end of life (Addington-Hall 2002; Elkington *et al.* 2004; Addington-Hall & O'Callaghan 2009).

2.8 The health care system and policy regarding ESRD in Thailand

The provision of care for ESRD in Thailand is inextricably linked to the way in which Thailand's health services are financed and organized. The Thai health care system is financed through a mixture of financial sources, namely general taxes, social insurance contributions, private insurance premiums and direct payments from service users (Tangcharoensathien *et al.* 2010). After the 1997 Asian economic crisis, in 2002 the Thai government launched the Universal Coverage (UC) Policy which significantly increased the public share of total health spending and significantly reduced household out-of-pocket payments. The UC scheme is financed by a general tax which comes from more than 75% of the total population. There are three major public insurance schemes providing health insurance coverage for the entire population in Thailand, including: 1) the Civil Servant Medical Benefit Scheme (CSMBS) from the Ministry of Finance; 2) the Social Health Insurance (SHI) from the Social Security Office under the Ministry of Labour; and 3) the UC scheme (Tangcharoensathien *et al.* 2010) from the National Health Security Office (NHSO) in the Ministry of Public Health (MOPH).

These three major public insurance schemes will pay for ESRD patients to receive Renal Replacement Therapy (RRT) including haemodialysis (HD) and peritoneal dialysis (PD). However, the Thai National Health Policy Programme from the Ministry of Public Health (IHPP) does not make provision for poor ESRD patients who do not have any insurance. In addition, these three insurance schemes do not cover long-term care for all age groups. Teerawattananon *et al.* (2007) found that the average cost of initial treatment with PD and the average cost of initial treatment with HD were 672,000 Baht (£13,440) and 806,000 Baht (£16,120) per quality-adjusted life-year (QALY) respectively. These were compared with the total cost of palliative care (conservative care) from a social perspective of 224,000 Baht (£4,480). In terms of cost effectiveness, Teerawattananon *et al.* (2007) strongly recommended that RRT generally should not be considered a

cost-effective option for older ESRD people in Thailand, especially patients with serious multiple comorbidities. Instead, palliative care (conservative management) should be the preferred option.

2.8.1 Palliative care in Thailand

The roots of Thailand's hospice palliative care movement can be traced back to the 1980s with a focus on pain relief, led mainly by anaesthesiologists (Wright *et al.* 2008a). In the early 1990s, the particular urgent care need was for people living with HIV and AIDS. Faith-based organisations founded hospice services, such as the Buddhist temple known as Wat Phrabat Nampu (near the city of Lop Buri). In 1996 the palliative care programme was established at the National Cancer Centre in Bangkok. Then, at the turn of this century, interest grew in palliative care training programmes and such courses were created in the south at Songklanagarind Hospital and in the north east at Khon Kaen Hospital. The Thailand National Hospital Accreditation Authority uses the provision of palliative and end-of-life care as a quality indicator (Nilmanat & Phungrassami 2006). The patient's right to refuse treatment was also endorsed in the National Health Act 2007, whereby patients have a right to die without recourse to cardio-pulmonary resuscitation.

Palliative care is beginning to gain ground, supported by its resonance with Buddhist teachings on the alleviation of suffering and a focus on the nature of death in the context of life. However, Thai health care policy is focused on curative care within the area of acute and chronic illness, with less interest in palliative care, especially for ESRD patients managed without dialysis. Therefore, it is unsurprising that the nascent palliative care movement is now perceived to have stalled (Wright *et al.* 2008a). The demand for care at the end of life is increasing because of the growing number of terminally ill persons seeking quality care. Thailand does not have hospice units for dying patients in every hospital. A handful of university hospitals have opened palliative care units with five to ten beds for inpatients and outpatients. Government-provided hospice care for dying patients does not exist. These services are currently provided by several temples in Thailand, which are regarded as convenient places for dying patients, particularly patients with AIDS. The majority of the Thai population (over 90%) are Buddhists, and a cultural perspective is critical for Thai people

with regard to promoting a peaceful death for persons who are dying. Therefore, this religion has a profound influence on end-of-life care in Thailand. Few hospitals provide a home-based palliative care service, and bereavement services are not formally provided for Thai families (Kongsuwan & Locsin 2009).

2.9 Conclusion

When considering older people with ESRD who are managed with conservative care in Thailand, there is no evidence about their experiences and health care needs. In order to develop palliative care aimed at improving the quality of life of these patients, knowledge is required about patients' experiences, symptom burden and health care needs as the end of life approaches. There are difficulties in conducting research with dying patients and older ESRD patients who have serious multiple comorbidities such as ischemic heart disease, pulmonary oedema, and uraemia (Murtagh *et al.* 2007a). Proxy reports are an accepted way by which to access the views of patients at this stage in their lives (Addington-Hall & O'Callaghan 2009). This study will therefore explore the experiences and health care needs of older ESRD patients from the perspective of bereaved relatives, by focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances of death. This research has the potential to benefit such patients and those who are caring for them in Thailand.

Chapter 3: Critical review of the literature

3.1 Introduction

This chapter describes the strategies used to identify and evaluate literature relevant to this mixed methods study. Then, the findings from this process are presented.

3.2 Strategies appropriate for conducting a literature review for mixed methods study

In mixed methods research the literature review is used by the researcher to support both qualitative and quantitative approaches to data gathering (Creswell & Plano Clark 2007). In particular, in an exploratory sequential approach, the literature is presented in each phase in a way that is consistent with the research method being used. For example, if the study begins with a quantitative phase, then the investigator is likely to include a substantial literature review that helps to establish a rationale for the research questions or hypotheses (Creswell & Plano Clark 2007). In this research, because the study begins with an exploratory qualitative phase, the initial literature review is broad and exploratory in order to convey an inductive design and the researcher incorporated it towards the end of the study to aid interpreting of the result. Creswell (2007) suggested ways to use literature whilst planning a mixed methods research as follows:

- Consider the most appropriate place for the literature in a qualitative study, and base the decision on the audience for the project; place it at the beginning to frame the problem, place it in a separate section, and use it at the end to compare and contrast with the findings.
- Use the literature in a quantitative study deductively, as a basis for advancing research questions or hypotheses.
- In a quantitative study plan, use the literature to introduce the study, to describe issues related to each section, and to compare findings.

- If a separate review is to be adopted or used, consider whether the body of literature will be comprised of integrative summaries of the results of qualitative and quantitative studies. As a typical practice in thesis writing is to advance an integrative review.

This is therefore the strategy that was adopted in this thesis.

3.3 Method used to systematically search and review research

The Critical Appraisal Skills Program (CASP) (Fowler 2001) aims to help health service decision makers make decisions, and develop the skills needed for the critical appraisal of evidence. CASP was applied to this review (see Figure 1). The application of an evidence-based approach to work practice involves the following sets of actions: ask, find, appraise, act and evaluate. The literature review started by asking questions, followed by defining a search strategy to include search terms and inclusion and exclusion criteria. The researcher then identified and selected potential relevant studies, and following this the studies were characterised and critically appraised based on the following three questions.



Figure 1 The evidence-based approach according to the Critical Appraisal Skills Program (CASP)

3.3.1 Asking questions

The researcher firstly started to review the literature by asking three questions:

- 1) *What are the main issues for ESRD patients in Thailand and worldwide?*
- 2) *What is the symptom experience of older ESRD patients while managing without dialysis in Thailand and worldwide?*
- 3) *What are the health care needs of older ESRD patients while managing without dialysis in Thailand and worldwide?*

3.3.2 Search strategy

The initial search aimed to identify research relating to the care of older ESRD patients who had withdrawn from or who were waiting for dialysis in Thailand and worldwide. According to Cooper 2010 (cited in Polit & Beck 2012), the four steps for formulating a search strategy include: 1) searching for references from bibliographic databases; 2) an “ancestry approach” which involves using citations from relevant studies to track down earlier research on the same topic; 3) a “descendancy approach”, finding on a pivotal early study and searching forward in citation indexes to find more recent studies which cite the key study; and 4) “grey literature”, i.e. conference papers, unpublished reports and so on. In this study, searching bibliographic databases was selected as the main search strategy. A systematic literature search was carried out in October 2009 and updated through to August 2013. Systematic literature searches were conducted and identified in CINAHL, MEDLINE (PubMed), the Cochrane Library, Web of Knowledge and NHS Evidence Health Information Resources. The researcher also repeated the search utilising databases in Thailand. There are three main official Thai databases available for searching via the internet, including: 1) the website of the Thai University Library; 2) the website of the Research Library of the National Research Council of Thailand; and 3) the website of the Nephrology Society of Thailand. Keywords or search terms focused on the relevant topics and population of the study (Table 2). Boolean operators (and, or and not/ non) were used to expand or delimit the search. The systematic search ended when information from new searches was found to be redundant when compared with existing results; in other words, the literature search achieved “data saturation” (Polit & Beck 2012). A total of 238

search results were retrieved in Thailand (Table 3), while 2,376 potentially relevant publications for retrieval were identified worldwide (Table 4).

Table 2 Keywords or search terms

Keywords or search terms
End stage renal disease
Older people and end stage renal disease
Dialysis withdrawal/non-dialysis/refuse dialysis
Older people and end stage renal disease and non-dialysis
Symptom experiences of ESRD patients managed without dialysis
Palliative care and non-dialysis
End of life care or conservative care or supportive care and ESRD patients managed without dialysis
Health care needs or health service provision and utilization for ESRD patients managed without dialysis

Table 3 Summary of search results from databases in Thailand

Databases/ search terms	Older ESRD patient sand non- dialysis	Non- dialysis	Symptom experien ces of ESRD patients	Symptom experien ces of ESRD and non- dialysis	Health care needs or health service provisio n for ESRD patients	(Health care needs or health service provisi on for ESRD) and non- dialysis	ESRD patients and (palliati ve care or conserva tive care or end of life care)	Non- Dialysis and palliative care	ESRD patients and (palliati ve care or conserv ative care or end of life care and non- dialysis)
Web of Knowledge	0	2 (clinical trials)	3 (view abstract)	0	1 (abstract)	0	3 (view abstract)	0	0
CINAHL	0	0	0	0	2 (full text)	0	0	216 (full text)	0
Medline (PubMed)	0	2 (1 full text)	4 (full text)	0	0	0	0	0	0
Cochrane Library	0	0	0	0	0	0	3 (clinical trials)	0	0
http://portal.nurse.cmu.ac.th/library/ Site Pages/Home.aspx	0	0	0	0	0	0	1 (Dissertat ions)	0	0
http://www.riclib.nrct.go.th/database/data base.html	0	0	0	0	0	0	1	0	0
http://www.nephrothai.org/trt/trt-l.asp	4	0	0	0	0	0	0	0	0
Total = 238	0	4	7	0	3	0	8	216	0

Table 4 Summary of search results from worldwide databases

Databases/ search terms	Older ESRD patient sand non- dialysis	Non- dialysis	Symptom experienc es of ESRD patients	Symptom experience s of ESRD and non- dialysis	Health care needs or health service provisi on for ESRD patient s	(Health care needs or health service provision for ESRD) and non- dialysis	ESRD patients and (palliative care or conservat ive care or end of life care)	Non- Dialysis and palliativ e care	ESRD patients and (palliativ e care or conserva tive care or end of life care and non- dialysis)
Web of Knowledge	19	86	73	0	188	3 (1 full text)	54	2	0
CINAHL	876 (216 full text)	70 (23 full text)	7 (full text)	5 (full text)	274	0	5 (full text)	1 (full text)	1 (full text)
Medline (PubMed)	7 (5 full text)	274 (58 full text)	62 (full text)	37 (22 full text)	37 (25 full text)	0	114 (full text)	5 (3 full text)	1 (full text)
Cochrane Library	0	38 (clinical trials)	28	3 (full text)	75	6	3	0	5
NHS Evidence Health Information Resources	0	0	0	0	0	5 (research reports)	12 (clinical guidelines)	-	
Total = 2,376	902	468	170	45	574	14	188	8	7

3.3.3 Study selection

Studies were screened and discarded based on the inclusion and exclusion criteria (see Table 5). In this study, the literature is reviewed and contained up-to-date studies. The researcher limited the searching based on the time frame of studies within the past 10-15 years (Polit & Beck 2012). Potential relevant publications were retrieved and analysed for study eligibility (see Figure 2). Reference lists from potential articles were also considered and searched to find primary data potentially missed in the search (Tong *et al.* 2008).

Table 5 Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> - Involving older patients (aged 60 years and over) with ESRD - Published between 2000 and 2013 - Focused on symptom experiences/health care needs of older ESRD patients managed without dialysis 	<ul style="list-style-type: none"> - Full text unavailable - Non-English language (except Thai language) - Not related to symptom experiences of ESRD, non-dialysis palliative, conservative, end of life care/ health care needs/health services provision - Duplicate articles

3.3.4 Data extraction

In this process a list of key assessment questions needs to be generated to extract the data and rate quality of the studies (Bowling 2009b). The researcher applied an evidence-based practice process by using the Critical Appraisal Tools for selecting the strongest evidence. The Critical Appraisal Tools (Taylor *et al.* 2004) applied in the study included: 1) 10 questions to help the researcher make sense of randomized controlled trials (Appendix A) and 2) 10 questions to help the researcher make sense of qualitative research (Appendix A). Then the researcher sorted the selected research papers into six main sub-headings in order to look through and examine the research processes within both the quantitative and qualitative research studies. The six

main sub-headings consisted of research title and authors, aims of the study, research type/design, instruments/outcome measurements, data collection/analysis, and results/impacts. The evaluation of the research evidence was divided into two parts: a review of the research evidence regarding older people with ESRD managed without dialysis a) in Thailand (Appendix B) and b) worldwide (Appendix C). The findings will be presented in two distinct sections.

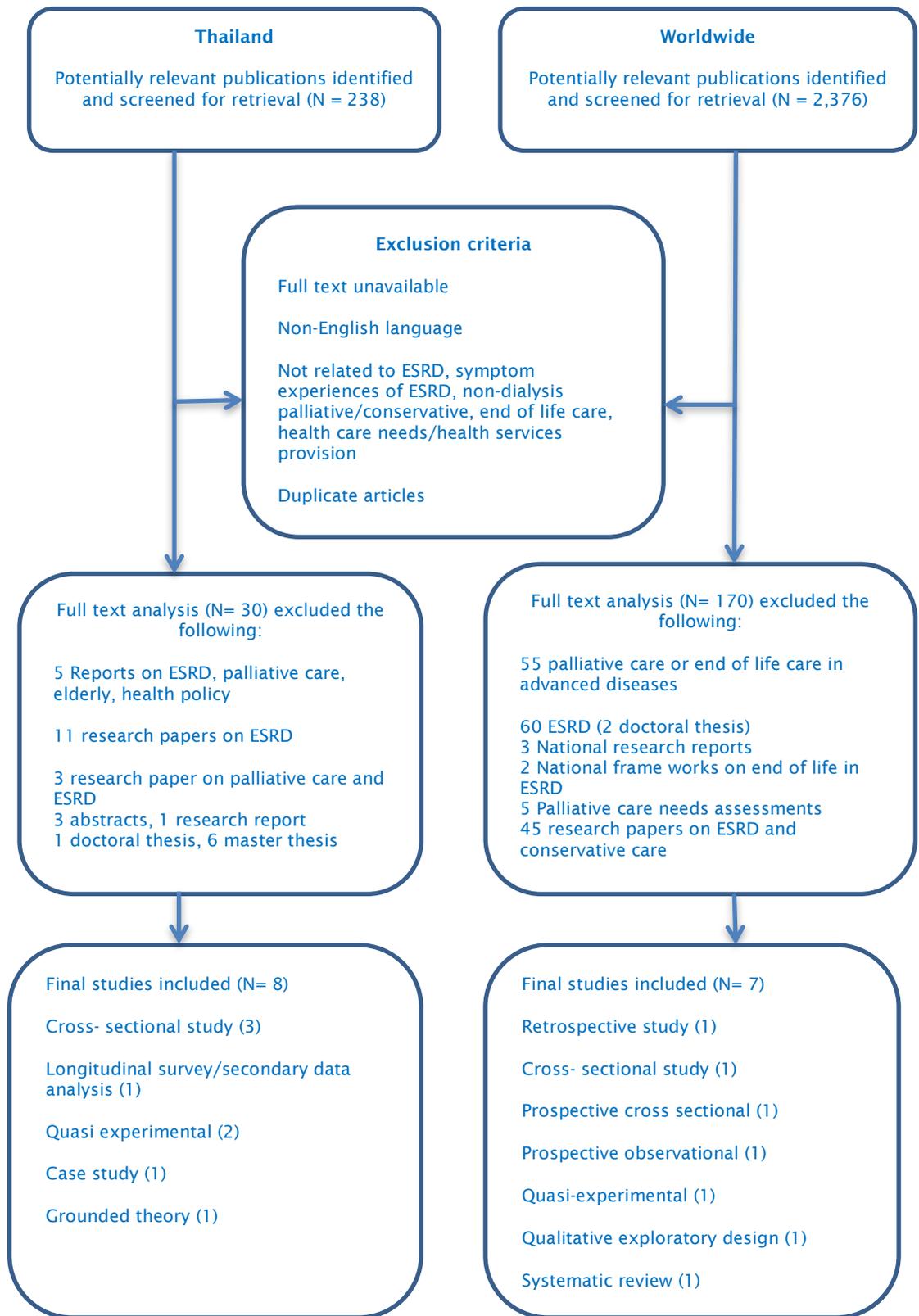


Figure 2 Flowchart of the literature review for the study

3.4 Characteristics of Thai studies

The researcher retrieved 30 full texts articles relating to Thai studies of which 22 studies were excluded as they did not meet the inclusion criteria and were not related to topic of the study. Finally, 8 studies were chosen which consisted of 3 cross sectional studies (Narenpitak & Narenpitak 2008; Perkovic *et al.* 2008; Ong-ajyooth *et al.* 2009) 1 longitudinal survey/ secondary data analysis (Teerawattananon *et al.* 2007), 2 quasi-experimental studies (Yowaphui 2008; Pungchompoo 2010), 1 case study (Prakongsai *et al.* 2009) and 1 grounded theory (Yodchai *et al.* 2011). A review and evaluation of the strengths and weaknesses for articles in Thailand is provided in Appendix B (Table 20 and 21).

3.4.1 Research design and objectives

The 3 cross sectional studies aimed mainly to describe and determine the prevalence of chronic kidney disease population in Thailand (Narenpitak & Narenpitak 2008; Perkovic *et al.* 2008; Ong-ajyooth *et al.* 2009). The longitudinal study was conducted to compare the cost effectiveness of three different treatments (PD, HD and palliative care) by statistical data drawn from the Thailand Replacement Therapy Registry (Teerawattananon *et al.* 2007). A case study assessed the economic impact of Renal Replacement Therapy (RRT) costs on Thai households with different economic status by focusing in three issues 1) the use of RRT, 2) the financial burden of health care payments and 3) household strategies for coping with RRT costs (Prakongsai *et al.* 2009). In addition, two classical experimental studies (Yowaphui, 2008; Pungchompoo *et al.* 2010) were implemented to examine the effectiveness of self-efficacy and self-management programs for improving the quality of life of ESRD patients who managed with dialysis in Thailand. The grounded theory study (Yodchai *et al.* 2011) was undertaken to understand how HD affected ESRD Thai patients and to explain their perspective about adapting to be dependent on HD. These selected papers may not directly address the two literature review questions relating to specific experiences and health needs of ESRD patients who managed without dialysis in Thailand. However, the papers address disease prevalence, risk factors and inadequacy of health care provision of ESRD patients in Thailand. Therefore they are relevant to the first literature review

question. However, there is clear need for research evidence on experiences and health care needs of the non-dialysis group. Even though a gap in service provision for this group suggests unmet needs, research is required to provide evidence about the experiences of patients waiting for, or opting not to have dialysis in Thailand. The research methodologies, including study design, population, sample methods, data collection instruments and data analysis techniques, are summarized and presented in Table 6 below. Judgements about the rigour of studies and the quality of the selected evidence from Thailand can be made based on the major strengths and weakness of the studies which are provided in Appendices B (Table 21).

Table 6 Summary of methodological matrix for reviewed articles in Thailand

Authors	Country / year	Study design	Population	Sample selection (size)	Data collection instruments	Data analysis
Ong-ajyooth <i>et al.</i>	TH/2009	Cross sectional study	CKD patients stage 3-5 aged 15 and over	The multistage stratified cluster-sampling (N= 3,117)	Physical examination and blood samples. Serum creatinine using the Jaffé method. GFR using the Chinese Modification	Logistic regression
Narenpitak & Narenpitak	TH/2008	Cross sectional study	CKD patients with type 2 diabetes stage 3-5 aged 30 to 92 years	The cluster sampling (N= 716)	Medical histories, physical examinations, and blood tests for glucose, creatinine, total cholesterol, and triglyceride after 9-12 hours fasting	Logistic regression
Perkovic <i>et al.</i>	TH/2008	Cross sectional study	CKD patients stage 3-4 aged 35 and over	The multistage stratified cluster-sampling (N=5,303)	Glomerular filtration rates from serum creatinine using the Cockcroft-Gault the simplified Modification of Diet in Renal Disease (MDRD) formulae.	Linear regression and Chi ² tests.
Prakongsai <i>et al.</i>	TH/2009	In-depth case study	ESRD patients who covered by Thai universal coverage scheme (UC) aged 23 to 84 years	Purposive sampling (N= 20 households)	Semi structured interviews and open-ended guide questions The observation and fieldwork diaries	Thematic analysis Content analysis
Pungchompoo <i>et al.</i>	TH/2010	Pre-post testing experimental study	ESRD patients received HD aged 20 and over	Purposive sampling (N = 40)	Demographic Data Form Six Minute Walk Test Tools Self-Efficacy Questionnaire A videotape showing self-management role modeling, Self-management questionnaire SF 36 version 2	T-test and one-way repeated measured ANOVA
Teerawattanon <i>et al.</i>	TH/2007	The longitudinal study	ESRD patients aged 20-70 years	Data extracted from a national cohort of the Thailand Renal Replacement Therapy Registry (N= 6,272)	The probabilistic Markov model was applied to examine the incremental cost-effectiveness ratio (ICER)	The nonparametric Kaplan-Meier approach
Yodchai <i>et al.</i>	TH/2011	The grounded theory	ESRD patients received HD aged 24 and 66 years	Purposive sampling (N= 5)	The open ended interviews guide Standard demographic data questionnaire Semi-structured interviews	Thematic analysis
Yowaphui	TH/2008	Pre-post-test experimental study	ESRD patients received HD aged 60 and over	Purposive sampling (N= 30)	Self-efficacy and Social Support Enhancement Program Perceived Self-Efficacy Questionnaire, Social Support Questionnaire, Exercise role modeling VDO, Self-Care Manual, Social Support for Exercise Manual and the Exercise Behavior Questionnaire.	Descriptive statistics and t-tests

3.4.2 Findings

3.4.2.1 What are the main issues for ESRD patients in Thailand?

Three studies provide evidence about the prevalence, risk factors, characteristics, and the gap between needs and health service provision for the ESRD population in Thailand. Perkovic *et al.* (2008) found that the prevalence of ESRD in Thailand was higher than the prevalence of ESRD in USA, Australia and Taiwan, especially for individuals aged over 60 years. In addition, the prevalence of ESRD in Thailand's rural areas was higher than in the urban areas. The study by Perkovic *et al.* (2008) met its objectives of estimating the prevalence of ESRD in Thailand. A multistage stratified cluster-sampling was applied and a good response rate was achieved (67%) with a large sample size (N=5,303). The sample was stratified by urban and rural areas, level of deprivation, aged and gender. Therefore, the observed prevalence is likely to be representative of the Thai population (Polit & Beck 2012, p. 286). However, biochemistry measurements such as GFR (taken from blood samples) were measured at one time point. Furthermore, GFR was calculated using the Cockcroft-Gault and Modification of Diet in Renal Disease (MDRD) formulae, which have not been validated within a Thai population. Therefore, the claim that the prevalence of ESRD in Thailand is higher than the prevalence of the disease in other countries might not be valid.

Ong-ajyooth *et al.* (2009) used multistage stratified cluster-sampling with 3,117 respondents. The sample was stratified by urban and rural areas, age and gender. The study found that the prevalence of CKD increased with advancing age (patients aged 60 years or over had the highest prevalence). CKD prevalence was found to be slightly higher among persons in rural areas than those in urban areas. CKD was more prevalent in the northeast than in other regions of Thailand. Diabetes and hypertension were the main factors associated with the prevalence of CKD. The limitations of this study are similar to those of the study by Perkovic *et al.* (2008), since the MDRD formula was used to measure the participants' GFRs. The MDRD formula was based on the original coefficient for the Chinese population, and the formula has not been validated for the Thai population. Therefore, this might have affected the

accuracy of the results.

The study by Narenpitak and Narenpitak (2008) also used a cluster random sampling design but with a smaller population than the previous two studies. They also found that ESRD is a major health problem, and diabetic kidney disease (DKD) was found to be the major cause of ESRD in Thailand. The study determined the prevalence of CKD among type 2 diabetics and identified risk factors of decreased kidney function using logistic regression analysis. This study provides further evidence about risk factors for ESRD such as the duration of diabetes, diabetes with a history of hypertension, triglyceride levels, and diabetic retinopathy, which were all significant independent risk factors for the presence of decreased kidney function. However, this study did not mention age or sex as independent risk factors, in contrast with previous studies. The study suggested that effective management such as the intensive and optimal treatment of diabetes is needed to slow the progression of ESRD. Full universal-coverage welfare is also an important issue to be considered for ESRD patients.

The sample size in this study (N=716) was smaller than in the studies by Perkovic *et al.* (2008) (N=5,303) and Ong-ajyooth *et al.* (2009) (N=3,117). The sample was selected from six primary health care units in the urban area of one province in the northeast of Thailand. The participants' setting is different when compared with the study of Ong-ajyooth *et al.* (2009), who found that the prevalence of CKD in rural areas is higher than in urban areas. Therefore, the study by Narenpitak and Narenpitak (2008) might not represent a complete picture of the prevalence and risk factors of ESRD in Thailand. The data collection instrument was similarly found to be a limitation because the MDRD formula has not been validated within the Thai population.

Evidence from these three studies (Narenpitak & Narenpitak 2008; Perkovic *et al.* 2008; Ong-ajyooth *et al.* 2009) confirms the high prevalence of ESRD in Thailand. There appears to be strong evidence that ESRD is a major health problem among the Thai population, and the incidence has been found to be increasing steadily in relation to independent risk factors such as diabetes,

hypertension and old age. In addition, the incidence of ESRD in rural areas has been found to be higher than in urban areas. Several studies discussed implications of the increase in the prevalence, in particular limited access to dialysis treatment, a lack of ESRD specialists and inadequate financial resources. These authors have also argued that the impacts include increasing morbidity and mortality rates, reduced quality of life, and a gap between health needs and inadequate health service provision (RRT services). However, the findings from these three studies do not provide evidence to support these arguments. These studies did not measure quality of life or health service provision. Furthermore, these cross-sectional studies are not able to provide the direction of an association in terms of causes and effects (Polit & Beck 2012) between factors such as ESRD and low quality of life, ESRD and needs and symptoms (physical and psychological aspects etc.), and symptom burden and inadequate health service provision.

The quantitative approach of these three studies suggested that the problem is underpinned by the increasing prevalence of ESRD in the older population, inadequate health services provision, which seem to be the critical issues to be concerned about in Thailand. The limitation of all three studies is that they have mainly approached the issues from a quantitative perspective, so that they were not fully able to capture the quality of data related to the symptom burdens and needs of ESRD patients within the context of non-dialysis management. Moreover, a culturally sensitive instrument, for use in evaluating symptom experiences and health care needs of non-dialysis patients in Thailand, does not exist; this is a clear need. Tests of the reliability and validity of the outcome measures are also important to enhance the accuracy of results.

3.4.2.2 What is the symptom experience of older ESRD patients while managing without dialysis in Thailand?

One study (Yodchai *et al.* 2011) used a grounded theory approach to explore the impact of haemodialysis and to understand the perspective of ESRD patients when they are dependent on haemodialysis. The study succeeded in exploring the experiences of 5 patients on haemodialysis, but the study does

not include non-dialysis patients. The study found that ESRD patients faced adverse effects from HD, including fluid restriction, fatigue, effects on sexual activity, altered body image, fear of dying, stress, depression and suicide. The treatment affected patients' lives and they required physical, psychological and social support to help them cope with the adverse effects. Four coping strategies emerged, including: 1) planning, 2) adjustment and avoidance, 3) belief in religion and superstition, and 4) living with hope. The first two strategies were applied to deal with social and physical changes, while the last two coping strategies were used to cope with mental and spiritual changes. The grounded theory approach used in the study was an appropriate design to identify basic social processes and generate new knowledge to address the study objectives. The sampling strategies and inclusion and exclusion criteria were appropriately provided, with the sample including people who had been diagnosed with ESRD and had received HD for at least one month. All of them received HD from one haemodialysis centre in southern Thailand during January and May 2010. The process of data collection and analysis were well designed, including in-depth individual open ended questions and thematic analysis. There were limitations associated with the small sample size (N=5); the sample may not represent a broad range of demographic characteristics. The participants were recruited from one tertiary hospital, which may further constrain the generalizability of the findings.

The physical, psychological, social and spiritual needs of non-dialysis patients and the way these patient groups cope with their symptoms is still unknown. Future qualitative research is needed to address this evidence gap for the Thai population.

3.4.2.3 What are the health care needs of older ESRD patients while managing without dialysis in Thailand?

Teerawattananon *et al.* (2007) focused on the relative cost benefits of different management approaches. The results suggested that providing RRT treatments for younger ESRD patients resulted in a significant improvement in survival, and there were gains in terms of quality-adjusted life year (QALYs) compared with the older age group. Offering peritoneal dialysis as an initial treatment

was found to be a better choice than offering haemodialysis in both younger and older groups. In contrast, the total programme cost of palliative care for an older population of ESRD patients was evaluated as the most cost effective treatment in Thailand. The study provided an overview of cost effectiveness of three different treatments (HD, PD and palliative care) based on large datasets, but it could not provide up-to-date and more specific details about the data (Polit & Beck 2012) regarding the appropriate type of palliative care for the older ESRD non-dialysis patients in Thailand. An evaluation of the cost effectiveness of health service provision for non-dialysis patients in Thailand is required. It was identified that the palliative care approach provided for non-dialysis patients in Thailand includes restricted fluid intake, high-dose diuretics, antihypertensive drugs, calcium bicarbonate, ferrous sulphate, blood transfusion and hospital admission when necessary. The focus is on providing medication for controlling the complications of ESRD. A comprehensive approach including psychological, spiritual and socioeconomic aspects is not described. The quality of life of ESRD patients managed without dialysis (0.60) in this study was found to be slightly lower than the quality of life of patients receiving PD (0.72) and HD (0.68). However, the study compared quality of life of patients without dialysis to those receiving dialysis without complications.

Prakongsai *et al.* (2009) used semi structured interviews, observation and fieldwork diaries to explore the impact of the costs of RRT on 20 Thai households of different economic status, focusing on three issues: 1) the use of RRT; 2) the financial burden of health care payments; and 3) household strategies for coping with RRT costs. Poorer ESRD patients were found to have inadequate dialysis and low quality of life, while richer patients had adequate dialysis resulting in a higher survival rate and better quality of life. Renal replacement therapy (RRT) and its associated costs created huge burdens, not only for patients but also for their family or relatives who provided financial support. Various coping strategies were employed by poorer patients, including reducing the frequency of dialyses, reducing food consumption, using public transportation to hospitals and taking high interest loans (Prakongsai *et al.* 2009). As a result, inadequate dialysis appeared to be a major cause of death for poor ESRD patients in Thailand. The sample size used

by Prakongsai *et al.* (2009) may be a limitation; the researchers were constrained by the declining number of potential participants since poorer patients were difficult to find as most of them had already died, while richer patients were not willing to be interviewed or were reluctant to join the study and reveal their income and household assets. A second limitation was related to missing data, since four participants had passed away before the end of data collection. This might affect the data quality, since ideally participants should be encouraged to reflect on their experiences and communicate effectively until data saturation can be achieved (Bowling 2009). These limitations in terms of sample size and missing data may have prevented the study from obtaining sufficient data for a deep understanding of these sensitive issues (Polit & Beck 2012). Furthermore, the short duration of qualitative data collection (three months) only provides a partial view of the long-term impact of lack of coverage of RRT and health services for ESRD patients in Thailand.

Two studies (Yowaphui 2008; Pungchompoo 2010) found that the provision of a self-management programme or a self-efficacy and social support enhancement programme could improve the quality of life of ESRD patients who received haemodialysis. The self-management programme was developed to enhance the patients' ability to control their food, water and medication. Overall, the quality of life of the experimental group was significantly higher than the control group. Both programmes are more appropriate for CKD patients during stages 1 to 3 rather than in stages 4 and 5 (ESRD), when patients are very ill and have to depend on others. These two quasi-experimental studies consisted of homogenous sample demographic data collected from experimental and control groups, but the sample sizes (Yowaphui 2008) (N= 30) and (Pungchompoo *et al.* 2010) (N= 40) were not large enough to yield clear results (Burns & Grove 2005). The researchers were not blind to the participants' allocation, as the researchers conducted follow-ups for the patients that they had recruited. This could indicate a potential bias in the results of the experimental studies (Parahoo *et al.* 2006). Furthermore, the study of Yowaphui (2008) was limited because of the short follow-up time (four months). Follow-up should be implemented for six months or longer in

order to allow time for the patients to change their behaviour and adapt to controlling their health (Sandstrom & Keefe 1998).

The eight reviewed studies did not provide evidence of the specific symptom experiences and health care needs of older ESRD patients who are managed without dialysis in Thailand. Further qualitative research is necessary to explore the characteristics, severity of symptom experiences and needs in terms of health service provision among older Thai ESRD patients who are managed without dialysis.

3.5 Characteristics of worldwide studies

The researcher retrieved 170 full texts of potential publications worldwide (published in Australia, Brazil, Canada, Hong Kong, the UK and the USA) for this study, of which 163 studies were excluded (please see Figure 2). A final set of, seven articles was selected for review, including one retrospective analysis (Murtagh *et al.* 2007e), one cross-sectional study (Gunda *et al.* 2005), one prospective cross-sectional study (Yong *et al.* 2009), one prospective observational study (Wong *et al.* 2007), one qualitative exploratory design (Noble *et al.* 2010), one quasi-experimental study (Weisbord *et al.* 2003) and one systematic review (Lorenz *et al.* 2008). A review and evaluation of the strengths and weaknesses of these articles is provided in Appendix C (Table 22 and 23).

3.5.1 Research design and objectives

In the UK, Murtagh *et al.* (2007e) conducted a retrospective analysis to compare the survival of elderly dialysis and non-dialysis (conservatively managed) patients with stage 5 ESRD. Gunda *et al.* (2005) performed a cross-sectional study to establish the current pattern of provision of palliative care for ESRD in the UK. Yong *et al.* (2009) conducted a prospective cross-sectional survey to explore the symptom burden and quality of life (QOL) of ESRD patients on chronic dialysis and palliative care in China (Hong Kong), while Wong *et al.* (2007) used a prospective observational design to evaluate the prognosis factors influencing the survival, hospitalization rates and survival

rates of non-dialysis treatment (NDT) patients in the UK. The prospective studies by Yong *et al.* (2009) and Wong *et al.* (2007) were analytical surveys which collected data in follow-ups within the same population (Bowling 2009b).

In the UK, Noble *et al.* (2010) conducted qualitative research to explore the experiences of ESRD patients managed without dialysis and their trajectories to death. Lorenz *et al.* (2008) did a systematic review to assess evidence about interventions to improve palliative and end-of-life care in the USA. In another study from the USA, Weisbord *et al.* (2003) did a pilot study using a pre-post-test experimental design to assess the symptom burden, Health Related Quality of Life (HRQoL) and advance care planning for seriously ill dialysis patients, to determine their suitability for palliative care. The study also assessed the acceptability of palliative care to such patients and their nephrologists. The research methodologies, including study design, population, sample methods, data collection instruments and data analysis techniques, are summarized and presented in Table 7 below. The judgement about the rigor of studies and the quality of the selected evidence from world-wide can be concluded and identified based on the major strengths and weakness which are provided at Appendices C (Table 23).

Table 7 Summary of methodological matrix for reviewed articles worldwide

Authors	Country /year	Study design	Population	Sample selection (size)	Data collection instruments	Data analysis
Murtagh <i>et al.</i>	UK/ 2007	Descriptive study/ retrospective analysis	ESRD patients managed with and without dialysis aged over 75 years	Stratified random sampling (N=129, 52 dialysis patients and 77 conservatively-managed patients)	Demographic data and data from individual comorbid factor questionnaire Renal registry categories The Modification of Diet in Renal Disease Formula (MDRD)	Mann Whitney U-tests and X ² A Cox proportional hazard regression model
Gunda <i>et al.</i>	UK/ 2005	Cross-sectional study	Clinical directors of all 69 UK renal units	Purposive sampling (N=69)	The palliative care provision questionnaire	Descriptive statistics (percentages)
Wong <i>et al.</i>	UK/ 2007	A perspective observational study	ESRD patients who chose not to have dialysis aged < 70, 71–80 years and >80 years	Stratified random sampling (N=30)	The Stoke Comorbidity Grade (SCG)	Cox regression multivariate analysis
Noble <i>et al.</i>	UK/ 2010	Qualitative study/ exploratory design	ESRD patients managed without dialysis (ages not provided)	Purposive sampling (N=30)	In-depth open-ended guide	Thematic analysis
Yong <i>et al.</i>	China/ 2009	A prospective cross-sectional study	ESRD patients from palliative care and dialysis groups aged 18 years and over	Stratified random sampling (N=179, 45 patients in palliative group and 134 patients in dialysis group)	Demographics and socioeconomic status questionnaire Modified Charlson Comorbidity Index (CCI) Prevalence and intensity of 23 ESRD-related symptoms Brief Pain Inventory and QOL by MOS SF-36	One-way ANOVA Pearson correlation coefficients
Weisbord <i>et al.</i>	USA/ 2003	Pre-and post-test quasi-experimental study (pilot study)	ESRD patients managed with haemodialysis (Charlson comorbidity scores ≥ 8) (average age of 59 years)	Purposive sampling (N=19)	Memorial Symptom Assessment Scale Short Form (MSAS-SF) Functional Assessment of Chronic Illness Therapy Spirituality Scale (FACIT-Sp) Dialysis Patient Choices at the End-of-Life Questionnaire (DPCELQ)	Wilcoxon sign-rank test Paired t-tests
Lorenz <i>et al.</i>	USA/ 2008	Systematic review	Articles related to end of life and chronic (fatal) illness, intervention studies (RCT or non-RCT) that addressed pain dyspnea, depression, advanced care planning, continuity and caregiving	N=33 systematic review, and N=89 intervention studies	Articles were searched from MEDLINE (January 1990 to November 2005) Database of Abstracts of Effects National Consensus Project for Quality Palliative Care bibliography from November 2005 to January 2007	Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) classification

3.5.2 Findings

3.5.2.1 What are the issues for ESRD patients worldwide?

Two reviewed studies from the UK, Murtagh *et al.* (2007e) and Wong *et al.* (2007), focused on the comparative survival of elderly patients with CKD stage 5 who were managed either with dialysis or conservatively (without dialysis) and factors affecting survival in advanced chronic kidney disease patients who chose not to receive dialysis.

Murtagh *et al.* (2007e) compared the survival rates of elderly (aged ≥ 75 years) ESRD patients managed with and without dialysis, and found that there was a significant difference in cumulative survival ($P < 0.001$). One- and two-year survival rates were higher in the dialysis group. Murtagh *et al.* (2007e) concluded that ESRD patients aged over 75 years who were referred to receive specialist nephrological care early and who choose to follow a planned management (dialysis) pathway have a survival advantage. The survival advantage of dialysis is possibly reduced by comorbidity due to other conditions such as ischaemic heart disease. Therefore, comorbidity should be considered when advising elderly patients managed with or without dialysis. Murtagh *et al.* (2007e) also suggested that conservative management should be considered for elderly patients with high comorbidity conditions including ischaemic heart disease. However, the decision to commence management without dialysis is complex for each patient.

It is important to recognise that conservative management (without dialysis) does not mean “without caring” or “absence of dialysis provision”; rather, it is active disease management and supportive care until death (Murtagh *et al.* 2007e). This retrospective study was not able to elucidate the complex process of how and why different dialysis decisions were made between the dialysis and conservative groups. Therefore, further research with a rigorous methodological design is needed to clarify and explore the problems underpinning how patients make their decisions about management with or without dialysis. In addition, work is recommended regarding prospective survival from the perspectives of both nephrologists and patients in terms of

the level of disease severity, symptom burden, patient preferences, quality of life and health service provision (such as referral system), which may all influence survival rate and decisions about dialysis. The small number of participants (N=129) and high attrition rate 63 (48.8%) (12 (23%) from the dialysis group and 55 (66%) from the conservative group) may produce bias in the comparison of survival rates between the groups. The small sample may not be representative of the population being studied (Parohoo 2006). In descriptive studies, response rates need to be high and the results could be biased if there is high sample attrition (Bowling 2009). In study described above, it is possible that the results might be related to differences in demographics, but they could also be related to the higher drop-out rate in the conservative group.

A prospective observational study from the UK (Wong *et al.*, 2007) involved 30 participants and used Cox multivariate regression to evaluate the prognostic factors influencing survival and hospitalization rates and the Renal Association Standard (RAS) in NDT (non-dialysis treatment) patients. Wong *et al.* (2007) found that the overall median survival of NDT patients was 1.95 years. The most common identifiable cause of non-dialysis treatment (NDT) was diabetic nephropathy. As with the studies carried out by Murtagh *et al.* (2007e) and Narenpitak and Narenpitak (2008), this research concluded that the number of elderly ESRD patients in UK is projected to rise steadily together with the increasing of prevalence of Type II diabetes mellitus. However, in contrast with the work of Murtagh *et al.* (2007e), Wong *et al.* (2007) found that age did not affect the survival rate as determined by the Stoke comorbidity grade (SCG). The study showed a statistically significantly lower survival rate related to comorbidities in those managed without dialysis. Ischaemic heart disease was found to be the most common comorbidity factor in patients managed with or without dialysis in the UK (Wong *et al.* 2007; Murtagh *et al.* 2007e). In addition, late referrals and ESRD complications may also reduce survival rate in both dialysis and non-dialysis patients. The study also revealed that more than 60% of non-dialysis patients were not admitted to a hospital over a three-year period.

Non-dialysis treatment may seem to make it more likely that ESRD patients will die at home where they are surrounded by their families, rather than in hospital. In order to achieve the best possible quality of life, a multidisciplinary approach to help ESRD patients choose the most appropriate treatment and an agreed care plan to support them during treatment are recommended by Wong *et al.* (2007). In addition, the integration of health services at primary care level, achieved by cooperation between community nurses and palliative care teams, should be considered for providing care at home and enabling a dignified death. The Stoke Comorbidity Grade (SCG) instrument, which evaluates the score system for the survival of patients on renal replacement therapy, was validated and has been used with many chronic diseases. However, the process of validating the instrument was not provided in the article. The study was reported to be the first prospective observational study that provides evidence for the use of the SCG as an independent prognostic indicator with NDT patients in the UK; the use of the SCG may help health professionals to provide good advice to patients when they choose NDT. In order to ensure the transferability of these results to different health care systems, such as Thailand, the identification of demographic variables and reliability of the instrument would be required.

3.5.2.2 What is the symptom experience of older ESRD patients while managing without dialysis worldwide?

Three studies were found from different countries including the UK (Noble *et al.* 2010), the USA (Weisbord *et al.* 2003) and China (Hong Kong) (Yong *et al.* 2009).

The US study suggested that symptoms of dialysis patients are highly prevalent, severe and may be underestimated by nephrologists. Furthermore, symptoms were correlated with health-related quality of life (HRQoL) (Weisbord *et al.* 2003). Impaired quality of life was also associated with a failure to provide advanced care planning for dialysis patients. The symptoms which caused the greatest burden in severely ill dialysis patients in Weisbord *et al.*'s (2003) study were pain (79%) (either neuropathic pain, e.g. numbness and tingling, or nociceptive pain) and fatigue (74%). Pain was reported to be one of

the most common and the most severe symptoms evaluated by MSAS-SF in the study. Secondly, the impairment of health-related quality of life was significantly related to high levels of co-morbid illness. The study also found inadequate advanced care planning by nephrologists, underscoring the potential value of palliative care for dialysis patients.

However, the study did not measure the change in symptom burden over time as the research was carried out over a short period (pilot study). This also meant that the study could not provide a picture of the symptom trajectory in dialysis patients. The small sample might not be representative of the whole population, and this influences the generalisability of the results. Further research is needed to replicate the study findings in a larger population over a longer period. Evidence regarding the validity and reliability of the instruments including MSAS-SF, FACIT-SP and DPCELQ was limited since these instruments have not been used with ESRD patients. Parahoo (2006) stated that self-report questionnaires can provide unreliable results as they rely on the participants' abilities to give an objective response and the researcher's ability to interpret the participants' meaning in their analysis. All study instruments should be tested for reliability and validity in order to minimise bias and to ascertain the generalisability of the research findings to the wider population (Laker 2007). Furthermore, the review of symptoms was based on nephrologists' documentation (charts and documentation of symptoms), not on direct questioning of patients or carers. Therefore, it is likely that some symptoms were not recorded, recognised or fully captured by the nephrologists. Recall bias by nephrologists is also a possibility. Adequately powered research studies are required, using appropriate validated questionnaires to explore the relationship between symptom burden, quality of life and the benefits of palliative care in dialysis and non-dialysis patients and carers.

One prospective cross-sectional study explored the symptom burden and quality of life (QOL) of ESRD patients in a hospital in China (Yong *et al.* 2009). This study reported that fatigue, cold aversion, pruritus, lower torso weakness and difficulty sleeping were the five most prevalent symptoms in a comparative study of dialysis and non-dialysis patients. Yong *et al.* (2009) used standardised questionnaires and reported that there was significant symptom

burden and impaired QOL in both dialysis and non-dialysis groups. Some symptoms were prevalent in both groups. However, skin changes, halitosis and sexual problems were more prevalent in the dialysis group, while dyspnoea was found to be higher in the palliative care group. Pruritus, changes in taste, bloated abdomen and limb numbness were more intense in the dialysis group. Pain was found to have similar intensity in both groups. The quality of life of dialysis patients seemed to be more impaired, and all quality of life domains had a negative relationship with the number of symptoms. Good symptom control for ESRD patients is recommended by Yong *et al.* (2009). In addition, these authors noted that patient characteristics such as older age, low socioeconomic status and more comorbidities might be factors that indicate patient choice for renal palliative care.

A limitation of this study was the representativeness of the results since the study was conducted in one hospital in Hong Kong. The sample size was 179 patients, 45 (25.1%) in the palliative care group and 134 (74.9%) in the dialysis group. The cross-sectional design provided information about symptom burden and quality of life of the both groups at one point in time, but these factors might change over time based on the trajectory of ESRD until death. Future research employing a mixed method design, for example a mixed method exploratory study recruiting patients from diverse health care settings, is needed to explore symptom burdens and trajectories of older ESRD patients who preferred palliative care.

A UK study conducted by Noble *et al.* (2010) involved a qualitative exploratory study to explore the experiences of 30 ESRD patients managed without dialysis. In-depth interviewing was used to collect the data. The study found a high prevalence of symptoms in this patient group. Thirty different symptoms were reported in the study, including altered taste, breathlessness, pruritus, lack of energy, dizziness, pins and needles in the legs, nausea, vomiting, diarrhoea, constipation, poor appetite, poor balance, trembling, pain, immobility, insomnia, depression, poor memory, sore mouth/tongue, confusion, aching body, cramps, poor vision, weight loss, weakness, incontinence, phantom pain, difficulty swallowing, dry skin and headaches. The most problematic symptoms for patients managed without dialysis included breathlessness, pruritus, lethargy, insomnia, nausea and vomiting

and pain. Some symptoms, such as fluid overload, pruritus and lethargy, were difficult to treat because they indicated that death was close. Noble *et al.* (2010) also noted that if the symptoms were well managed, then anxiety decreased.

Recommendations were made for further studies focusing on the control of specific symptoms such as pain. Knowledge of symptom profiles and patterns of change is urgently required to help nurses and health care professionals prevent or relieve distress and provide optimum end of life care to these patients. Evidence about the effectiveness of pharmacological interventions, alternative treatments and appropriate psychological and practical support such as massage should also be considered. Furthermore, staff training about symptom assessment and end-of-life care was recommended so that staff will be better able to provide support for patients and carers. Ethical issues involved in conducting research with dying patients also had implications for the study findings. Patients at the end stage of their disease may not be able to provide full information in order to determine their physical and mental health conditions (Bowling 2009). The process of qualitative data analysis was not clearly explained in the study, and this might influence the credibility of the results. The study did not explore the changes in symptoms over time (until death). Future studies should be longitudinal to explore symptom experiences and health service provision for ESRD older patients from the perspective of carers during the time that patients are managed without dialysis until their deaths. This will help to ensure that optimum symptom management and good quality of life will be maintained through the disease process as the end of life approaches.

3.5.2.3 What are the health care needs of older ESRD patients while managing without dialysis worldwide?

Two studies, a descriptive survey by Guanda *et al.* (2005) and a systematic review by Lorenz *et al.* (2008), both carried out in the UK, are reviewed under this heading.

Guanda *et al.* (2005) conducted a national survey to find out about the current pattern of provision of palliative care for ESRD patients in the UK. Sixty-nine clinical directors, encompassing every renal unit in the UK, were purposively selected to answer a palliative care provision questionnaire. The issue of increasing numbers of ESRD patients who were not suitable or who refused to receive dialysis treatment was raised. This issue is more common in elderly patients who are likely to withdraw from dialysis treatments. This is because elderly patients become too frail and are unable to tolerate dialysis treatments. Palliative care services for older ESRD patients are needed. Palliative care seems to be able to reduce suffering during the dying process. However, Gunda *et al.* (2005) found that 55% of renal units do not have a written protocol for palliative care. The study found significant variation in the provision of palliative care services across the UK, since palliative care services were not provided for ESRD patients in some units. This may be related to lack of resources and renal staff workload. Gunda *et al.* (2005) addressed the needs of palliative care services for ESRD patients, recommending that services should include symptom control, advanced care planning, and special attention to ethical, psychological and spiritual dimensions. Maintaining the quality of life and quality of dying, and also improving the knowledge and skills of nephrologists and renal staff about a palliative care approach, were recommended.

A limitation of the study is that explanations of the research design, method of data collection (the validity and reliability of the instrument) and analysis were not clearly provided. Therefore it was difficult to evaluate the accuracy of the data or the credibility of the results (Polit & Beck 2012; Bowling 2009). The recruitment process and demographic characteristics of participants were not fully explained. Furthermore, as the participants were all clinical directors of renal units, they might try to provide positive portrayals of their roles, reducing the quality of the data collected. Further research is needed that uses an effective instrument to explore and gather detailed information related to symptom burdens and the needs of palliative care services for non-dialysis groups. Patients, carers and other members of the renal team should be recruited to participate and share their experiences.

Lorenz *et al.* (2008) conducted a systematic review to inform improvements in palliative care at the end of life. Thirty-three high-quality systematic review articles and eighty-nine intervention studies were included in the study. The reviews found that the critical issues surrounding caring at the end of life included preventing and treating pain and other symptoms, supporting families and caregivers, ensuring continuity, making informed decisions, attending emotional well-being (including spiritual aspect), sustaining physical function, and increasing the survival period. The identification of patients who could benefit from palliative care was found to be important, and a palliative care approach also required effective management and the good coordination between patients, carers and health care staff. Several strategies for the relief of symptoms and suffering (such as pain, dyspnea and depression) during the end of life were recommended, including pharmacological treatment as well as complementary and alternative treatments (exercise or acupuncture, reflexology, aromatherapy and massage). However, more evidence is needed to support the identification of effective treatments. Finally, twenty studies supported the suggestion that palliative care, which consisted of pain and symptom control, care planning, patient education and alternative medicine approaches such as massage, should be delivered to patients at the end of life. The study was limited by using non-specific search terms in domains of spiritual support and bereavement. The end-of-life and palliative care of ESRD patients managed without dialysis was not addressed in the study. Therefore, the results for improving palliative care at the end of life cannot be directly transferred to those patients.

3.6 Conclusions

The main topics studied were related to the high prevalence of ESRD, risk factors (diabetic, hypertension and ischemic heart disease), population age group, the cost effectiveness of three different treatments (PD, HD palliative care), and symptoms of ESRD patients who have received haemodialysis that derive from studies conducted in Thailand. The eight relevant Thai studies clearly provide insufficient evidence related to the symptom experiences and health care needs of older ESRD patients who are managed without dialysis. No

research was located that sought to explore the needs of ESRD patients for whom HD/PD is not provided, or who refuse to receive RRT, and the provision of health services to support them. Particularly, the current health services for these patients need to be evaluated and potentially improved to meet patients' needs. In contrast, issues of comorbidity, risk factors, symptom burdens and quality of life among dialysis and non-dialysis patients were addressed by the worldwide articles. The Western studies have identified the survival rate and comorbidity between dialysis and non-dialysis groups, symptom distress, unmet needs, and poorly managed symptoms. Comprehensive management such as conservative care for non-dialysis groups was also recommended from the worldwide studies. However, an adequate picture related to the trajectory of symptom experiences until death and the specific evidence of end of life support for non-dialysis patients was not provided by the worldwide studies. In addition, the outcome measurement, demographic results and findings from the seven worldwide studies may not be generalizable to other settings, especially Thailand where there is a different cultural context and health care system. Regarding symptom burden and lack of specialist services for the non-dialysis group in Thailand, research using a robust research design and rigorous methodology is needed to fill the knowledge gap for this group and generate clinical innovations necessary to improve the quality of care and maintain patients' quality of life.

These critical literature reviews have informed the research design adopted in the current study. The use of an exploratory sequential design that combines qualitative and quantitative methods will address some of the limitations of previous studies. This design explicitly interrelates and connects qualitative and quantitative stands (Creswell & Plano Clark, 2011). The researcher will use qualitative findings from the first phase to generate the culturally specific VOICES-ESRD/Thai questionnaire, which was then used for collecting the quantitative data in the second and third phases. Therefore, the combination of qualitative and quantitative approaches should provide a better understanding of the specific symptom experiences and health care needs of older ESRD non-dialysis patients in Thailand. The development of a culture-specific instrument, sensitive to the specific symptom experiences, culture and beliefs and health system in Thailand, will enable the collection of quantitative

data providing accurate information about the symptom experiences and health care needs of this group. Future research using the VOICES (Views of Informal Carers – Evaluation of Services) questionnaire will enable the collection of data that is representative of the Thai population. Concerning ethical issues and the difficulty of conducting research with dying patients (Bowling 2009), the research adopts a retrospective post-bereavement approach in order to collect the data. A proxy report technique was used to explore bereaved relatives' perspectives on the deceased patients' experiences because the proxy account is a good method for collecting data regarding aspects of care relating to service provision (Elkington *et al.* 2005).

To achieve the best outcomes, this study therefore seeks to address weaknesses in the current evidence base by meeting three main objectives according to the three phases of the study:

Phase I: to explore the last year of life of older ESRD patients managed without dialysis from the perspective of bereaved relatives, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death.

Phase II: to develop/ adapt the VOICES-ESRD/Thai questionnaire for use in a population survey in Thailand.

Phase III: to test a prototype of the VOICES-ESRD/Thai questionnaire through conducting a pilot survey of the experiences and health care needs of older people with ESRD managed without dialysis in Thailand.

Chapter 4: Overview and introduction to research design of the study

4.1 Introduction

In this chapter the mixed method, exploratory sequential design will be discussed in order to explain how this approach enabled an exploration of symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. A summary of the 3 different phases of the study will be provided, along with how participants were approached and consented to take part along with core ethical issues.

4.2 Research design

4.2.1 Mixed methods research

According to Greene (Greene 2007) mixed methods can be defined as “...multiple ways of seeing and hearing, multiple ways of making sense of the social world and multiple standpoints on what is important and to be valued and cherished” (p.4). This concept opens up the researchers’ point of view to think about how the research design, approach and methods could be applied to explore the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. In order to better understand the nature of mixed method research and the philosophical assumptions behind such a model, Creswell & Plano Clark (2007 & 2011) provided the following definition of mixed method research:

“Mixed method research is a research design with philosophical assumptions as well as methods of inquiry. As a methodology, it involves philosophical assumptions that guide the direction of the collection and analysis of the data and the mixture of qualitative and quantitative approaches in many phases of the research process. As a method, it focuses on collecting, analysing, and mixing both quantitative and qualitative data in a single study or series of studies. Its central premise is

that the use of quantitative and qualitative approaches, in combination, provides a better understanding of research problem than either approach alone.” (p.5)

Mixed methods design may be fixed, where the use of qualitative and quantitative methods is predetermined and planned at the start of the research process, and procedures are implemented as planned, or emergent, where the use of mixed methods arises due to issues that develop during the process of conducting the research (Creswell & Plano Clark 2011). In addition, the researcher has to consider which approach (typology-based, dynamic or synergistic) should be used. There are four key decisions involved in choosing an appropriate mixed methods design, these being 1) the level of interaction between the strands (the component of a study that encompasses the basic process of conducting quantitative or qualitative research); 2) the relative priority of the strands; 3) the timing of the strands and 4) the procedures for mixing the strands (Creswell & Plano Clark 2011). A researcher must consider which basic mixed methods design, such as a convergent parallel design, explanatory sequential design, exploratory sequential design and embedded design, might be suitable for a study. The next step then involves the researcher choosing a specific design and offering reasons why that design is appropriate. An explanation of these issues in related to this study now follows.

4.2.2 The exploratory sequential design

This study aims to explore the symptom experiences and health care needs of ESRD older people who managed without dialysis in Thailand and to develop and test an instrument for measuring the experiences and needs of those patients. The researcher selected an exploratory sequential design. The purpose of a mixed-method exploratory sequential design is to explore issues qualitatively, with a small sample, and then to determine if these findings generalize in a quantitative pilot survey (Creswell & Plano Clark 2011, p.114). One reason for choosing the exploratory design is that such a qualitative research method can help develop or inform the second or quantitative method (Greene *et al.* 1989 cited in Creswell & Plano Clark 2011). The mixed-method exploratory sequential design begins qualitatively; it is best suited for exploring a phenomenon and it

is particularly useful when the researcher needs to develop and test an instrument (Creswell *et al.* 2004; Creswell & Plano Clark 2011). Since the exploratory design begins qualitatively, the research problem often calls for the qualitative strand to have greater priority than the quantitative strand, within the design. Bearing the points above in mind, the researcher has to work from constructive principles during the first phase of the study to gain a deeper understanding of the problem. Then, the researcher moves to the quantitative phase; the underlying assumptions shift to principles of positivism to guide the need for identifying and measuring variables and statistical trends.

In addition, the exploratory sequential design uses sequential timing by beginning with and prioritizing the collection and analysis of qualitative data in the first phase. Building from the exploratory results, the researcher will then conduct the second phase focusing on gathering quantitative data, in order to test or generalize the initial findings. The level of interaction between the qualitative and quantitative strand occurs when the researcher develops an instrument as an intermediate step between the phases that builds on the qualitative results and is used in the subsequent quantitative data collection (Creswell & Plano Clark 2011, p. 86).

The exploratory sequential design with three phases used in this study is briefly set out in Figure 3, 4 and Table 8 below before fuller details on method are described later in the thesis.

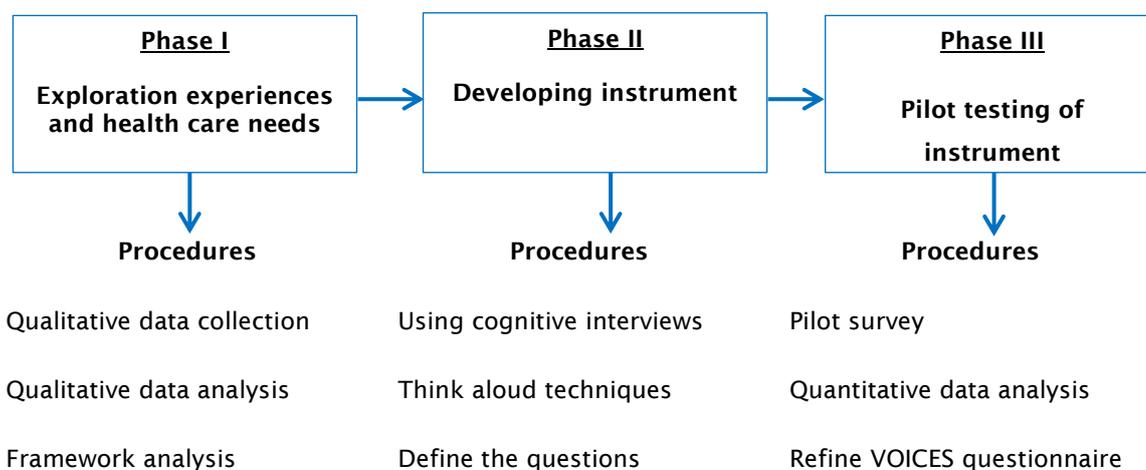


Figure 3 Diagram of the study design

Table 8 Brief summary of three phases of the study

<p>Phase 1: Exploration of symptom experiences and health care needs of older people with ESRD managed without dialysis.</p> <p>Objective: To explore the last year of life of ESRD older patients managed without dialysis from the perspective of bereaved relatives, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death. Research adopted a retrospective post-bereavement approach to collect qualitative interview data. A semi-structured interview was conducted with 12 bereaved relatives of ESRD older patients managed without dialysis between 5-10 months after death. Data were digitally recorded, transcribed and analysed through Framework Analysis.</p>
<p>Phase 2: Developing a survey instrument</p> <p>Objective: To develop/ adapt VOICES for use in a population survey in Thailand. The qualitative results from phase 1 were transferred to adapt the VOICES questionnaire for use in a population-based survey with ESRD older people who are managed without dialysis in Thailand. The focus of the questionnaire was upon symptoms, symptom control and health care needs of older people with ESRD managed without dialysis. A cognitive interviewing technique was applied with a sample of 10 bereaved carers using the prototype of an ESRD-specific, culturally relevant VOICES questionnaires.</p>
<p>Phase 3: The pilot testing of instrument</p> <p>Objective: To test prototype of ESRD version of VOICES questionnaire through conducting a pilot survey of experiences and health care needs of older people with ESRD managed without dialysis in Thailand. Phase 3 tested the adapted VOICES questionnaire. The purpose of this stage was to test method of recruitment and administration, examine response rate, instances of missing data, identify redundant data items and further refine the VOICES questionnaire. The questionnaire was the interviewer-administered with a sample of up to 20 bereaved relatives of older people with ESRD managed without dialysis between 5-10 months after death. Data were analysed using descriptive statistic SPSS version 17.</p>

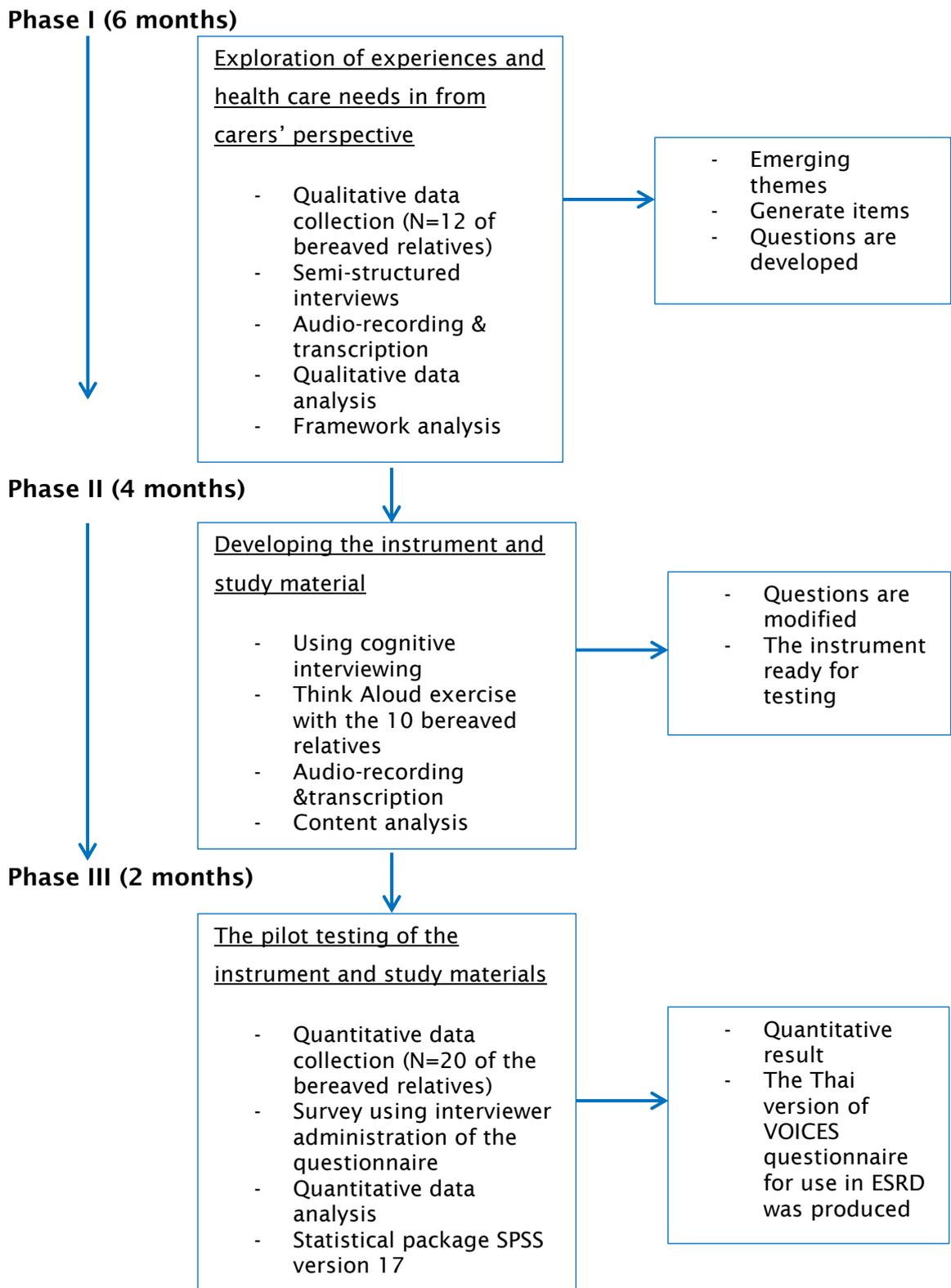


Figure 4 Procedure for sampling, data collection and analysis for the study

4.3 Eligibility criteria

4.3.1 Inclusion criteria

The participants for the study within the three phases consisted of bereaved relatives of older people aged 60 or above with ESRD managed without dialysis

- involved in caring for patient in the last three months of life,
- willing and able to participate in the study
- capable of providing informed consent (not cognitively impaired), and
- experienced the death of a person with ESRD 5-10 months previously

4.4 The participant information sheet

The participant information sheet (see Appendix H) was prepared for participants. Likewise, a separate, comprehensive information sheet with study details and contact details of the study were prepared and given to participants directly by the researcher at the first meeting. Three participant information sheets were written for the participants of each phase. These sheets were in the information pack which consisted of the participant information sheet, the consent form (see Appendix I) and a reply slip for potential participants to complete. The renal nurse phoned to provide initial information and sent the invitation letter (contact letter) (see Appendix G) to potential participants. The reply slips with name and contact details of participants were returned to the researcher. Next, the researcher sent the information pack to potential participant, providing time for them to read and decide. Then, the researcher phoned to confirm willingness to take part. If potential participants had not received the information pack, they were given further information and an invitation to join the study over the phone. In this case, the information pack was provided to potential participant by the researcher at the first meeting.

4.4.1 Consent

In each phase, participants were asked to provide written consent to participate in the study and for the researcher to collect the data. After the researcher had phoned potential participants to enquire if they were willing to participate in the

study, the consent form (see Appendix I) was sent with the enclosed information pack. Then, the researcher arranged the date for the meeting by phone and consent was obtained at this meeting.

4.5 Project management and document preparation

The project protocol was prepared in English to facilitate supervision and an extended peer review. After the content of all the documentation had been agreed, all study documents were translated into Thai (by the researcher) and checked by three Thai experts on ESRD and two Thai experts on language (both in English and Thai language). This included the translation of the Thai version of VOICES questionnaire. This translation was back-translated to ensure consistency. All interviews were conducted in Thai. The initial data analysis was carried out in Thai. The researcher translated the essential data into English to facilitate sharing the process of data analysis with her supervisors (please see Appendix U). The integration of findings from the three phases of the research occurred during the interpretation and the reporting phase.

4.6 Ethical considerations

The study protocol was approved by the Research Ethics Committee at the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand and the Research Ethics Committee from two hospitals (Nakorn Ping hospital and Chiang Mai Ram hospital), before the process of data collection began (see Appendix D). Concerning sensitive issues with bereaved relatives who might be suffering and distressed from the death of their relatives, the researcher sought to respect their rights and protect them from discomfort and harm (based on the ethical principles of beneficence and non-maleficence including the physical, emotional and social aspects (Burns & Grove 2009). The study was concerned with balancing accuracy of information and avoiding emotional distress to relatives. Thus, the study was performed between five and ten months after the death of the deceased person (Elkington *et al.* 2004; Elkington *et al.* 2005a; Elkington *et al.* 2005b).

The invitation letter and participant information sheet (see Appendix G and H) were based on the standard templates used within Chiang Mai University. The researcher briefly explained the purpose and the procedure of the study to participants. Potential participants were given at least 24 hours to make a decision as to whether to participate in this study. Written and oral consent were taken when a person chose to participate. Participants were also informed there were no anticipated risks to taking part in the research and reassured their care would not be affected by participating in this study. In each phase, participants were informed they could withdraw or not continue to complete the interviewing process at any time without penalty.

4.7 Data protection

Prospective participants were assured their privacy would be protected at all times (Polit & Beck 2004). Participants' information was kept in locked storage facility accessible only by the principle investigator (PI). Electronic data were anonymized. Study participants were identified by a unique study identification number, the key/code to which was held by the PI. Study data were held in locked storage, separate from the participant identifying data. The study data were therefore confidential and accessed only by the PI and others involved in analysis of the data. Study records will be stored as described above for a period of 10 years according to data protection policy developed by the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University and the Faculty of Health Sciences, University of Southampton.

4.7.1 Phase 1 Exploration of symptom experiences and health care needs of older people with ESRD managed without dialysis

In the process of conducting the semi-structured interview (see Appendix K), the researcher allowed time for participants to rest, listened to them, or stopped the interviewing if they were unable to continue to answer the questions. Then re-arranged the next meeting based on their convenience. Finally, the qualitative data are quoted and attributed are presented.

4.7.2 Phase 2 Developing the instrument

During the cognitive interview participants were informed they could withdraw or not continue to complete the interview process at any time without penalty. The researcher explained to participants the process, including how to use the think aloud technique, by following the guideline for conducting the cognitive interview (see Appendix L). The participants were allowed time to understand, interpret and answer the questions.

4.7.3 Phase 3 The pilot testing of the instrument

In regard to the quantitative data, the participants were interviewed at home or hospital, based on subject's convenience. The time taken to complete the questionnaire was up to one hour. The data were analysed and the results reported as a group. The participants were assigned unique code numbers identified on the questionnaires (see Appendix R and S). The codebook that lists the subject's names and numbers was stored in a locked cabinet accessed only by the PI.

4.8 Researcher safety

In order to respond to specific issues about carrying out interviews in the home situation related to lone working, the researcher followed the Lone Interviewing Risk Assessment Guidance, the Lone Interviewing Checklist and the Lone Interviewing Contact Procedure and Location Form that was provided by the Research and Enterprise Service Office, at the University of Southampton Faculty of Health Science, United Kingdom. However, the study was planned to be conducted in Thailand. Therefore, the emergency contact address was the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand.

4.9 Support for research participants

When participants felt emotionally distressed during the data collection process, the researcher observed closely and provided information or telephone numbers for them to contact the renal nurse for support at the renal unit. If the researcher noted the participant was facing severe distress after participation in the data collection process and felt they might need treatment or care, the researcher (with the person's permission) referred the participant directly to general physician (GP) at the emergency department of the Nakhon Ping Hospital or discussed the issue with the renal nurse and the general physician and they were able to refer the participant to receive specific treatment.

Chapter 5: Methodology of phase I: Qualitative interview data

5.1 Introduction

This chapter explains the methodology used to conduct the qualitative phase of the research. Purposive sampling was used to recruit 12 bereaved relatives of older ESRD patients. The qualitative data collection and analysis are also described below.

5.2 Design

This phase of the study involved a qualitative exploration of the experiences and health care needs of older people with ESRD being managed without dialysis. The findings of this phase were used to inform the data collection in the second and third phases. A descriptive or exploratory design was used to explore the phenomena as experienced by the study population. This provided the researcher with a way to understand the symptom experiences that patients were faced with, and explain what health services they needed during the time when they were managed without dialysis. Retrospective, exploratory data collection was employed in this phase by recording information about older peoples' experiences of ESRD managed without dialysis from the perspective of bereaved relatives.

5.3 Objective

The first phase of this project aimed to explore ESRD elderly patients' experiences and health care needs when managed without dialysis, from the perspective of bereaved relatives.

5.4 Sample

Qualitative research is not aimed at generalizing from the sample but rather aimed at developing an in-depth understanding from a small number of participants (Creswell & Plano Clark 2011). Numbers may range from between 1 or 2 people to 20 or 30 depending on the question and type of qualitative approach (Creswell & Plano Clark 2011). In qualitative research, purposive sampling means the researcher will intentionally select (or recruit) participants who have experienced the central phenomenon, or the key concept, being explored in the study (Creswell & Plano Clark 2011). In this study purposeful sampling was used to recruit participants based on the criteria of sex, age, relationship with the patient, income and area of living (rural or urban). It was aimed to recruit a sample of up to 15 bereaved relatives of older people were managed without dialysis from the renal unit at Nakon Ping Hospital and Chiang Mai Ram Hospital, Chiang Mai Province, Thailand.

5.4.1 Access to settings

After the protocol was approved by the Faculty of Health Sciences, University of Southampton, UK, the research protocol was submitted to the Research Ethics Committee at the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand and the Research Ethics Committee from two hospitals (Nakorn Ping government hospital and Chiang Mai Ram private hospital), to allow the researcher to conduct the research in Thailand. Once approval had been received from the IRB at the Faculty of Nursing (see Appendix D), Chiang Mai University and the two hospitals (see Appendix D), the researcher sent the information letters and copies of the protocol to the administrators of the relevant Renal units to ask them for permission to collect the data. Collaboration with the renal nurses to facilitate the recruitment process was begun when the researcher received permission. Potential participants were selected from specialist renal units in hospitals in Chiang Mai Province. Nakorn Ping hospital is the tertiary government hospital and consists of 800 patients' beds. While, Chiang Mai Ram hospital is the main private hospital in Chiang Mai province which consisted of 350 patients' beds. The researcher selected two different types of hospitals that both provide general care to ESRD patients in Thailand. These two different hospitals serve patients referred directly or indirectly from more than 25 district hospitals and 25 community hospitals in Chiang Mai

Province. The renal units also had a register of people who were waiting to receive or had refused dialysis and also the names of people who register a death whilst waiting to receive dialysis and those who had refused dialysis.

5.4.2 Recruitment process

The two renal units where the study was undertaken had a database of all ESRD patients who have died. This included older patients managed without dialysis and the name of the informant who registered the death. Their details were not passed to the researcher. The informant who registered the death was identified by the renal nurses who were trained how to select participants by the researcher. The instructions for renal nurses were developed by the researcher and then provided to the renal nurses (see Appendix E). The recruitment process, in regard to approaching potential participants for the study, is shown in Figure 5 and consisted of 7 steps. Potential participants were asked to identify the informal carer who provided the most care to the older ESRD patients. If they were not the person registered the death they were asked to identify the person who provided direct care to the patient. The renal nurse phoned to provide initial information and sent the invitation (contact) letter (see Appendix G) to potential participants. The reply slips with name and contact details of participants were returned to the researcher. Next, the researcher sent the information pack to potential participant, providing time for them to read and decide participant information sheets as written for the participants (see Appendix H). These sheets were in the information pack which consisted of the participant information sheet, the consent form (see Appendix I) and a reply slip for potential participants to complete. Then, the researcher phoned to confirm willingness to take part. If potential participants had not received the information pack, they were given further information and an invitation to join the study over the phone. In this case, the information pack was provided to potential participant by the researcher at the first meeting. Likewise, a separate, comprehensive information sheet with study details and contact details of the researcher was prepared and given to participants directly by the researcher at the first meeting.

In the first phase, the informants' accounts were used as a proxy for the deceased person's experience. Twenty five carers were approached but only 12

interviewed. The reasons for this included 1) flooding during the rainy season in Thailand (8 persons); 2) moving their place of residence from rural areas in Chiang Mai province to urban areas in Bangkok in order to get a job (3 persons) and 3) having no time available to be interviewed (2 persons).

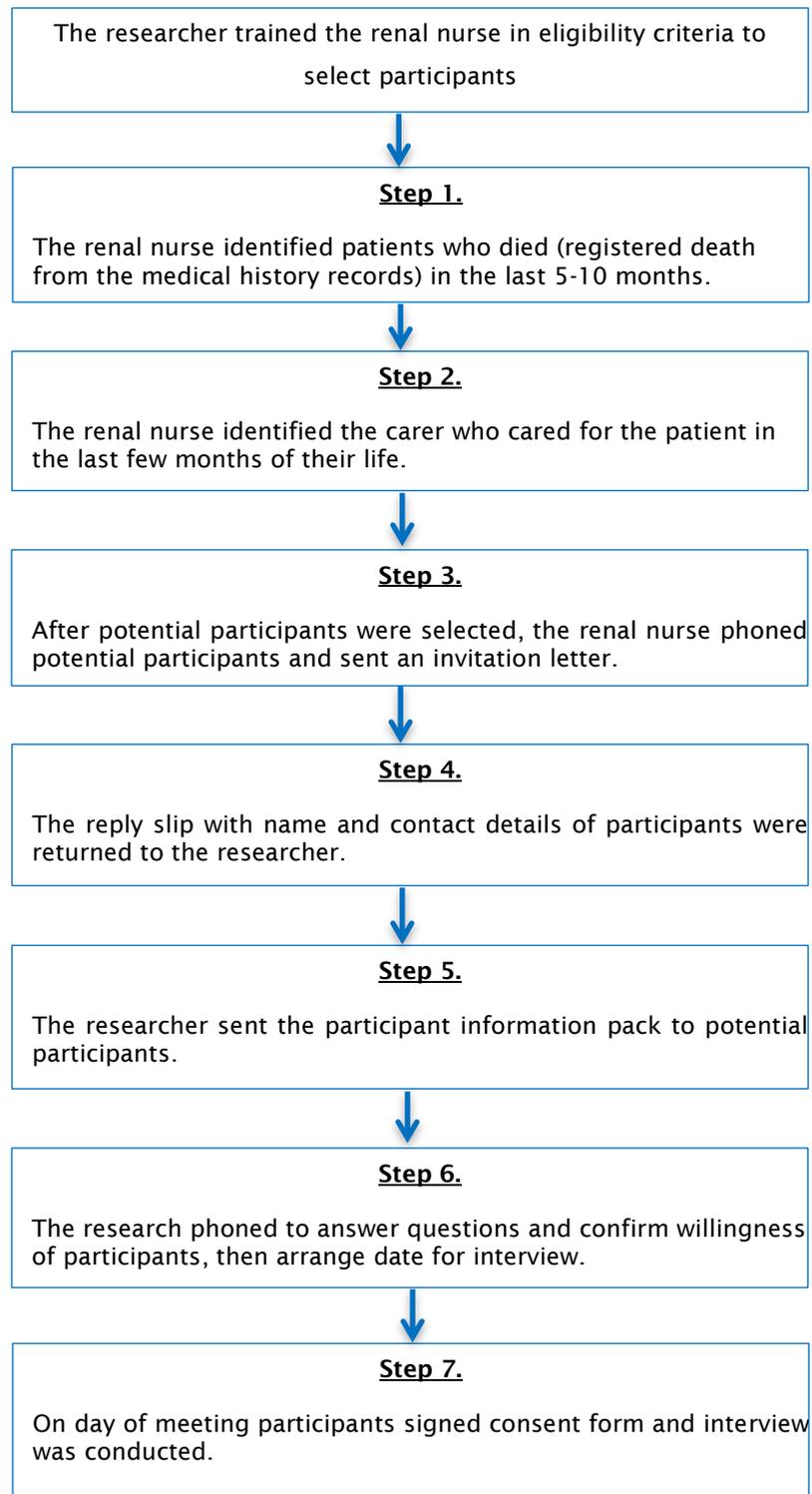


Figure 5 The recruitment process to approach potential participants in the three study phases

5.5 Data collection

5.5.1 Retrospective data collection

In a mixed methods exploratory design researchers first collect qualitative data, analyse it, and then use the information to develop a follow-up quantitative phase of data collection (Creswell & Plano Clark 2011). The retrospective approach to data collection, in which carers' accounts are used as proxies for a deceased person's experiences, is a well-established method for gathering information about the last year of life (Elkington *et al.* 2004). A retrospective study involves collecting data about the past and provides useful information or indications for any future investigation (Bowling 2009a). Twelve bereaved relatives were interviewed between 5-10 months after the death of the family member they were caring for. According to Elkington *et al.* (2005b) it may not be acceptable or appropriate to approach subjects for a proxy account sooner than five months after death. However, the shorter the time interval between an event and its report are the better the recall. Therefore, a balance needs to be struck between accuracy of information and avoidance of emotional distress and also the weakening or growing inaccuracy of the recall process (Elkington *et al.* 2005b).

5.5.2 Semi-structured interviews

Following the approach to potential research participants by healthcare staff and agreement to participate, data were collected. Semi-structured interviews were used to explore patients' experiences of symptoms, symptom control, contact with health care services and information received. With an exploratory study design data collection is likely to be less structured, especially in an area where little is known or the key objective is to understand how participants' conceptions or values emerge through their speech and their narrative (Ritchie & Lewis 2011a). But, the researcher also wished to be certain that a specific set of topics were covered during the interview (Polit & Beck 2012). During a semi-structured interview the interviewer asks key questions in the same way each time and does some probing for further information. However, probing is more limited than in unstructured or in-depth interviews (Ritchie & Lewis 2011a). Semi-structured interview schedules or topic guides consist of mainly fixed

questions but with no or few response codes and are used flexibly to allow the interviewer to probe and enable respondents to raise other relevant issues which are not covered by the interview schedule (Bowling 2009c). In this study, the form of these interviews was face-to-face and most of the interviews took place in the subjects' homes, a few by phone and one at the subject's work place for the subject's convenience. The researcher prepared a topic guide, which comprised a list of questions to be covered with each participant (Polit & Beck 2012). Then, the researcher encouraged participants to talk freely about the topics on the guide, and to tell stories in their own words.

5.5.3 The interview topic guide

The interview topic guide was developed based on the VOICES questionnaire (View of Informal Carers-Evaluation of Service) which has been used to evaluate experiences and health care needs of patients with a range of chronic diseases in the last year of life (Addington-Hall 2002). According to Ritchie & Lewis (2011) the interview topic guide is developed for use as a broad agenda of topics or themes for the interviewer to explore. The topic guide offers a tool to enhance the consistency of data collection and helps ensure relevant issues are covered systematically, while allowing flexibility to pursue details that are salient to each individual participant (Ritchie & Lewis 2011a). A topic guide was created to include questions in a logical sequence from general to the specific (Polit & Beck 2012). The topic guide included probes in order to elicit more detailed information such as "What was the main concern of the patient...? and how?", "When that... happened, how did patient feel about it?" The researcher avoided asking questions that required one- or two-word responses such as "yes" or "no" (Polit & Beck 2012). The researcher also provided time for participants to express their experiences about the topics under study.

5.6 Data analysis

5.6.1 Framework analysis

During the initial qualitative phase, Creswell & Plano Clark (2011) recommend that a typical, qualitative data analysis should consist of identifying useful

quotes or sentences, coding segments of information, and the grouping of codes into broad themes. The researcher will then be able to use the central phenomenon as the quantitative construct to be assessed by the instrument, the broad themes as the scales to be measured, the individual codes within each theme as the variables, and the specific quotes from individuals as specific items or questions on the instrument (Creswell & Plano Clark 2011). In order to develop qualitative data categories for developing the instrument a framework should be applied whilst analysing the qualitative data (Caracelli & Greene 1993; Creswell & Plano Clark 2011). Ritchie & Lewis (2011) stated that “The analysis method framework is a matrix based, analytic method which facilitates rigorous and transparent data management such that all the stages involved in the analytical hierarchy can be systematically conducted. It also allows the analyst to move back and forth between different levels of abstraction without losing sight of the raw data” (p. 220). Regarding the recommendation above, the interviews were analysed using the framework approach. Framework analysis consists of five stages (Elkington *et al.* 2004; Adams *et al.* 2012; Hanratty *et al.* 2012): a) familiarization (immersion in the raw data); b) identifying a thematic framework (drawing on a priori issues and questions as well as issues which are raised by participants themselves, in order to examine and reference the data); c) indexing (applying the thematic framework to all the data); d) charting (grouping the data according to the part of the thematic framework to which they relate using distilled summaries linked to transcripts via page numbers or hyperlink) and e) mapping and interpretation (mapping the range of phenomena and, where appropriate, creating typologies and/or finding associations between themes with a view to providing and explaining) (see Figure 6 for a flowchart of the framework analysis process).

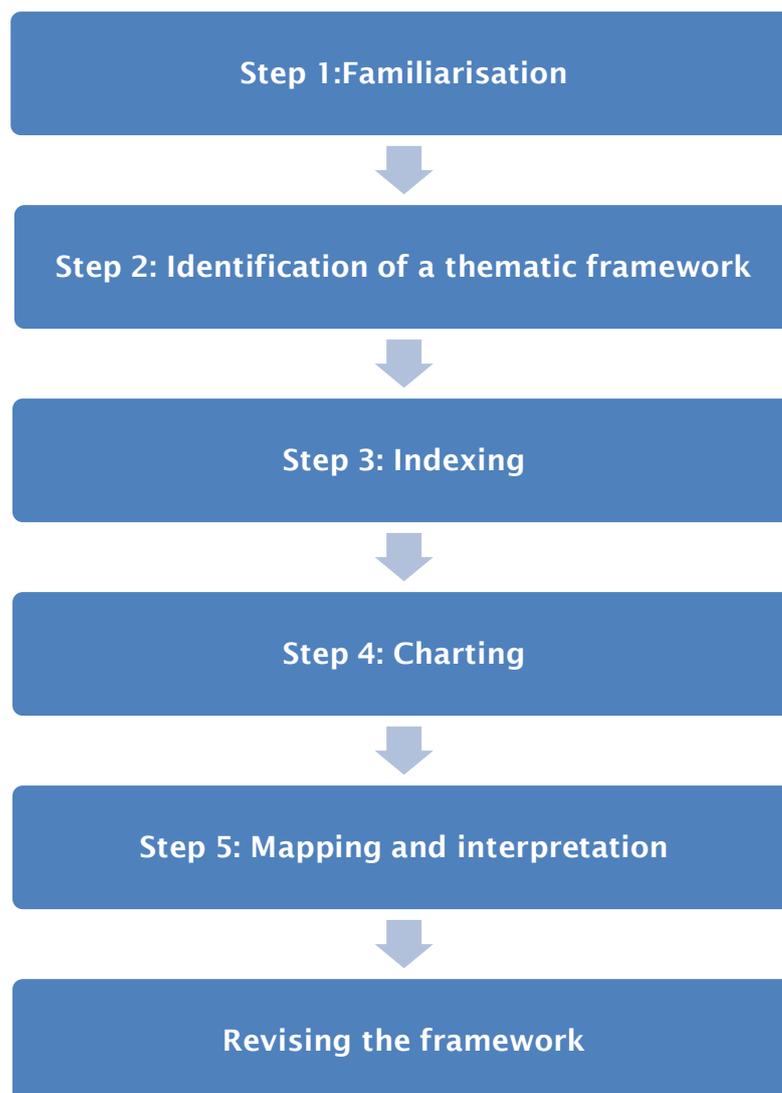


Figure 6 Flowchart of the framework analysis process

The interviews were digitally recorded and transcribed. The final few interviews demonstrated no new information or insights and it was felt that saturation of data had been reached. Each interview was referenced by the researcher using a code number, 01 being the first and 12 being the last. Three transcriptions were selected from the 12 interviews and the transcriptions translated into English by the researcher and proof read by an English proof reader. To validate the accuracy of the translation and ensure nothing was lost in translation, back translation was conducted in order to check content validity by an advanced renal nurse practitioner and one academic health professional with expertise in caring for the elderly. My supervisors evaluated and provided feedback on the selected transcriptions. The procedures for data analysis for the study are presented in Figure 7 below;

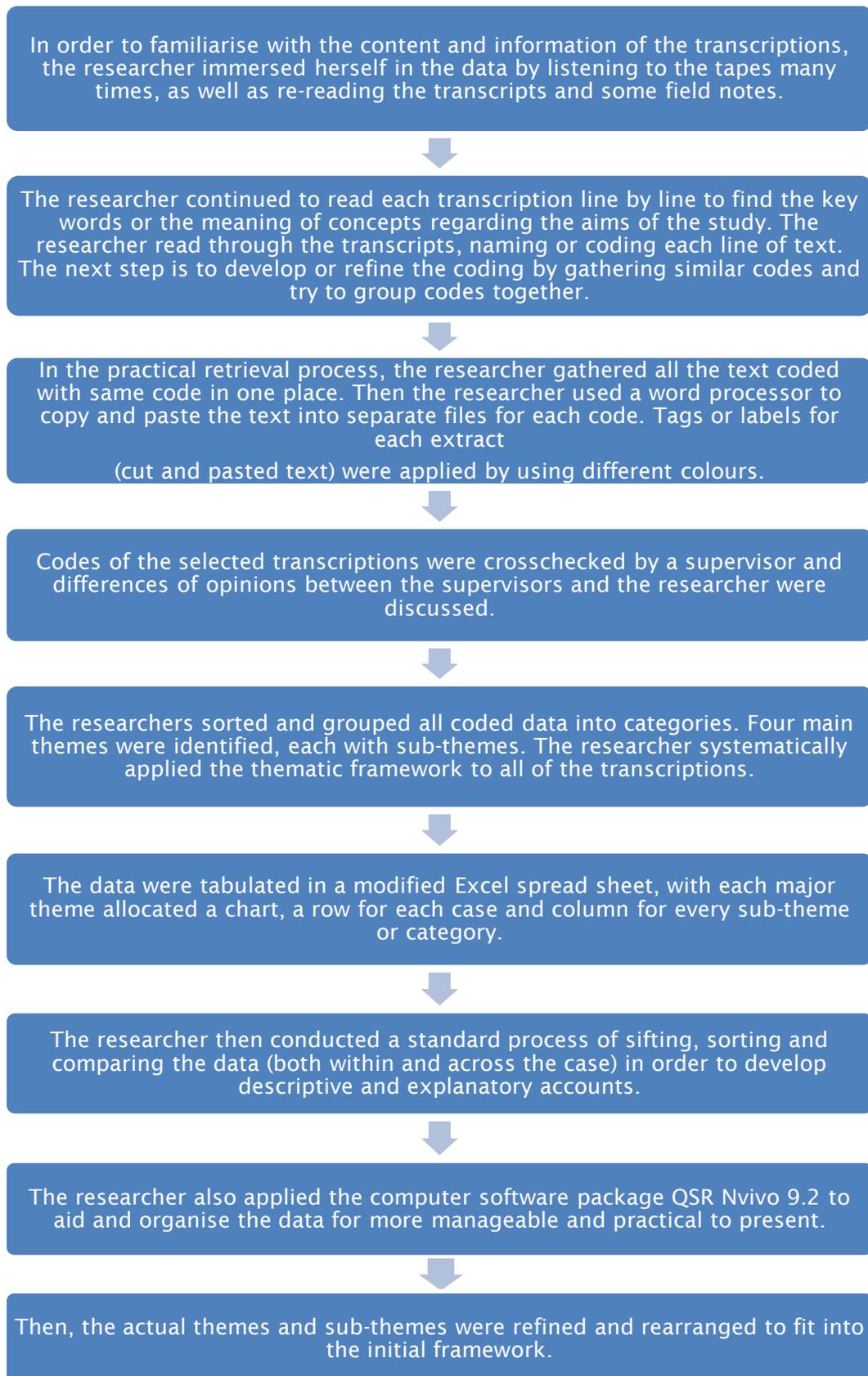


Figure 7 The procedures of data analysis of the study

The initial framework progressed through the three key stages (see Table 9) of framework analysis becoming more organized, increasingly specifying the important symptom experiences and health care needs (see Table 9 column 1). The researcher then discussed the initial framework with her two supervisors, reread the interviews, and noted down recurrent themes and any unusual topics that arose. The researcher used the analytical framework to index the interview transcripts, taking into account the manner, as well as the substance, of what was said. Therefore, the existing framework was modified as new elements were identified and others were combined or revised (see Table 9 column 2). A table summarising stages of framework analysis was created. The researcher then concentrated on the most important themes and sub-themes in mapping out the range of carers' views and perspectives (see Table 9 column 3) regarding the aims of the study. In order to ensure credibility and trustworthiness of the analysis the whole process of applying the framework to the data were discussed regularly between the researcher and two supervisors. An extract of framework analysis in this study can be found in Appendix J.

Table 9 The three key stages of framework analysis

Initial framework	Revised framework used in indexing	Themes and sub-themes used to map the range of views and experiences
<p>1.Symptom experiences 1.1 Physical symptoms & impacts - Breathlessness - Pain - Oedema - Weakness/fatigue - Weight loss - Dependency 1.2 Psychological symptoms & impacts - Stress/worry - Depression - Anger/ Aggressive 1.3 Spiritual distress 1.4 Financial problem</p> <p>2. Symptom control 2.1 Pharmacological managements - Pain relief medicines - Others medicines 2.2 Medical interventions - Oxygen support 2.3 Alternative managements - Massage - Music therapy - Pray to Lord Buddha</p> <p>3. Health service utilization 3.1 the 30 Baht scheme 3.2 Possibility to received HD 3.3 Hospital based care 3.4 Home visiting 3.5 The end of life care 3.6 Information sources(doctor, nurse, anyone else)</p> <p>4. Unmet needs 4.1 Health services for ESRD patients who managed without dialysis - Need for effective referring system - Need for home visiting before & after the death 4.2 The need to care by specialists 4.3 The information support - Providing full information - Need time to explain - Need for good communication 4.4 The financial support - Free for the treatment - Free for the cost of transportation</p>	<p>1.Symptom experiences 1.1 Physical symptoms & impacts - Breathlessness - Pain - Oedema 1.2 Psychological symptoms & impacts - Stress/worry - Depression - Fear to die 1.3 Spiritual distress 1.4 Financial problem</p> <p>2. Symptom control 2.1 Pharmacological management - Pain relief medicines - Others medicines 2.2 Medical interventions - Oxygen support 2.3 Alternative managements - Massage - Music therapy - Pray to Lord Buddha</p> <p>3. Health service utilization 3.1 Hospital based care 3.2 Home visiting 3.3 Type of care - Care from doctor - Care from nurse - Care from specialist 3.4 Information sources (doctor, nurse, anyone else)</p> <p>4. Unmet needs 4.1 Need for end of life care - Need care by specialist - Need for effective referring system - Need for home visiting 4.2 The need to care by specialists 4.3 The information support - Providing full information - Need time to explain - Need for good communication 4.4 The financial support - Free for the cost of transportation</p>	<p>1.Symptom experiences 1.1 Physical symptoms - Breathlessness - Pain - Oedema 1.2 Psychological symptoms - Worry - Low mood 1.3 Spiritual distress</p> <p>2. Impacts 2.1. Breathlessness & its impact 2.2 Pain and its impact 2.3 Oedema & Its impact 2.4 Emotional impact 2.5 Spiritual impact</p> <p>3. Current symptom managements 3.1. Breathlessness & its management 3.2 Pain and its management 3.3 Oedema & Its control 3.4 Psychological management 3.5 Spiritual support</p> <p>4. Health care needs and utilization 4.1 Health service provision 4.2 Home visiting 4.3 Spiritual need 4.4 Financial support</p>

5.7 Chapter summary

In this chapter, the methods involved in the qualitative interview data collection, including purposive sampling, the recruitment process, retrospective data collection, semi-structured interviews, the interview topic guide and framework analysis have been discussed. The analysis was implemented by producing the three key stages of framework analysis. The qualitative findings, including symptom experiences and specific health care needs of, and utilization by, older people with ESRD managed without dialysis in Thailand will be explored and explained in the next chapter.

Chapter 6: Findings for phase I

6.1 Introduction

This chapter presents the qualitative findings of the first phase of the study looking at the experiences and health care needs of older people with ESRD in Thailand who were managed without dialysis. It begins with the demographic characteristic of the informants and the deceased. It then moves on to examine the qualitative findings which are presented in two main parts including symptom experiences and health care needs and utilization. The chapter ends with a short section that draws conclusions and leads on to the next chapter.

6.2 Results: Demographic characteristics

6.2.1 The informants

Of the twenty-five carers who were contacted, twelve agreed to be interviewed. The reasons for declining to participate in the study have been explained in previous chapter. The interviewees were aged between 35 and 67 years. More than 40 % of the informants were aged between 60 and 69 years (five individuals). Nearly 92 % of the informants were female (11/12 individuals). The relationships of the interviewees to the deceased were: wife 33.33 % (4 cases); daughter 33.33 % (4 cases); daughter-in-law 16.67 % (2 cases); husband 8.33 % (1 case); and niece 8.33 % (1 case) (see Table 10).

Table 10 Characteristics of the informants (n= 12)

Characteristic	N (%)
Age of the informant	
30-39	3(25)
40-49	4(33.3)
50-59	-
60-69	5(41.7)
Sex of the informant	
Male	1(8.3)
Female	11(91.7)
Relationship of the informant to the deceased	
Wife	4(33.3)
Husband	1(8.3)
Daughter	4(33.3)
Niece	1(8.3)
Daughter in law	2(16.7)

6.2.2 The deceased

Half of the deceased were aged between 60 and 65 years. One quarter of the deceased were aged between 66 and 70 years. The average age of death was 77 years. More than 58 % of the deceased were male (seven individuals), and nearly 42 % (five individuals) were female. All the informants reported that the deceased had lived at home while they were managed without dialysis. Half (50 %) of the deceased died at home; the other half died in hospital. Nearly half (41.67 %; (five individuals) died within twelve months after the decision had been made to pursue management without dialysis. One (8.33 %) died within one month of the start of management without dialysis (see Table 11).

Table 11 Characteristics of the deceased (n= 12)

Characteristic	N (%)
Age of the deceased	
60-65	6(50)
66-70	3(25)
71-75	2(16.7)
75+	1(8.3)
Sex of the deceased	
Male	7(58.3)
Female	5(41.7)
Duration of being managing without dialysis	
1 month	1(8.3)
3 months	3(25)
6 months	1(8.3)
12 months	5(41.7)
24 months	1(8.3)
36 months	1(8.3)
Place of death	
Home	6(50)
Hospitals	6(50)

6.3 The findings

The final analysis revealed four themes associated with the carers' accounts. The first and second themes relate to symptom experience and impact. The third theme relates to symptom management, and the fourth to health care needs.

6.3.1 Symptom experiences

Relatives of End Stage Renal Disease (ESRD) patients managed without dialysis described the type, duration and pattern of symptoms which caused suffering to patients and affected their everyday life. Physical symptoms included breathlessness, pain and oedema. Psychological symptoms included worry, and low mood.

6.3.1.1 Physical symptoms

From the carers' accounts, the physical symptoms that affected patients in the year before death included breathlessness, pain and oedema. During the few months before death, carers explained that the intensity of those symptoms increased dramatically and reflected a rapid decline in a patient's physical health. In order to help patients to manage their physical symptoms, oxygen support, pain relief medicines and diuretics were used to control those symptoms.

6.3.1.1.1 Breathlessness

According to the carers breathlessness caused the most suffering for patients; all of the patients had experienced breathlessness, which was the main symptom of concern during the last year of life. Breathlessness increased and became more problematic during the last months before death:

Breathlessness caused the most suffering to him during the last months of management without dialysis. While he was being managed without dialysis, breathlessness was the symptom that caused him to be readmitted to the hospital many times until he died (05).

Carers reported that breathlessness caused patients to struggle to breathe, which caused them to suffer. This would also mean that patients were unable to perform the activities of their normal lives:

During the last 2-3 days before the patient died, she suffered with breathlessness. Her abdomen was too expanded. This caused her to feel very tired and caused breathing difficulties. When she walked out from her room, she felt very tired and had great difficulty in breathing (02).

From the carers' accounts it can be seen that breathlessness created the greatest sense of difficulty for patients. The impact of breathlessness was explored in greater detail.

6.3.1.1.2 Breathlessness and its impact

Carers suggested that breathlessness and physical weakness interacted together. The physical weakness was seen as a negative consequence of breathlessness. Physical weakness made the patients feel they lacked energy to do things. Many carers (6/12) reported that, after breathlessness had developed, patients became weaker and experienced a decrease in physical energy:

His breathlessness was serious. This also made him feel really weak and he had no energy to do his daily activities. In the last three days before he died, he felt really weak. He said *"I feel really weak and I am unable to breathe properly, please take me to the hospital"* (04).

The majority of carers explained that physical weakness could and did exert a negative influence on the patient's activities relating to daily living, leading to dependence on others. This was because it caused patients to become exhausted and made them lack the energy to perform activities of daily living such as taking a bath, dressing, cooking, shopping and going to hospital by themselves.

In several interviews, the carers described that dependency increased in severity during the last six months before death. The deceased became increasingly dependent on their carers towards the end of life. In the last

month of the patients' lives, many patients had to rely completely on their carers, twenty four hours a day:

Two weeks before he died, he was admitted to hospital. He was really weak and depended on us since he couldn't work nor do activities of daily living by himself such as taking a bath, walking to toilet (03).

Breathlessness also impacted on the deceased in that they were often unable to socialize with others, caused, in part, by a lack of energy which prevented them from performing their social activities:

She normally liked to go outside but due to the illness she had to stay at home. She found it difficult to walk or do activities outside the home (09).

Breathlessness was also reported to affect patients' sleep patterns. Carers explained that their patients couldn't sleep at night when experiencing severe breathlessness. The change to sleep patterns decreased patients' quality of sleep:

His breathlessness caused him to be unable to sleep at night. His sleep time was changed from the night to the day. Sometime it made him really exhausted on the day as he couldn't get enough rest from the night (04).

In summary, breathlessness had an extremely negative impact on the patients through the last year before death. During the last month, patients became completely dependent on their carers and needed help to manage their breathlessness.

6.3.1.1.3 Breathlessness and its management

Many carers reported that breathlessness was the main symptom which influenced patients' readmissions to hospital during the period leading up to their deaths. In the months preceding the death of their relatives, five carers

explained that breathlessness caused exhaustion. Their relatives couldn't do anything and oxygen support was needed to control the symptom:

During the last month before death, I took him to the hospital 2-3 times to have oxygen support. Sometimes, I took him to the hospital at midnight as his breathing got really worse (04).

Most carers (10/12) explained that medical interventions were used, such as, oxygen support (mask, nebulizer or T-Piece) and ET tube with a respiratory machine (Bird ventilator) in order to reduce patients' breathing problems. However, all oxygen support was provided by physicians and nurses in the hospitals. Carers explained that a patient's only opportunity to access oxygen management was in the hospitals. Patients did not have the option to choose to receive oxygen management at home:

The month before he died, he couldn't breathe properly. The oxygen support was provided to him on the days that he was in the hospital. When he went back home, he still needed the oxygen support since he couldn't breathe without it but the physician in the hospital did not provide the oxygen equipment for patients to take home. This caused him to die very quickly only 3-4 hours after back home (04).

Moreover, exacerbation of breathlessness caused patients to return to the hospital many times. Employing an ET tube accompanied by a respiratory machine at the hospital often did not help patients with their breathing:

The next day, he got worse in regard to the breathing problem, I had to take him to the hospital as fast as I could. The respiratory machine was used again, however, he did not feel any better. He suffered a lot with that machine. He told me *"Please take me home"* (04).

It can be seen from the carers' accounts that the current approach to oxygen management in Thailand has a distressing effect upon both patients and their carers as it requires patients' to be readmitted to the hospital on repeated occasions. Oxygen support and respiratory machines worked for only a short

period of time and unfortunately could not be used to help patients manage their breathlessness at home. Moreover, the latter form of intervention, the respiratory machine, was extremely invasive and caused patients to suffer significant discomfort.

6.3.1.2 Pain

Carers reported that pain often made ESRD patients suffer for extended time periods and this affected the patients' ability to perform their daily living activities during the last year before death. Five carers explained that the pain caused patients to feel uncomfortable and, in the last months of their lives, unable to move their bodies as usual:

...While he was being managed without dialysis, the back and hip pain caused suffering to him. During the 3 days before he died, he got pain around both legs and abdomen. Both legs felt very painful when he walked or moved (05).

6.3.1.2.1 Pain and its impact

Many carers 7/12 described how many patients were not to be able to walk and they felt more pain when they stood:

He felt very painful when he had to walk since he got oedema around his body (12).

The pain also affected the patient's ability to do their job. This reduced patients' self-esteem as patients were unable to perform their social role. Sometimes, it made patients feel depressed and as though they wanted to give up on living:

... Sometimes, he cried "*I can't tolerate this pain let me die*". Pain caused him to be unable to work. He used to be the leader of the family but I had

to work instead of him in order to get money for buying foods for us and to pay for the transportation to take him to the hospital. (05)

Pain symptoms could occur in any part of the patient's body such as legs, hands, head, chest, bone, back, hip or abdomen, but especially in the chest which reduced the patient's ability to breathe properly:

... Both his legs were edema and very painful when he walked or moved. The abdomen was swollen and expanded. This made him feel pain on his chest which affected his breathing as he couldn't breathe properly (04).

Pain had negative consequences throughout the patient's life as it created a sense of discomfort. Pain also decreased patients' self-esteem and affected their ability to breathe properly. More effective management of pain is required if patients' suffering is to be reduced.

6.3.1.2.2 Pain management

According to the carers' accounts, pain was a major cause of suffering in the year before death. Five carers reported that they had to take patients to see physicians in hospitals in order to control their pain symptoms. Two carers (04 and 06) explained that patients had severe pain and needed to receive a morphine injection every 4-6 hours during their stay in hospital. The only way to access advanced pain management (i.e pain relief by injection) was for patients to go to the hospital:

He had to receive pain relief medicines from the physician such as paracetamol at hospital. When he was readmitted to hospital with severe pain, the physician injected some medicines such as morphine to relieve his pain (01).

She sometimes cried when she had abdominal pain and requested a nurse to give her quickly the pain relieving medicine (06).

In the last year of life, suffering with pain, particularly intense pain in swollen legs, made patients unable to have, or to keep, appointments with the doctor in the hospital. Paracetamol (the most readily available pain relief) is not likely to be an effective pain control during the last few months of their lives. Analgesics suitable for more severe pain such as a morphine injection, are required but this approach is only provided in the hospital, which patients were not always able to access in order to relieve their suffering at home.

6.3.1.3 Oedema

Oedema is a specific symptom of ESRD. All ESRD patients in this study experienced oedema. Carers explained that their relatives developed oedema following the onset of ESRD. This symptom increased in severity during the last year before death:

2 months before she died, we could see that oedema was in every part of the patient's body such as her legs, arms, hands, face and abdomen (10).

He got oedema for 1-2 years in his legs and it was very painful when he walked or moved. In the three days before he died, he also had swelling in his abdomen. So, it gradually got worse and extended to different parts of the body (04).

6.3.1.3.1 Oedema and its impact

Oedema limited patients' physical activities during the year before death. According to the carers, oedema was a significant barrier to the patients' mobility as it caused patients to feel pain when they moved:

Oedema meant he couldn't walk and it caused him was in pain when he stood or started walking (03).

Some carers observed that restricted mobility due to oedema indirectly resulted in patients being dependent on their carers:

The oedema in her legs and body meant she couldn't walk as normal. She depended on a nurse or her son when she wanted to move or go to the toilet (06).

Eight carers explained that having oedema made patients feel their body image had changed, as their bodies were swollen. This resulted in decreasing patients' confidence to go outside their home to socialize with friends or others:

He was a security guard and he used to look smart all the time. After, he got oedema, he was quite concerned about his body. He never went outside home after getting oedema. He felt shamed and lacked confidence as his body was swollen (08).

6.3.1.3.2 Oedema and its control

One carer described diuretic medicines were used to control oedema as it excreted the extra fluid from the patient's body. However, oedema still increased in severity during the last few months before the patients' death. Carers mentioned that they would like to help their relatives control oedema when their relatives were at home. It could be argued that education for ESRD patients managed at home without dialysis and their carers should be provided in order to help them control their relative's oedema:

The patient got medicine to reduce oedema on her legs and medicine to excrete water out of her body. I think that the doctor or nurse should also provide information for caregivers how to control patients' symptom such as oedema at home (02).

From the perspective of many of the interviewees, patients managed at home without dialysis, felt that current symptom management regimes could not meet their needs because they frequently had to go to hospital to receive medical treatments. Effective symptom management is required by patients,

and it should be provided proactively at home for the management of breathlessness, pain and oedema.

6.3.2 Psychological symptoms

The ‘management without dialysis’ option for patients with ESRD also affected patients’ psychological well-being. Psychological symptoms included worry and low mood. The impact and management of psychological symptoms are explained in more details below.

6.3.2.1 Worry

Four carers explained that their relatives worried about their lives during the last year of life. In the last months before a patient’s death, some carers described how their relatives appeared to become more worried about the end of their life:

He looked really worried and he always looked out of the window and cried. He used to say that *“I may not live too long. I have not much time to live”* (05).

Being managed without dialysis and its accompanying physical health problems, particularly breathlessness, was the major cause of patients’ worries about their future life. Increasing severity of breathlessness, together with becoming more dependent on their carer, made patients think they were burdening their families:

He was worried about his health problems such as breathing and oedema. This was because he thought his health problems made him unable to help himself and he became a burden for the family, which he didn’t want (01).

6.3.2.1.1 Worry and its impact

Worry impacted on the patients' self-images, in that it caused patients to feel they had become useless persons. This was because patients were unable to help themselves to perform their basic activities of daily living. This could lead patients to feel like giving up the will to live:

She was quite worried about her breathing problem as it got more severe and it caused her to be unable to do her daily activities by herself during that time. Sometimes, she felt like giving up and cried. She complained that *"I want to die. I look like a dead person."* (10).

Some carers reported that worry affected patients' moods. Patients were also unable to control their emotions and got angry more easily than when they were less worried. Moreover, an increasing level of breathlessness led patients to panic about, and be fearful of, dying particularly in the days immediately before death:

After being managed without dialysis, she got angry and aggressive more easily. Sometimes she blamed her partner without any reason (09).

During the last three days before his death, he suffered from breathlessness, he screamed and cried *"I can't breathe, anybody please help me"*. I had to calm him down and told him that *"I was with him and helping him. Please, don't worry"* (04).

In summary worry created multi-emotional impacts on the patients. Worry impacted on patients, causing the development of a sense of becoming a useless person which led them to feel like give up living. In the last days of life, patients, when faced with severe physical symptoms, might panic, lose control of their emotions and become fearful of dying.

6.3.2.2 Low mood

Seven carers described how low mood developed in the last year of the patient's life and how it increased in severity during the few months before death. The carers explained that the patient's level of low mood had increased and that it was related to suffering caused by traumatic medical intervention to manage breathlessness:

She looked really low mood after experiencing breathlessness and had to retain an ET tube with a respiratory machine. The physician told us that she tried to turn off the respiratory machine many times by holding the ET tube out of her mouth. In the hospital, I saw her cry every day and every time the nurse came to provide the suction for her (06).

6.3.2.2.1 Low mood and its impact

One carer reported that low mood resulted in their relative becoming less interested in participating in social activities with others, unlike his usual pattern. The patient liked to keep quiet and preferred to live alone in his own room:

He didn't want to say any word to us. He sometimes cried. During the week before he died, he was quite low mood and slept on the bed all day (01).

Another carer reported that low mood was one factor which caused their relative to have less concern for himself. Particularly in the last month of his life, the patient didn't want to take care for himself as well as he used to do. This also caused his health condition to decline dramatically during this period:

Last month, he lay down and slept on the bed the whole day. He didn't want to care about his health and didn't take medicines. He also drank alcohol too much. I thought those caused his health to get worse very quickly (11).

Low mood developed through, and was related to, the suffering which was caused by the techniques (and lack of them) for managing of breathlessness. The impact of low mood was described in terms of a decreased interest in participation with others and lack of concern for themselves. Low mood eventually resulted in deterioration in the patient's physical health.

6.3.2.2.2 Psychological management

In order to deal with emotional distress, including worry and low mood, one carer reported that music therapy was used. The carer (01) explained that this kind of support was suggested by a nurse, who visited the patient at home. The nurse had explained that music therapy can partially help the patient relax and calm down from the suffering of physical and psychological symptoms. From the carer's point of view, the music therapy reduced the patient's level of worry as well as helping the patient to control their emotions:

The nurse also told us the best thing was that *"Caregivers should be with the patient and make him feel as comfort as possible."* Sometimes I played the Dhamma song to make the patient feel relaxed and calm, which is quite good for controlling the patient's emotional state (01).

It can be concluded that psychological support was not routinely considered at an early stage by health care professionals as a way to prevent patients' emotional distress. Moreover, access to psychological care was not available to all patients. Only one carer reported that music therapy was encouraged by a nurse to relieve distress during the last few months prior to death.

6.3.3 Spiritual distress

Spiritual distress also resulted from the patients' illness, and was related to their physical and psychological symptoms. During the last year of the patients' lives, symptoms such as breathlessness, oedema and pain impacted

on ESRD patients' capacity to maintain their spiritual activities. This was because patients couldn't go to the temple or church to pay respect to the monks as they had done when they were healthy:

Normally, he loved to go to the temples. He used to pray to the monks and receive blessing at each Buddhist event. When he got ill, he never went to the temple (01).

He always helped monks prepare or clean the temple for Buddhist holy days. He told me he loved doing this. During his difficult time with ESRD, he couldn't do it (03).

6.3.3.1 Spiritual support

Praying to Lord Buddha is related to the religious belief of Thai people. They found peace by praying to Lord Buddha's picture or providing offerings of small portions of food, water and flowers. Five carers reported that praying to Lord Buddha sometimes made patients feel happy and often released their tension as well:

When she was ill, she loved to put fresh flowers and a small portion of food in front of Lord Buddha's image by herself at home. As you know, this indicates respect to put fresh flowers, water and food in front of Lord Buddha's picture at home when you cannot go to pay respects to monks at the temple. This could also make her feel happy and released her tension in another way (02).

Some carers mentioned that spiritual support might be considered as one of the most important aspects at the end of patients' life. However, it was felt to be ignored by health care professionals. Spiritual support was not offered by health care professionals but it was fully taken into account by patients' carers during the end of their patients' lives.

6.3.4 Health care needs and utilization

Four sub-themes relating to patients' health care needs emerged and related to health services provision, home visiting, spiritual needs and financial needs.

6.3.4.1 Health services provision

The usual provincial and district hospital and community health services were available to ESRD patients being managed without dialysis in Thailand. Patients who lived in rural areas had to go to a community or district hospital to receive general health services, including some medicines to relieve their symptoms. However, from carers' accounts it would seem advanced treatments and specialist care for this group were only available at the provincial hospital:

The patient routinely visited the district hospital for follow up and to receive medicines related to their health problems, such as breathlessness, pain and oedema. 5 days before he died, my husband was admitted to the district hospital as he got severe breathlessness. Then 3 days later, he was referred to meet with the ESRD specialist at the provincial hospital (03).

6.3.4.1.1 Need for an effective referral system

Many carers suggested more effective referral systems including effective arrangements for the transfer especially in the last months of a patient's life, from the community/district hospital or at patients' homes to receive specialist care at the provincial hospital:

The last time, the patient was referred to the provincial hospital the physician and nurse at the district hospital didn't have an available car for transferring the patient. It is disgusting since my daughter and I had to prepare a car and took the patient to the provincial hospital by ourselves. Unfortunately, he died on the way to the hospital (07).

The district hospital should have a good referral system. My husband had to wait at the district hospital for 3 days before he was referred to the provincial hospital. He then died 2 days later (03).

6.3.4.1.2 Need for specialists and support at the end of life

Carers argued the physician at the provincial hospital should be a specialist (nephrologist doctor) in ESRD in order to undertake effective investigation and management of patients' symptoms:

I would like to complain that the physician should provide effective investigation into the patient's disease and get to know that the patient had ESRD and needed effective managements as early as possible. The physician needs to be a specialist in order to be able to help the patient as early as possible (12).

Moreover, many carers complained the patient did not get access to the necessary treatment or support from the specialist nephrologist or renal nurse at the hospital as the end of a patient's life approached. For example, one carer explained that lack of support as end of life approached at home caused the patient to feel like giving up and not wanting to meet the physician again:

The patient complained to me that he didn't want to see the doctor again. The doctor couldn't help or didn't do anything to help him when he was staying in the hospital. The physician and nurse also didn't contact or provide any support to the patient when he went back home (12).

Carers explained that lack of specialist input and support for patients at the end of life had negative consequences which may have contributed to a sense of hopelessness and also to carers' disappointment with service provision.

6.3.4.1.3 The need to provide care with dignity

Carers explained their relatives were not impressed with the way physicians and nurses treated them. One carer reported her relative was 'blamed' by

physicians and nurses for being unable to control his blood urea nitrogen at a normal level:

I think the doctor at the district hospital should provide a better way to treat patients. The physician blamed me and the patient when he saw the result of the blood test in the high level. I and the patient didn't like to see the doctor if it was not necessary (03).

Carers expressed the view the doctor and nurse lacked respect for a patient's dignity. Carers mentioned that lack of concern about dignity by health care professionals caused patients to come to the decision to not receive the hospital support:

One time that my father was admitted to the hospital, the nurse blamed him very loudly. It was because he made dirty on the bed as he couldn't help himself for going to the toilet. He felt a lack of dignity and I felt that the nurse was rude to him. The patient felt really ashamed before the other patients. The nurse and hospital staff didn't show respect to my father (04).

6.3.4.1.4 Need for health education

Information was provided by physicians and nurses at the district and provincial hospitals to both patients and carers. Carers explained that doctors and nurses were important sources of information about diagnosis, treatment, symptom control and preparing for the end of a patient's life:

I think the physician and nurse are important persons who told the patient that he had to control his diet by not eating salty foods. They also gave me the leaflet to control foods and fluid to take to the patients at home (04).

However, seven carers reported physicians and nurses at the hospital did not have enough time to explain the information to patients and their carers,

especially about symptoms and their management. After patients had made the decision to manage without dialysis, carers felt they needed physicians and nurses to explain more about the type of symptoms that patients might have and how to care for patients when they were at home:

...physicians and nurses should provide time and explain to the patient how to take care of his/her health more clearly in order to avoid misunderstanding, as my grandmother had. My relatives and I had to find out the information related to management with the patient's symptoms by ourselves (02).

Many carers described that clear information related to symptoms of ESRD and their management should have been provided as early as possible and certainly when the patient was near the end of their life:

I think that the doctor or nurse should provide clear information for patients and caregivers regarding the ESRD's symptoms and management as early as possible before patients are back home (02).

Particularly, carers would like to help their relative control the oedema experienced at home. They knew from doctors and nurse that ESRD patients should be restricted with salty foods, fluid intake and have a good medical regimen regarding the control of oedema. However, they would like to know certain practical things like what kinds of food patients should eat and how much water to drink per day when managed without dialysis at home:

The physician and nurse told us about ESRD and the treatment but they didn't explain more how to control his oedema when he was managed without dialysis at home (07).

6.3.4.2 Home visiting

In this study many carers mentioned the home visiting was not available for all patients. This complaint may be a result of the policies of each hospital, especially as to whether they visited patients at home. Only two carers reported patients were visited by general nurses from the district hospitals.

During these visits nurses provided support in terms of some medicines for pain relief, a lotion to reduce itching and also some foods. This was reported to be a very positive aspect in that patients' symptoms were regularly monitored:

Nurse visited patient at home once a week or twice a month for doing basic check-up such as vital sign and health assessment. Sometimes, nurse brought foods for the patient or asked "*what kind of medicine that you need I will bring it next time?*" (01).

Do you know? One thing I thought: it was good that the nurse from the district hospital came to see him at home to assess his health such as blood pressure and provide some medicines every month (08).

6.3.4.2.1 Need for regular home visits

Ten of the twelve carers interviewed agreed home visits before death were an important thing which the renal nurse should do in order to assess a patient's health problems at home; prepare and provide end of life care and help carers to deal with the situation. Visits should be provided regularly and more often if a patient's condition was severe, especially in regard to pain, breathlessness and oedema:

During the time a patient is living at home, we need physicians or nurses to come to see the patient more often, not only 1-2 weeks before patient died (01).

I do think that this is important to the patient's family as the physician and the nurse can assess the patient's health problem or conditions at home. It will help the patient and the family prepare everything as early as possible (06).

6.3.4.2.2 Need for home oxygen support

Many carers explained that oxygen support was often required by patients in order to combat breathlessness during the last months before death. Carers expressed that oxygen support and oxygen equipment should be available for patients to borrow to use back home when they were discharged from the hospital, as patients spent most of their time at home and they suffered from breathlessness:

We would like the physician to support the patient in terms of oxygen equipment at home. We didn't have money to buy oxygen equipment. We need to borrow or rent it from the hospital. However, the physician said that they did not have a policy for patients to rent the oxygen equipment back home and also oxygen equipment was not sufficient for use by patients in the hospital (01).

One carer explained how she had to deal with the difficult time on her own when the patient needed oxygen support at home but the physician would not allow her to borrow the oxygen tank and related equipment from the hospital. The carer expressed her belief that the lack of oxygen support at home was one of the reasons that caused the patient to die prematurely:

...When he would like to go back home but he still needed the oxygen support as he couldn't breathe without it. The physician said that *"The number of oxygen supports in the hospital is limited. I can't allow you to bring the oxygen support back home"*. Because of this he died very fast in 3-4 hours after he was taken home (04).

6.3.4.2.3 Need for pain management at home

The majority of carers reported the doctor or nurse didn't come to see patients at home regarding the control of patients' pain. Carers had to take patients to hospital when they were experiencing severe pain. Carers pointed out that patients experienced oedema in both legs which caused them to be unable to

walk and they felt more pain when they stood. Therefore, it was difficult for patients to go to see the doctor or nurse at the hospital. Seven carers thought it would be better if the nurse or doctor could come to monitor patient's symptoms and provide pain management at home:

The doctor or nurse didn't come to see him at home. Normally, we went to the hospital to receive the medicines for controlling his pain. I had also to take him to the hospital more often when he had severe pain (05).

Moreover, pain relief medicines such as paracetamol might not be effective for the control of long term pain as patients still suffered with pain. According to this, three carers were asked to undertake pain relief massage to help their relatives feel comfort at home:

During last 3-5 months before he died, he always complained about the back and bone pain and asked for help. *"Please help me or do something for me to relieve these pains"*. Sometimes, he asked us for a massage. *"Please put pressure on my back or give me a massage"* (01).

Home visiting, whether by a GP, nurse or other health care professional, was an important element of proactive service provision required by patients and carers. From the carers' perspective this should include the provision of active monitoring, oxygen supporting, and pain management.

6.3.4.3 Spiritual need

The spiritual dimension of life was also described as an important aspect of support for ESRD patients in order to control their emotions, release tension and help patients feel peaceful and happy during the end of their lives.

Therefore, some patients tried to perform their religious activities at home even though health problems were often a barrier:

She normally liked to go to the temple on every Buddhist event like many Thai elderly people. When she was ill, she loved to put fresh flowers and small portion of food in front of Lord Buddha's image by herself at home since she couldn't walk out of her room. This would also make her feel happier and relieve her tension (02).

Many carers tried to support patients to maintain activities that contributed to their spiritual wellbeing. One carer (04) explained that helping her relative to fulfil her spiritual needs would help relieve suffering during the last period of the patient's life. She also thought it enabled the patient to die peacefully:

During the time he died, we invited monks to come to visit and give the blessings. He tried to hold his hands to pay respect to the monks, even if, he didn't have energy at that time. 2-3 hours after that, he died.

While he was dying, he wasn't suffering and he died very peacefully. We thought that receiving blessings from the monks would help him fulfil his spiritual needs, especially in the last hours (04).

In this study, spiritual support was described by carers as a vital element to relieve patients' suffering at the end of their life and support patients to enable them to die peacefully. In order to help fulfill patients' spiritual needs, the spiritual support should be considered by health care professionals as a holistically care and it should be participated by carers.

6.3.4.4 Financial support

Many carers explained that seeking professional support for symptom management impacted on patients' finances, since ESRD patients were often poor and did not have enough money to pay for the cost of transportation to hospital. Exacerbation of symptoms, such as breathlessness, also cost patients and carers a lot of money in order to go to see the doctor which they had to do more often as patients' symptoms became more severe:

As I told you, we were poor and she was suffering with many symptoms. I took her to see a physician 1-2 times a month at the district or provincial hospital when she got exacerbation of the breathing problem. Meanwhile, I had to take her to the community health service to get the medicines to control her hypertension and DM. Sometimes, she and I did not have enough money to pay for transportation (02).

Six Carers explained that ESRD patients who were managed without dialysis had to see physicians in hospital many times, due to the exacerbation of their symptoms, especially near the end of their patients' lives. They thought the government should support them in terms of providing the money for this purpose:

I had to take her to see a physician 1-2 times a month when she got exacerbation with her breathing problem and we had not enough money to pay for transportation. It will be better if the government could support the transportation cost for us (02).

The financial aspect was the leading cause of patients being unable to have regular health check-ups with the physicians, which resulted in patients being unable to maintain their physical health.

6.4 Conclusion and chapter summary

This study has provided accounts of the experiences and health care needs of ESRD older patients in Thailand managed without dialysis during the last year of life, from the perspective of their bereaved relatives. Four themes were created in order to map the range of views of the deceased. The symptom experiences and health care needs of the patients were then explored including 1) symptom experiences (physical, psychological and spiritual aspects); 2) impacts; 3) current symptom managements (physical, psychological and spiritual managements); 4) health care needs and utilization (health services provision, home visiting, spiritual need, and financial support). The results from the framework analysis of the symptom experiences

and health care needs of older people with ESRD, managed without dialysis, in Thailand are summarised in Figure 8.

These findings reveal important information about the symptom experiences and health care needs and utilization of this elderly population in Thailand. The first phase of the study has begun the process of giving voice to an isolated and relatively inaccessible group of patients. In listening to carers' accounts of their experiences, a mismatch between patients' needs and services received has been demonstrated. The findings from phase 1 will inform the content of the prototype VOICES questionnaire that could subsequently be used to determine healthcare needs and experiences of this patient population. Regarding the sequential approach to data collection and analysis, the researcher applied the lessons learnt from the first phase in order to inform the subsequent development (the second phase) and testing of the instrument (the third phase) (see Table 12). The three main strategies for connecting to the subsequent phases included: 1) analysing the qualitative data to develop an instrument; 2) analysing the qualitative data to enhance later design; and 3) use rigorous procedures for developing and validating a new instrument. The methodology of developing of the VOICES-ESRD/Thai version will be explained in the next chapter (7).

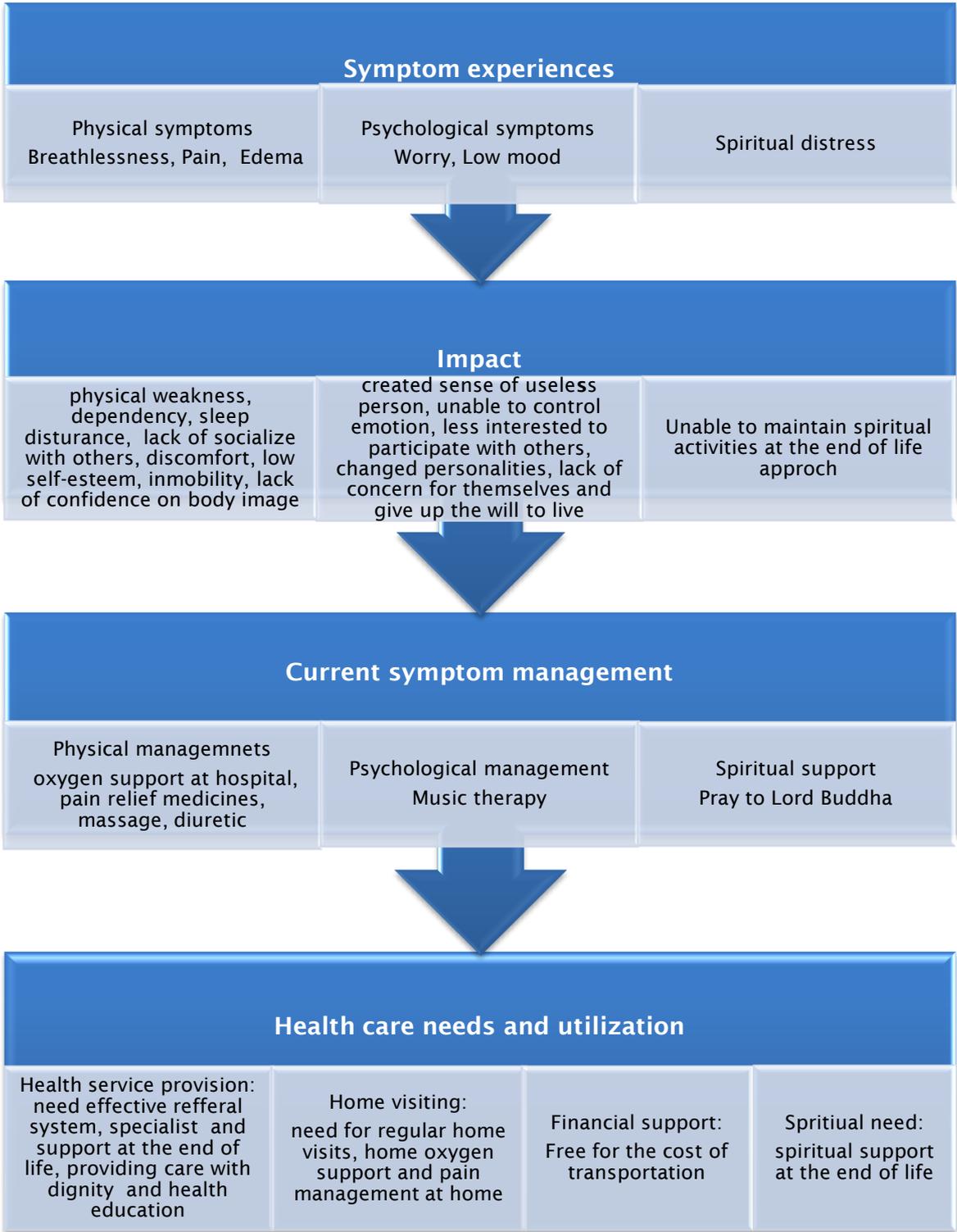


Figure 8 The framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand

Table 12 Strategies for connecting to subsequent phases

Strategies	Application in this study
<p>Analyze the qualitative data to develop an instrument. (Creswell & Plano Clark 2011, p.236).</p>	<p>1) The researcher looked for natural differences in responses so that categories can be formed by paying attention to participants' language to develop good terms to use when writing items.</p> <p>2) According to the framework analysis process, it helped the researcher to identify useful quotes, codes, and themes that could be used in designing the items, variables, and scales on the instrument.</p> <p>3) Regarding the three key stages of framework analysis (Table 2), it was particularly useful for the researcher to specify the content to be included when developed the instrument by following themes, sub-themes, codes of the table and quotes from the qualitative findings.</p> <p>4) From the above points, it could be illustrated that the researcher used qualitative categories from four main themes to organize the questionnaire by drawing on specific symptom experiences and health care needs to formulate the sub-themes, codes and quotes into items. Then, the researcher created response categories for the items and translate the questionnaire into the language of participants in the study.</p>
<p>Analysing the qualitative data to enhance later design (Creswell & Plano Clark 2011, p.242).</p>	<p>5) To obtain an adequate explanation and significant results, the researcher selected the different participants from the qualitative phases to follow up of the findings in the cognitive interviewing phase. In order to achieve an appropriate sample the researcher also selected different participants within a large sample size for testing the instrument in the quantitative pilot survey.</p>
<p>Use rigorous procedures for developing and validating a new instrument. (Creswell & Plano Clark 2011, p.237).</p>	<p>6) The researcher created the procedures for developing the instrument. The instrument was reviewed and validated by experts in the file of ESRD, instrument development and linguistic. The cognitive interviews technique was applied to evaluate the understanding of interviewees before the refined VOICES-ESRD/Thai questionnaire will be implemented in the survey.</p>

Chapter 7: Methodology of phase II: Developing the instrument

7.1 Introduction

This chapter provides a description of the methods used to arrive at a questionnaire suitable for pilot testing. The method of cognitive interviewing was used to refine the VOICES-ESRD/Thai version of the questionnaire, and this will be described here, followed by a discussion of the steps taken to develop the final version of the questionnaire prior to the pilot study.

7.2 Design

This phase of the exploratory sequential design was focussed on modifying an instrument. It is built on the qualitative results from the previous stage, and the results were intended to be used in the subsequent phase to pilot the quantitative data collection method (Creswell & Plano Clark 2011). The results from the first phase were used to adapt the VOICES questionnaire for use in a population-based survey with older ESRD patients who were managed without dialysis in Thailand. The focus of the questionnaire was on symptoms, symptom control and the health care needs of older people with ESRD who are managed without dialysis. A cognitive interviewing technique was used with a sample of ten bereaved carers, using a prototype of an ESRD-specific, culturally relevant VOICES questionnaire. Two cycles of cognitive interviewing were used, with revisions to the prototype questionnaire made after each cycle.

7.3 Objective

The objective of this phase was to develop and adapt VOICES to make it suitable for use in a population survey in Thailand.

7.4 Sample

In this phase, the researcher selected different participants from the qualitative phases in order to follow up on findings in the cognitive interview phase. According to Creswell & Plano Clark (2011), the primary data collection decisions for exploratory designs are the determination of samples for each phase. The target population in this study was restricted to people who were bereaved relatives of older people with ESRD aged sixty or over who were managed without dialysis. The participants could be either female or male, but they were all the main carers of ESRD patients, and they all met the inclusion criteria. Participants in a quantitative follow-up phase (the instrument development stage) of an exploratory design are typically not the same individuals who provided the qualitative data in the initial phase (Creswell & Plano Clark 2011). Creswell & Plano Clark (2011) argue that participants in the cognitive interviewing phase should not be the same as the participants in the qualitative phases, since the purpose of the quantitative phase is to generalize the results to a population. Therefore, different participants were selected for the quantitative follow-up stage.

7.5 Eligibility criteria

The eligibility criteria for this part of the study are similar to the criteria for phases 1 (see page 54).

7.6 Setting

During the second and third phase, data were collected in Nakorn Ping hospital. In the first phase, the researcher chose to collect the data from two hospitals (Nakorn Ping government hospital and Chiang Mai Ram private hospital). This was to ensure that an adequate sample size was achieved and also to assess how many patients were in these two hospitals in order to inform the subsequent stages of the study. However, the research realised that Nakorn Ping government hospital is the most fruitful place to get the sample and it would be sufficient for collecting the data within one place (a tertiary government hospital) (see page 60-61).

7.7 Sample size

Convenience sampling was used to select the participants for this phase of the study. A sample of study participants who met the inclusion criteria was selected. During the period between 1 January 2012 and 30 May 2012, there were nineteen potential participants who registered the death of a patient with ESRD in the previous five to ten months at the renal unit of the Nakorn Ping Hospital, and who met the inclusion criteria for the study. In the first cycle the total number of potential participants who were contacted to participate in the interviews was eight cases. Five of these eight respondents were willing to take part in the study, and they were invited to take part in cognitive interviews. In the second cycle the total number of potential participants was eleven cases, but only five of them agreed to take part. Therefore, the final number of respondents recruited between 1 January 2012 and 30 May 2012 who were willing to participate in the two cycles of cognitive interviews was ten individuals, since those five respondents were recruited in each cycle. According to Willis (2005), five to ten respondents is the recommended sample size with which to undertake each cycle of a cognitive interview study.

7.8 Recruitment process

In the second phase, the recruitment process was similar to the procedures used in phase 1 (refer to pages 61-62 and see Appendices E and G). During recruitment in the first phase of the study, the researcher noticed the number of the carer informants who agreed to be interviewed in the first phase was less than 50% (12) of the total number of carers contacted (25). In order to increase the number of individuals willing to enrol in the study, it is essential that potential participants have the research project clearly explained to them so they are able to understand the study's purpose. In the first cycle of recruitment for this phase of the study, the total number of carers contacted was eight, but only five agreed to take part in the study. With regard to improving the enrolment success, the number of potential participants who declined to take part in the first cycle of cognitive interviews was less than 38% (3 of 8 cases). The main reasons that people gave for declining to participate were that they were busy and had no time available to be interviewed. In the

second cycle of cognitive interviews, eleven carers were contacted and five agreed to be interviewed. Six of the eleven carers were excluded and refused to participate in the study, based on reasons such as that they were not the main carers, they were impossible to contact or they were unable to participate.

7.9 Data collection

7.9.1 Developing the instrument

The VOICES (Views of Informal Carers – Evaluation of Services) questionnaire was developed by Addington-Hall (Addington-Hall *et al.* 1995). VOICES is a survey questionnaire consisting of eight sections, including help at home, general practitioner care, district nursing care, symptoms and treatment, other health care received, care received in the last week, and circumstances surrounding the patient's death (Burt *et al.* 2009). Items are predominantly fixed-response, with the opportunity for free-text comments. There have been several versions of VOICES, including the most recent version which was specifically designed for hospice and specialist palliative care services developed in conjunction with St Christopher's Hospice (VOICES-SCH), a stroke version, a heart version, a cancer version, a COPD version and the VOICES short form National Council for Palliative Care (2012).

In this study, the version of the questionnaire was based on adapting relevant questions from three versions of VOICES (VOICES-SF, VOICES-COPD, VOICES-Stroke) (see Appendix M) to best reflect the qualitative findings from the first phase of the study. The starting point was the most recent version of VOICES-SF, to which items were added (from VOICES-COPD, VOICES-Stroke or developed by the investigator), removed or adjusted. There were three main reasons that the researcher chose these three versions of the VOICES instrument (VOICES-SF, VOICES-COPD and VOICES-Stroke). Firstly, VOICES-SF is the latest and newest version, and it has been used and validated many times compared with other two versions. It is a very good version in terms of its evaluation of health services provided for patients at the end of life. The

questionnaire is good in term of its organisation of questions and domains. However, it does not focus on the specific symptom experiences of this patient group. Nine sections of the VOICES version of ESRD in Thailand were applied from the version of VOICES–SF questionnaire, including (Appendix M):

- Help at home,
- Urgent care provided out of hours,
- Provincial, district and community nurses,
- General practitioners (GPs),
- Last hospital admission
- The last three days
- Circumstances surrounding the patient’s death and spiritual aspects,
- Information about the informant,
- Information about the deceased.

Two sections (Care homes and Last hospice admission) from the version of VOICES–SF questionnaire were not included in the VOICES version of ESRD in Thailand. This was because care homes and hospice care are not part of the health care system in Thailand.

Secondly, the COPD version of VOICES provided specific questions about symptom experiences such as physical symptoms, breathlessness or pain, and emotional symptoms. This version was useful for the researcher to use as a model for adapting questions especially in the section regarding Symptom experiences and treatment. The sections of the VOICES version of ESRD in Thailand adapted from the COPD version of VOICES included:

- Help at home,
- Symptom experiences and treatment,
- Provincial, district and community nurses, health volunteers,
- General practitioners (GPs), and
- Last hospital admission, the last three days, circumstances surrounding the patient’s death and spiritual aspects.

Questions related to spiritual aspects of care were adapted from the Stroke version of VOICES, including:

- Sections: Last hospital admission, the last 3 days, circumstances surrounding the patient's death and spiritual aspects.

Regarding the development of instrument procedures recommended by DeVellis (1991) cited in Creswell & Plano Clark (2011, p. 189), the stages include: 1) Determine what the researcher wants to measure, and ground yourself in the theory and in the constructs to be addressed (as well as in the qualitative findings); 2) Generate an item pool, using short items, an appropriate reading level, and questions that ask a single question (based on participants' language when possible); 3) Determine the scale of measurement for the items and the physical construction of the instrument; 4) Have the item pool reviewed by experts; 5) Consider the inclusion of validation items from other scales or instruments; 6) Administer the instrument to a sample for validation; 7) Evaluate the items (e.g. item-scale correlations, item variance, reliability); and 8) Optimise scale length based on item performance and reliability checks. The procedures of developing an instrument for this study were guided by the approach outlined in the above procedure (DeVellis 1991). However, not all of the above procedures are relevant to the development of the VOICES-ESRD/Thai questionnaire, as it was developed from a pre-existing questionnaire. Five steps were undertaken in this study, as explained below:

7.9.1.1 Step 1: Determine what the researcher wants to measure.

The researcher explored the experiences and needs of older ESRD patients who were managed without dialysis by focussing on their symptoms, experiences and health care needs during the last three months of life, and on the concept of conservative care. The researcher also used the findings from the qualitative phase to adapt the VOICES-ESRD/Thai questionnaire.

7.9.1.2 Step 2: Generate an item pool.

The researcher sub-divided the questionnaire into 10 sections. Each section mostly contained closed-ended questions and a few open-ended questions. The questionnaire looked at the natural differences in responses within a specific

population, so that categories could be formed by paying attention to participants' language to develop good terms to use when writing items. According to the framework analysis process, this helps the researcher to identify useful quotes, codes and themes that may be used in designing the items, variables, and scales on the instrument. Regarding the three key stages of framework analysis, it is particularly useful for the researcher to specify the content to be included when developing the instrument by following themes, sub-themes, codes of the table and quotes from the qualitative findings. The researcher used qualitative categories from four main themes to organise the questionnaire, drawing on specific symptom experiences and health care needs to formulate the sub-themes, codes and quotes into items.

7.9.1.3 Step 3: Determine the scale of measurement for the items and the physical construction of the instrument.

The researcher created multiple choice and Likert-type scales with codes Excellent (1), Good (2), Fair (3), Poor (4) and Don't know (5) for the items in the questionnaire, and translated the questionnaire into the language of the participants in the study. The questionnaire included sixty-nine questions, divided into ten sections as presented below (see Appendix R and S):

- Section 1: Help at home, consisting of four questions.
- Section 2: Urgent care provided out of hours, consisting of four questions.
- Section 3: Symptom experiences and treatment, consisting of seven questions.
- Section 4: Provincial, district and community nurses, consisting of ten questions.
- Section 5: General practitioners (GPs), consisting of eight questions.
- Section 6: Last hospital admission, consisting of five questions.
- Section 7: The last three days, consisting of seven questions.
- Section 8: Circumstances surrounding the death, consisting of seventeen questions.
- Section 9: Information about the informant, consisting of four questions.
- Section 10: Information about the deceased, consisting of four questions.

7.9.1.4 Step 4: Have the item pool reviewed by experts.

The VOICES-ESRD/Thai questionnaire was reviewed and the contents validated by a panel of four experts (see Appendix T). Among the experts were the researchers who developed the original VOICES questionnaire, including Prof. Julia Addington-Hall and Dr. Katherine Hunt. After revising the VOICES-ESRD/Thai instrument following the recommendations from the four experts, and once the content of all revisions had been agreed, the VOICES-ESRD/Thai questionnaire was translated into Thai (by the researcher) and checked by three Thai experts on ESRD and two Thai experts in the English and Thai languages. This translation was then back-translated into English to ensure the consistency of the instrument. It was reviewed again by experts and supervisors, who finally confirmed that the questionnaire was ready to be used in the cognitive interview process.

7.9.1.5 Step 5: Administer the instrument to a sample for validation.

The researcher used the prototype of the VOICES-ESRD/Thai questionnaire with ten respondents, conducting two cycles of cognitive interviews. The cognitive interview technique was used to assess respondents' understanding of each question. Read- and think-aloud techniques with concurrent probing were conducted to evaluate the questionnaire. The problems and solutions that arose during the cognitive interviews were explored and analysed using content analysis. After this process was complete the modified VOICES-ESRD/Thai was ready to be used in the pilot survey.

7.9.2 Validity and reliability of the VOICES-ESRD/Thai questionnaire

One important objective during questionnaire design is to develop good questions that limit response error, especially when the questionnaire is developed or modified for use in a particular study population (Willis 2005; Murtagh *et al.* 2007d). Psychometric testing is sometimes used in questionnaire design to demonstrate reliability and validity by considering the psychological elements inherent in the questionnaire response process (Willis 2005). However, Willis (2005) has argued that “*psychometric approaches are*

useful for ongoing quality control and evaluation, but not as means for pretesting at the early stages in the questionnaire development process.”

Accordingly, and because VOICES is a survey instrument rather than a psychometric scale designed to measure an underlying construct, psychometric testing is not a necessary step in the development of this type of questionnaire (Young *et al.* 2008; Department of Health 2012).

The VOICES questionnaire has been successfully applied and validated in more than thirteen surveys and over 4,000 respondents by assessing the quality of care given to dying patients from many different diseases (e.g. cancer, stroke, COPD, chronic heart failure and dying in a hospice) (Hunt & Addington-Hall 2011). Furthermore, there are a variety of evaluation methods that can be used to improve the design of survey questionnaires including focus groups, alternate forms comparison, pilot studies and cognitive interviewing (Drennan 2003; Murtagh *et al.* 2007d). Validity and reliability are ensured by following the principles of good questionnaire development and design (Boynton & Greenhalgh 2004; Addington-Hall *et al.* 2013) and these techniques have been applied to the development of VOICES over the last decade. For example, reliable questionnaires yield consistent results from repeated samples and different researchers over time. Differences in results come from differences between participants, not from inconsistencies in how items are understood or how different observers interpret the responses. A good questionnaire is one that is written and administered so all participants are asked precisely the same questions in an identical format and responses recorded in a uniform manner.

In relation to this study a number of different versions of the VOICES questionnaire (COPD, stroke, cancer and heart failure) were accessed and items selected through a careful process of development, repeated cycles of cognitive interviewing and piloting a consistent approach to the researcher administered VOICES questionnaire. Moreover, the standard VOICES-SF questionnaire has recently been subject to a process of redesign by using cognitive interviews to ensure validity of survey findings and make it suitable for research administration and this led to reductions in response bias and

increased response rates (Department of Health 2012). The current VOICES questionnaire short form (VOICES-SF) is therefore a validated questionnaire completed by bereaved relatives (Hunt *et al.* 2013). The findings from the pilot survey of the VOICES-SF demonstrated the survey instrument was and is able to detect differences in the quality of care provided in different care settings (Department of Health 2012).

In this study the study population had very specific demographic characteristics and this required careful consideration whilst refining VOICES-ESRD/Thai version for use with older ESRD patients managed without dialysis in Thailand. Data from individual interviews helped assure content validity. A cognitive interviewing process was applied to further validate the questionnaire content and understand respondent processes for responding to survey questions, whilst standard piloting procedures identified issues related to response rate, recruitment process, method of interview and missing data. The findings of this study proved beneficial in refining the VOICES-ESRD/Thai questionnaire for use with a specific population in Thailand. In future large scale surveys there will be an opportunity to make population estimates of palliative care need and understand respondents' perspectives with respect to different patient groups (waiting for, refusing and not suitable for receiving dialysis) and between care settings.

7.9.3 Cognitive interview technique

7.9.3.1 What is the cognitive interviewing?

Cognitive interviewing is a general method that has been developed to critically evaluate the transferring of information (Willis 2005). Cognitive interviewing techniques are particularly used to study the manner in which targeted audiences understand, mentally process and respond to the material the researcher presents to them (Willis 2005). The cognitive interview technique was developed by Fisher and Geiselman (1992, cited in Wallis 2005). However, the technique was used widely and was shown to be important in improving the effectiveness of messages in influencing attitudes (Murtagh *et al.* 2007d).

In the health sciences, cognitive interviews were developed in the 1980s to improve the information gained from surveys by evaluating sources of response error. Since that time they have gained a wide acceptance for use in national surveys (Smith 1993).

The techniques draw on cognitive theory in order to aid understanding of how survey respondents think, process and respond to survey questions. Cognitive interviewing is a one-to-one interview methodology in which verbalisation is used to access thoughts and feelings, and to understand the ideas and interpretations of respondents who are being asked to process the information (Willis 2005). The interviews are normally carried out through either think-aloud interviewing, or through verbal probing techniques (Willis 2005). According to Murtagh *et al.* (2007d), think-aloud interviewing requires subjects to explicitly 'think aloud' as they answer the questionnaire, with their cognitive processes being revealed in their verbalisations. The think-aloud technique is most useful when it is used as a concurrent approach (during the time that a questionnaire is being answered). This is because in this context the technique maintains immediacy, captures cognitive processes more readily and minimises the potential for recall bias (Murtagh *et al.* 2007d). Another benefit of the think-aloud technique is that it also has the advantage of being open-ended, allowing for further information to be gathered. In addition, verbal probing is another approach which the researcher can use to ask respondents for further responses to the questionnaire items (Murtagh *et al.* 2007d). Verbal probing may be scripted or unscripted, and can be either concurrent or retrospective.

7.9.3.2 How the cognitive interviewing was applied in this study?

In this study, the cognitive interviews were carried out face-to-face. Cognitive interviews were carried out in two cycles, where each cycle included five respondents. Willis (2005, p. 146) stated "the number of rounds to be conducted, one of the greatest strengths of the cognitive interviewing technique is the ability to test our modification subsequent to a first testing round and it is always helpful to be able to conduct at least two such rounds". Willis (2005) suggested the questionnaire could be tested in one hour for a ratio of 2:1 between "cognitive interview time" and "field time". Interviews

lasted approximately 60 minutes (1 hour), 30 minutes should be used to complete in the field. In addition, no more than three interviewings in a single day are recommended. After the first round the questionnaire may be revised based on comments and discussions, and a second round of interviewing can be conducted to test the change made and to provide additional testing of questionnaire segments that were not changed (Willis 2005). In the first round, the interviews are focussed not only on particular question wordings, but also on more global issues – for example, the appropriateness of the survey’s measurement of the major concepts that the questionnaire is attempting to cover. Then, the second round will focus on specific question wordings and some missing data. A total of ten respondents completed the cognitive interviews. The researcher interviewed each respondent using the VOICES-ESRD/Thai version of the questionnaire.

Before the researcher arranged the date of the meetings for conducting the cognitive interviews, the researcher had two or three telephone calls with each respondent to introduce herself and explain the objectives and method of the study. On the day of the meeting, the researcher introduced the cognitive interviewing technique to each respondent again. In order to ensure that each respondent felt comfortable with the interview process and that they understood what the researcher required them to do, the researcher explained and demonstrated to them how the interview would proceed. At the beginning of the interview the respondents were provided with the VOICES-ESRD/Thai questionnaire for an initial look. Then, the researcher gave them time to ask any questions that they might have. After that, the researcher asked them to complete the questionnaire, but to also read aloud each question and think aloud in order to report their thoughts. For some respondents who did not feel confident to read, the researcher read the questions for them and then asked them to think-aloud and explain their thoughts in response to the questions. The researcher also asked the respondents to write their thoughts and answers to the open-end questions. During the interviews using the read-aloud/think-aloud techniques, the researcher also applied concurrent and spontaneous verbal probing to explore any unexpected verbal or non-verbal behaviours such as hesitations, confusion or uncertainty, and to seek specific information. The interviews were tape-recorded and transcribed verbatim so that they might be

discussed with both supervisors. In the first cycle, three interviews were undertaken in the subjects' own homes, and the other two were conducted in the subjects' work places. In the second phase, the length of the cognitive interviews was shorter than in the first cycle. Two interviews were undertaken in the subjects' own homes, another two were interviewed in hospitals near the subjects' homes, and the final one was conducted in the subject's work place.

7.10 Data analysis

During this phase the researcher used the themes from the initial qualitative phase to adapt the VOICES questionnaire. A cognitive interviewing technique was applied to improve the information gained from the survey by evaluating sources of response error following a technique described by (Willis 2005). Think-aloud interviewing was used to explore the cognitive processes of the respondents when answering the questionnaire, and to identify ways to improve and refine the questionnaire (Murtagh *et al.* 2007d) (see Appendix L, N, O and P). Content analysis was used to identify the content and context of difficulties in questionnaire responses, and to elucidate emerging themes (Creswell & Plano Clark 2011). Content analysis procedures used included coding (by themes or category), analysing and presenting the frequency of qualitative findings (Bowling 2009b). The main focus of applying content analysis is to identify the theme and the frequency of it happening (Ritchie & Lewis 2011). The researcher listened to tape recordings, transcribed and analysed the data.

Then, the researcher used the findings to refine the questionnaire. Two cycles of content analysis were conducted in order to maximise the benefits from the cognitive interviews (Murtagh *et al.* 2011). A preliminary analysis of the data from the first cycle of cognitive interviews was conducted in order to modify the overall VOICES-ESRD/Thai version questionnaire in terms of understanding, general comments, wordings, and an appropriate format used in the questionnaire (see Appendix N). Then, the modified VOICES-ESRD/Thai questionnaire was used in the second cycle of cognitive interviews (see Appendix O and P). The content analysis of the data from the second cycle

focussed on specific problems raised in the questions, the length of the questionnaire and the interview, and the possibility of changes in the light of recommendations from the respondents. In addition, specific and prepared verbal probes were used in the second cycle, alongside spontaneous probes, to explore issues identified in the first cycle. The final modifications of the questionnaire were then made following discussion with both supervisors and Dr. Katherine Hunt. Finally, the VOICES-ESRD/Thai questionnaire was modified and made ready for use in the pilot testing phase (see Appendix R and S). The findings from this phase of the study are presented in the next chapter.

Chapter 8: Findings for phase II

8.1 Introduction

The summary of demographic characteristic of respondents and the findings from two cycles of cognitive interviews will be presented in this chapter.

8.2 Demographic characteristics of respondents in first cycle

Of the eight carers contacted, five agreed to be interviewed. The reasons people gave for declining to participate in the study were that they were busy and had no time available to be interviewed. The respondents were aged between 30 and 59 years. Of the five who took part, 2 were aged between 30 and 39 years a further 2 aged between 40 and 49 and 1 age 50–59. 3 of 5 of the respondents were female. The relationships of the interviewees to the deceased were: wife, (1 case); daughter, (1 case); daughter-in-law, (1 case); and son, (2 cases). The length of the cognitive interviews varied from 42 to 68 minutes. Three interviews were undertaken in the subjects' own homes, and the other two were conducted in the subjects' work places (see Table 13).

8.3 Demographic characteristics of respondents in second cycle

In the second cycle of cognitive interviews, eleven carers were contacted and five agreed to be interviewed. Six of eleven carers were excluded and refused to participate in the study based on the reasons that they were not being the main carers, impossible to contact and unable to participate. Three cases were excluded from the study because the researcher was given the mobile phone numbers of persons who were not providing care to patients. These mobile phone numbers the researcher received from the nurses in the renal units were not the numbers of the main carers and belonged to a relative, friend or neighbour who took patients to the hospital in emergencies, but didn't provide

care to patients at home and they didn't know the mobile phone numbers of the main carers. With respect to the other two, one carer had moved to live outside Thailand after her mother (the patient) died and another did not respond to phone calls despite three attempts to contact him. One further carer was busy at the time of contact, but she also lived at Phisanolok Province, which was a long way from Chiang Mai Province. Therefore, it was not possible for her to take part in a face to face interview.

The five respondents were aged between 30 and 59 years. Of the five who took part, three were aged between 30 and 39 years, and the remaining two were aged between 40 and 59 years. Four out of the five respondents were female. The relationship of the interviewees to the deceased were: wife (1 case); niece (1 case); daughter (1 case); daughter-in-law (1 case); and son (1 case). The length of the cognitive interviews varied from 30 to 45 minutes. Two interviews were undertaken in the subjects' own homes, another two were interviewed in hospitals near the subjects' homes, and the final one was conducted in the subject's work place (see Table 13).

Table 13 Characteristics of the respondents (n= 10)

Characteristic	1 st cycle N (%)	2 nd cycle N (%)
Age of the respondent (years)		
30-39	2(40)	3(60)
40-49	2(40)	1 (20)
50-59	1(20)	1(20)
60-69	-	-
Sex of the respondent		
Male	2(40)	1(20)
Female	3(60)	4(80)
Relationship of the respondent to the deceased		
Wife	1(20)	1(20)
Niece	-	1(20)
Daughter	1(20)	1(20)
Son	2(40)	1(20)
Daughter-in-law	1(20)	1(20)
Length of interview		
30 -39 minutes	-	2(40)
40- 49 minutes	3 (60)	3(60)
50- 59 minutes	1 (20)	-
60- 69 minutes	1 (20)	-

8.4 Findings from the first cycle of cognitive interviews

Some predominant themes were identified from the first phase and associated with difficulties relating to: the appearance or formatting of the questionnaire; specific wording (medical terms) or phrasing of items; specific questions; and the interpretation of response categories. Specific prepared verbal probes were used in the first phase of interviews, alongside spontaneous probes, to explore the problems identified in this phase (see Appendix N). When they were asked to think aloud, spontaneous comments from respondents included:

“I am not sure what this means”;

“I think it wants me to say that...”;

“I understand that...”;

“Yes, these are the kind of symptoms that happened to the patient”;

“I don’t think this will work for me”; and

“It would be better to change, add, or delete this”.

In terms of the problems identified in the first phase of cognitive interviews (see Appendix N), the difficulties relating to the appearance or formatting of the questionnaire related to the font size being a bit small and difficult to read. This point was addressed by increasing the font size. The difficulties with specific wording (medical terms) or phrasing of items made respondents feel unsure and confused and resulted in them not understanding and needing definitions, explanations or examples. Difficulties with specific questions were raised by respondents who felt that certain questions were difficult to answer. In response to these identified difficulties the following types of changes were made to the questionnaire: provision of explanations and meanings for specific words (medical terms) or phrases; rearrangement or rewording of questions or phrases; and the addition of examples.

Regarding difficulties with response categories, two kinds of problems emerged. These were that some items lacked specific response categories and some questions had too many response categories which were not all thought necessary. Furthermore, respondents commented that the response categories were too complicated for some questions. The respondents also mentioned that for some questions the response categories were difficult to interpret because the response categories were unclear and were only suitable for those respondents related to patients who died in hospital. To overcome the problems related to response categories, response categories were added, unnecessary response categories were deleted, and response categories difficult to interpret were revised. Furthermore, the researcher recognised the need to provide time for respondents to become familiar with the different types of response categories. Finally, the respondents felt that the overall length of the questionnaire was long, but not too burdensome. This issue was expected to be resolved after revisions to VOICES-ESRD/Thai version following the second round of cognitive interviews.

8.5 Findings from the second cycle of cognitive interviews

In the second phase, the researcher interviewed five subjects using the modified VOICES-ESRD/Thai instrument developed from findings from the first phase of cognitive interviews. Overall, comments were positive (see Appendix O). After asking respondents the questions standard text was read aloud and the researcher explained things to respondents in the same way. Following this respondents were given time to think and talk about what they thought about the meaning of each question. Therefore, it could be said that the five respondents were able to answer the questions in a way that truly reflects the objective of each question, obtaining answers related to the intended meaning and also reflecting what they thought and believed.

8.5.1 Difficulties with specific wording (medical terms) or phrasing/terminology

Terminology was a problem when respondents tried to translate the meaning of technical terms and jargon. Following phase I the term ‘breathlessness’ Question No. 26 was replaced by “hard to catch his/her breath”. The phrase “respect and dignity” was also changed to “respect”, “worry/anxiety” changed to “worry”, and “depression/low mood” was altered to “low mood”. In this second cycle the five respondents said they felt more familiar with the new wordings or phrases than the old technical terms. These changes were recommended by respondents in phase 1, since they were and felt better than reading a long explanation of terms accompanying each question. One respondent thought that question 27 (What does the term “itching” mean to you?) was a very good question, because she didn’t know before that itching was a common symptom experienced by ESRD patients. She recognised that her relative had always felt uncomfortable with this symptom, but nobody had told her what it was, and why itching was happening to her grandfather (the patient). Now, she realised and understood more about the experience and physical symptoms of her grandfather whilst he was managed without dialysis at home (see Appendix O).

Additionally, one respondent made a comment on question 9 that it was a bit long and the response categories presented too many choices, but then she said,

“This question is OK for me because if the question is made shorter than this it might not be clear for the reader”.

However, it was decided an additional instruction should be added (“Please tick one or more”) in case respondents wanted to choose more than one response category. For question 14 the same respondent suggested that

“I think the section about “Household tasks (e.g. shopping, cleaning)” needs to be cut or deleted, as this task is not normally the task of a healthcare professional”.

The recommendation was implemented, since healthcare professionals in Thailand normally only provide healthcare services to patients both in the hospital and at home and there is no provision for help with household tasks.

8.5.2 Difficulties with specific questions

During phase 1 two specific questions (question 7 and question 56) were considered difficult for respondents to interpret. After discussion with academic supervisors and the researcher who developed the original version of the VOICES questionnaire, question 7 was rewritten from “How long had he been ill before he died?” to “How long was it after he was diagnosed with ESRD and managed without dialysis until he died?”. Question 56 can be skipped if the patient didn’t receive health services at home. In the second cycle of cognitive interviews by applying the revised VOICES-ESRD/Thai questionnaire with the five subjects, they did not have any problems in interpreting these revised questions, and correctly reported the meanings of questions 7 and 56. For question 17 and question 22, one subject mentioned that

“I think the response categories about ‘Out of hours hospital number’ should be changed to ‘The hospital’s operator’”, and

“Something else’ should be changed to ‘Someone’” (see Appendix O).

This is because the question asked “Who did the patient contact or who was contacted on their behalf?” So the response categories should refer to persons or someone/somebody, rather than something.

8.5.3 Difficulties regarding the response categories

To address the problem of response categories, i.e. the lack of specific response categories for questions 17, 22 and 34, the researcher added the response category “nobody or couldn’t contact” for questions 17 and 22. The researcher also added the response category “no nurse(s) or nurses visited him at home” for question 34.

In contrast, for questions 18 and 23 respondents recommended that some response categories should be deleted. Respondents said that there were too many response categories, and a few responses did not make sense – for example, “Given medical advice over the telephone”, “Given another number to ring to get medical advice” and “Advised to go to private clinic”. Another problem with the response categories for questions 51 and 52 was that they were too complicated for subjects to make a decision and provide an answer. Subjects needed more time to think before they were able to answer. Therefore, the researcher changed the responses to another type, which the respondents felt familiar with and recommended. In addition, the response categories for questions 26 to 33 were considered difficult to interpret. This was because the level of response should have differentiated between “Yes” and “Yes rarely”. The new levels of response category provided for different interpretations. In phase 2, it was decided best to revise all the response categories by following the commendation of respondents certain response categories were revised. Subjects suggested that question 55 should have an extra response category, i.e. “I didn’t have contact as he/she died at home”. Subjects commented that their relatives had died at home, not in the hospital.

Following revision of the VOICES-ESRD/Thai questionnaire used in the first phase, the five respondents in the second phase said they didn't have any problems with the response categories for the six questions mentioned above. However, in this cycle, different questions (numbers 44 and 56) were queried, and it was suggested that the number of response categories should be reduced. The response categories for question 49 was considered to be too complicated and needed to be rearranged to make easier for respondents to interpret and answer. Regarding question No 13, two respondents also suggested that

"This is fine for me, but I don't know if the response categories include the amount of hours, will this question be OK for others caregivers or not?"

The number of hours in the responses may make it difficult for elderly caregivers to count, and they might be unable to remember how many hours they spent caring for their patients. It might be better to phrase it as the number of days, so that "5 to 10 hours per week" should be changed to "1 to 3 days a week" (see Appendix O). After discussion with supervisors about the main objective of each question, the response categories of questions No 13, 44, 49 and 56 were kept the same.

8.5.4 Difficulties with the questionnaire

Five respondents considered the questionnaire was overall not difficult to answer. However, they felt the questionnaire should take account of the different levels of education received, as many of them may have a low level of education and some had left school after the primary stage. They might not understand items when they are reading the questionnaire for themselves.

"I do think they need someone to read the questionnaire or provide an explanation of any questions that might not be clear, for example the questions in the sections about Help at home, Urgent care and Last

hospital admission. Moreover, many informants are older people, and they might need someone to help them in completing the questionnaire.”
(02)

“However, I do think in the way you interview the carers, you should explain for some points where they might not clear, like you did with me. This is a better way and you would be able to get the information that you want.”(04)

The researcher used the question “Which way would you like to answer this questionnaire?” to ask each respondent about their preferred way to answer the questionnaire (by post, in an interview or by email). Five of them preferred to be interviewed using the administered questionnaire (see Appendix O). This was because they would be able to ask questions if they were unclear or if they did not understand. It would help them understand the question correctly, and they would have more confidence to answer.

“Many carers are at a low level of education and some are older. For example, in my village (in the mountains of Mae Tang district), few people graduated at diploma level and we do not have internet access in the village. I am sure they would need assistance to answer this questionnaire. I am also thinking that email or a survey questionnaire does not work for these people to do the questionnaire, compared with the administered questionnaire.” (04)

8.5.5 Length of questionnaire and length of interview

Regarding the revised questionnaire used in the second cycle, the overall length for the questionnaire to be used in the pilot survey was reduced from 42 pages to 38 pages. The total number of questions was reduced from 78 to 69 questions. The total time spent during interviewing in the first cycle was between 42 and 68 minutes. In the second cycle the time reduced to between 30 and 45 minutes. All respondents thought that the time spent doing the questionnaire was not too long and not too burdensome (see Appendix O). The researcher asked five respondents the following questions: “What do you think

about the length of the questionnaire?"; "Is it too long?"; and "How do you feel about the time spent during the interview?" They answered as follows.

"I don't think the length of the questionnaire was too long to make it a burden to me or others." "We didn't spend too much time on this job."
(01)

"I think the questionnaire is not too long. I like the way you separated the questions into ten sections. This will make the questionnaire feel like it goes part by part, and the length of the questionnaire seemed like it was not too long because many questions were split into ten sections."
(04)

Finally, the researcher wanted to evaluate whether the questionnaire was ready to be used, or whether it still needed some improvements. The researcher asked the question: "Anything else that you think could be done to improve this questionnaire?" All respondents felt the questionnaire was good and that it did not need any changes.

"I do think the questionnaire should be OK and ready to use. I don't think it needs to be added to or change anything." (04)

"I think this questionnaire will provide useful information when it is used to find out the needs of health services and patients' experiences when they manage without dialysis at home." (05)

8.6 Data from open ended responses "Respondents' experiences of caring"

The findings from the cognitive interviews were interpreted (please see Appendix N, O, and P). A formal analysis of the cognitive interviews was undertaken, in that the cognitive interviews were transcribed and content analysis used to categorise and summarise the findings. The cognitive interviewing outcomes were analysed according to four main characteristics, including: problems related to dealing with the difficulties of specific wording

(medical terms) or phrasing/terminology; problems related to dealing with difficulties with specific questions; problems regarding difficulties related to the response categories; and the length of the questionnaire and the interview. It is also useful to recognise the complexity of reasons for the way respondents think about and answer the questions. This included their experiences of caring for their patients, complained in term of response to open ended questions.

Question No. 12: “Apart from special equipment that the patient needed at home to help her get better from her symptoms, was any other equipment needed that she didn’t have?” Many respondents answered “Yes”, and most of them explained that the required equipment was for oxygen support. This was because oxygen support at home was required and important for helping the patients find relief from their breathing problems.

“He really wanted oxygen support at home and we were told by the nurse at the provincial hospital that we had to buy the oxygen mask and its equipment ourselves. I therefore asked the nurse from the community hospital to borrow the oxygen and its equipment during the time he was at home until he died.” (01)

Question No. 14 asked: “Did you get help from healthcare professionals with any of the following?” All respondents answered “No”. One respondent said:

“I had to do everything by myself, and it is difficult to count how many hours I spent caring him as I thought I had to care him all the time till he died.” (01)

This indicated that all the respondents had to provide care by themselves, without any help or support from healthcare professionals, during the time patients stayed at home until they died. Respondents complained that this was

their main burden in terms of caring. It also reflected that help at home from healthcare professionals in Thailand needs to improve in order to help carers to provide the proper care for ESRD patients who manage without dialysis at home.

Question No. 40 asked: “How much did the doctor understand about her renal problems? (breathlessness, pain, oedema, worry and low mood etc.)” In response to this question, many respondents answered “*Good*”. They said that they believed and thought the physicians and nurses understood about the patients’ renal problems and tried to provide good care to their patients, even though the patients had many complications while they were waiting to receive dialysis.

“I think the physician understood the patient’s symptoms quite well and treated the patient well too. For example, the patient was sent to have an X-ray, blood tests and so on.” (01)

Analysis of participants’ experiences of caring for ESRD patients who managed without dialysis was possible by examining responses to the open-ended questions.

8.6.1 What, if anything, was good about the care?

In response to this question, three respondents answered “*Good*” and another two answered “*Fine*”. This might reflect the fact respondents’ experiences were positive with regard to health services received during the time their patients managed without dialysis (see Box 1).

Box 1 Open ended responses “What, if anything, was good about the care?”

Fine (Try to help)	Good (Provide a good care)
2/5	3/5
<p><i>“I think overall the physicians and nurses at the hospital tried to help patients, but having too many patients, it was difficult for them for provide good care for all patients. I understand this point.” (04)</i></p>	<p><i>“In the hospital, the physicians and nurses provided good care to the patient. They didn’t do any harm to the patient’s physical and emotional state. I understand they had many ESRD patients waiting to receive dialysis.” (02)</i></p>

8.6.2 What, if anything, was bad about the care?

Regarding this open-ended question, three respondents expressed dissatisfaction and used the word “*Poor*” to describe the care the patients received, especially for haemodialysis, a lack of early health education (how to control symptoms, diet control), and lack of home visits and help at home (see Box 2).

Box 2 Open ended responses “What, if anything, was bad about the care?”

The long queue	A lack of early health education	Lack of home visits and help at home
4/5	2/5	3/5
<p><i>“I think the patients had to wait in more than one hundred queues before receiving HD. It took time to get HD and he died before getting it. I think this is why my husband died very quickly.” (01)</i></p>	<p><i>“...the physician or nurse didn’t tell him early to control his diet. He knew he had to control his diet when he was diagnosed at the end stage of the renal disease. I think he had health education quite late in order to prolong his life.”(01)</i></p>	<p><i>“The physicians and nurses should not leave the patient at home and do nothing, they should visit the patient regularly, the same as they did at the hospital.” (03)</i></p>

8.6.3 Please use the space below if there is anything more you would like to say about the care provided

The researcher finished the cognitive interviews with this final question in order to find out what respondents thought about the care provided. The opinions of the respondents were expressed in terms of how to improve care, with statements such as: *“Not waiting for a long time to get in the queue”*, *“Provide early health education”*, *“Need regular home visits”*, *“Free treatment”* and *“Good referral system”* (see Box 3).

Box 3 Open ended responses “Anything more about the care provided?”

Provide early health education	Not waiting for a long time to get in the queue	Need regular home visits	Good referral system
2/5	4/5	3/5	2/5
<p>“...physicians or nurses should provide health education about things such as the disease, symptoms, treatment and how to control diet related to the disease for the patient at an early stage of the disease.” (03)</p>	<p>“I think the government hospital should have enough HD beds to support ESRD patients who need dialysis, because many patients were very poor and couldn’t afford to pay for HD treatment themselves. Many patients had to go back home, and most of them died at home.” (01)</p>	<p>“I also think home visits should be provided regularly for ESRD patients who manage without dialysis at home.” (02)</p>	<p>“I needed a good referral system from the community hospital to the provincial hospital. This was because the patient was left at the community hospital for many days but he died on the way to the provincial hospital.” (05)</p>

8.7 Overall reflection on cognitive interviewing technique

Cognitive interviews, can be used to identify respondents’ interpretations of questionnaire items, and investigate the selection of response categories from the respondents perspective. The use of cognitive interviews, as part of a multi-stage approach to developing and testing, can help to reduce missing items or selection of incorrect answers and this contributes to ensuring the validity of an instrument. In this chapter, the problems and difficulties a Thai population face when responding to the VOICES-ESRD/Thai questionnaire are discussed and critiqued on the basis of findings from the two cycles of cognitive interviews. Then, the process of the two cycles of cognitive interviewing (see Figure 9), limitations and recommendations are also set out.

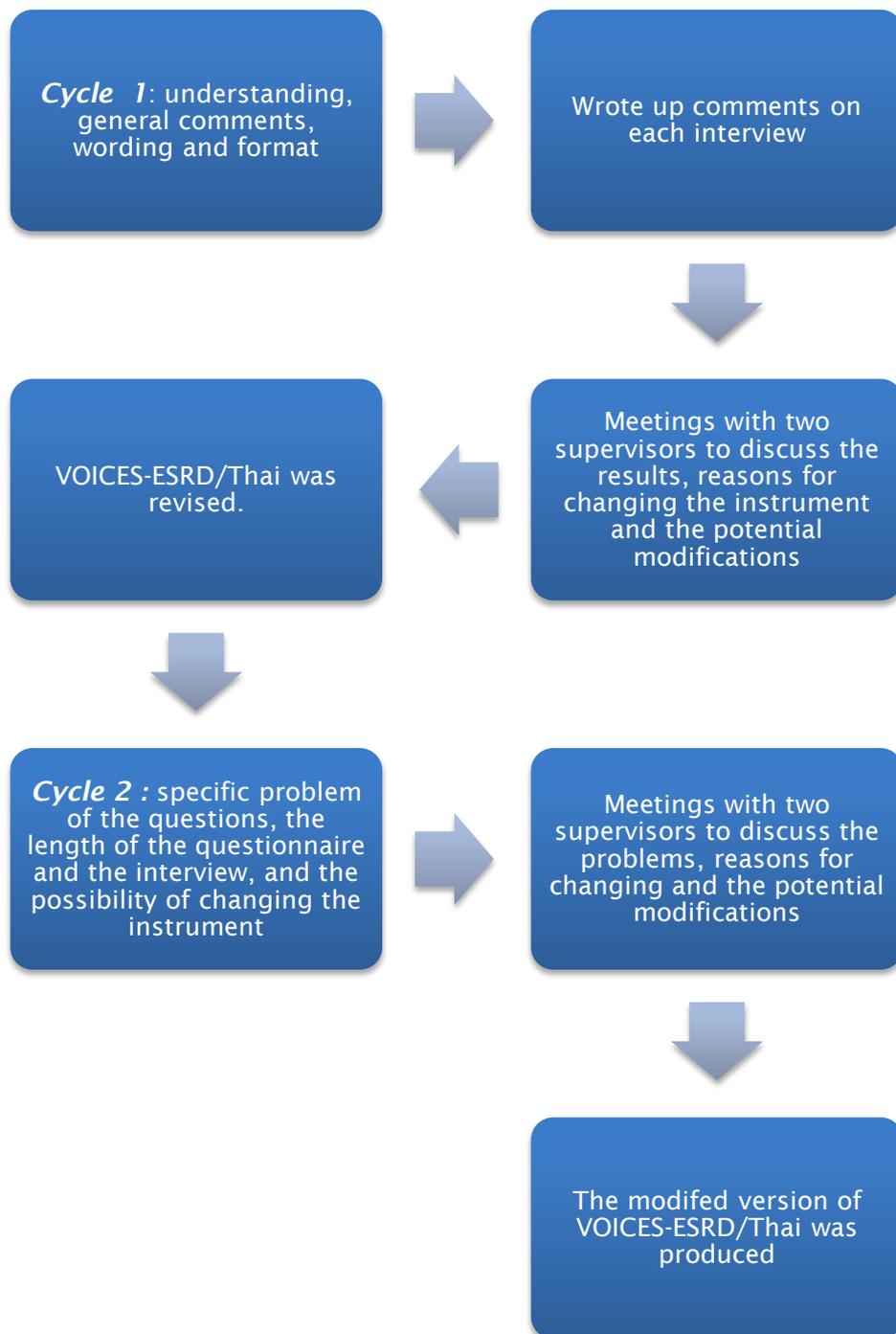


Figure 9 The process of two cycles of cognitive interviews of the study

8.7.1 Reflection on the problems of questionnaire design

Normally, problems encountered during cognitive interviewing include respondents' difficulties with interpretation and comprehension of questions, the retrieval of answers (the mental process that respondents use to arrive at the information needed), and judgement and social desirability in relation to how much information respondents are comfortable to provide (Pasick *et al.* 2001). These difficulties may result in respondents not following instructions, misunderstanding questions' objectives, skipping items, providing obviously incorrect answers and failing to answer questions (Drennan 2003). In this study, two cycles of cognitive interviews identified five problems with questionnaire design, as follows: 1) difficulties relating to the appearance or formatting of the questionnaire; 2) difficulties with specific wording (medical terms) or phrasing; 3) difficulties with specific questions; 4) difficulties regarding the response categories (lack of some categories, too many response categories and the response categories were too complicated); and 5) difficulties with interpreting response categories. Conrad and Blair (1996, cited in Drennan 2003) developed a classification of possible response problems that might occur during questionnaire completion. It consisted of five categories, namely: lexical problems, inclusion/exclusion problems, temporal problems, logical problems and computational problems.

8.7.1.1 Lexical problems

Lexical problems are related to respondents' understanding of the meaning and use of words and the context in which they are used on the questionnaire. Words that are familiar to one group may not be familiar to another, or participants may interpret a different meaning (Conrad & Blair 1996; Drennan 2003). In this study, using the medical term "breathlessness" in question 26 may well have been understood by health care professionals, but it caused respondents difficulties in understanding its meaning. The context of questions may also create lexical problems – for example, when giving feedback about question 9, "When he/she was at home in the last three months of his/her life, did he/she get any help at home from any of the services listed below?", respondents were asked about "the services" that patients received at home during the last three months. This led to a lexical

misunderstanding because respondents looked really confused when the researcher read the words “the services”. The respondents asked the researcher what the services were, and who had to provide them. The researcher had to explain that “the term services means health services which are provided by health care professionals, such as nurses, doctors or health volunteers, to the patient at home”. Other words that caused lexical misunderstanding among the respondents included: “special equipment”, “personal care”, “night time care”, “something urgent”, “bereavement services” and “religious and spiritual belief”. Dillman (2000) stated that lexical problems can occur when developing questionnaires because the researcher may overestimate the understanding and vocabulary of respondents, particularly in questionnaires that involve nursing or medical terminology.

8.7.1.2 Inclusion/exclusion problems

The second category relates to problems of inclusion/exclusion. This kind of problem is associated with determination of the scope of the question. In this study, inclusion/exclusion problems related to the categories in a question (Conrad & Blair 1996). For example, question 7 asked “How long had he been ill before he died?” This question was a bit confusing to respondents because they thought they were being asked to identify the period of time before the patients died (i.e. the time between when the patients were allowed to return home and their death). In fact, the object of this question was the duration of the period between when patients were diagnosed with ESRD and refused to receive dialysis, until the point at which they died. Another example comes from question 56; the phrases “hospital services” and “services outside the hospital” were confusing to respondents. The phrase “hospital services” means health services that were provided by health care professional to patients when they were in the hospital, but the phrase “services outside the hospital” means health services that were provided by health care professionals to patients when they were at home. Respondents might have thought that “services outside the hospital” referred to any service –not only health services, but also social services or financial services provided to the patients at home. This may have led to problems with respondents producing incorrect responses while a specific answer should be provided.

8.7.1.3 Temporal problems

Temporal problems are represented in questionnaire design by their relation to time, both in terms of time periods and time spent on activities (Conrad & Blair 1996). Examples of temporal problems in this study include the phrase “in the last three to twelve months” and “in the last three months” (question 26), which may have a number of meanings including “the last three to twelve months of the calendar year” or “the last three to twelve months before the patient’s death”. Similarly, the phrase “in the last three months” could be interpreted as “in the last three months of the calendar year” or “the last three months before the patient’s death”. In addition, response categories like those in questions 51 and 52, such as “yes, always”, “yes, most of the time” and “yes, some of the time”, may confuse the respondents about selecting an appropriate option. In these cases a precise option would be more suitable.

8.7.1.4 Logical problems

Another issue is logical problems, which are related to respondents’ difficulties in relation to words that connect concepts – for example, “and” or “other than” – and the use of presuppositions in questions (Conrad & Blair 1996). Connecting words may lead respondents to attempt to answer more than one question at a time (Conrad & Blair 1996), while presuppositions are associated with the relevance of the question to the respondent and whether they can answer the question or not. Respondents may not answer the question appropriately or provide no response to the question because they are unable to supply the information requested. In this study, the researcher did not find any difficulties related to connecting words or presuppositions.

8.7.1.5 Computational problems

The final problem is a computational one, involving long-term memory recall, questions with complicated structures and those involving mental calculation (Conrad & Blair 1996). From the study, questions 51 and 52 had different types of response categories to other items in the questionnaire. This might hinder the subjects in answering the questions. It would be better to have one type of

response category or the familiar types of response category, especially when the questionnaire is used with subjects who are at primary school level in terms of their educational experience. Another computational problem occurred in questions such as question 13, which asked respondents “How much time did family and friends (including yourself) spend on these tasks (person care, night time care)?” Respondents may be unable to report the precise number of hours that they used to spend in caring for their patients, and this may result in high numbers of non-response to that item. Time referent questions posed another problem because they required mental calculation. For example, question 35, “How often did the nurses visit the patient at home?” asked respondents to calculate how many times their patients received a visit from a nurse at home over the last three months before the death. Similarly, question 14 asked “How often did she or you get help from health care professionals?” requiring respondents to calculate how many times their patients received help from health care professional at home. These answers may be impossible or difficult to remember, leading to non-responses or other errors.

8.8 Conclusion

The cognitive interviewing technique employed here was beneficial in clarifying the precise nature and cause of respondents’ issues with questionnaire answers. The technique delineated clearly some of the difficulties respondents encountered in answering the questionnaire, and the reasons why these difficulties arose. The process of cognitive interviewing enables the questionnaire to be viewed from the perspective of the respondent rather than the researcher. This helps the researcher to understand the reasons why problems arose, which the researcher may not have anticipated. This also facilitates data compatibility in that it ensures that the majority of respondents can interpret questions in the same way. In this study, retrospective verbal probing techniques were used to help respondents recall their memories. Think-aloud techniques were applied to maximise the information gained and to include areas usually addressed within standard pilot studies, such as completion time, general comments and overall research burden to complete the VOICES questionnaire. The researcher prepared concurrent probing

techniques specifically in order to amplify the information obtained from the first cycle of the cognitive interviews. The activities necessary to confirm or refute of potential problems were concluded within the second cycle. The sample size in this cognitive interviewing study was small (ten respondents across two cycles). However, Willis (2005) stated that “the number of respondent in each cycle was dependent on several factors and there is little benefit in conducting more interviews before modification are made to the questionnaire. Two or more interviews may be sufficient in the early state of developments”. According to Murtagh *et al.* (2007d), although the use of a small sample size in conducting cognitive interviews is not ideal, it should be recognised that the small samples in this type of study are not uncommon, and a small number of respondents can potentially provide an intensive and rich data yield.

Moreover, cognitive interviews are valuable in pretesting complex or sensitive questions and for specific groups (Murtagh *et al.* 2007d). This is firstly because of problems with recruitment and achieving the desired sample size, a particular issue in the field of for the palliative care. In this study, the participants were the main carers of older ESRD patients managed without dialysis in Thailand. The number of potential participants was not large, and some of them were not available to participate in the study since they lived in rural areas a long way away from Chiang Mai province. It was difficult for them to attend interviews. Some moved house to live in other provinces inside or outside Thailand. In addition, some informants did not like to talk or felt uncomfortable when they were asked to recall the suffering and death of their loved one or relative. It was not possible to include all of the individuals who met the inclusion criteria for the study. Therefore, cognitive interviews are important to minimise problems with the questionnaires, and make the best used of the data collected from the remaining participants.

Finally, the cognitive interview is a good technique to apply in the specific circumstances that privacy may be required in order to discuss issues about death and dying. In section 10 of the VOICES-ESRD/Thai questionnaire, respondents are asked 17 questions about the circumstances surrounding the

patient's death and also about their attitudes towards religion, beliefs or faith in God. According to Murtagh *et al.* (2007d) cognitive interviewing is able to help the researcher to identify the range and depth of difficulties with questions, and it might provide particular benefits when instruments are used in different combinations or applied to new study populations. Pasick *et al.* (2001) suggested that the cognitive interview can help develop a deep cultural understanding of the relevance and comprehensiveness of an ethnic group health survey. Drennan (2003) summarised that cognitive interviewing is particularly successful when used to investigate new or poorly described concepts by developing questionnaires for groups that have particular needs and perceptions. Cognitive interviewing can also identify response difficulties, and is able to bring a very real appreciation to the researcher regarding to the precise nature of the phenomenon while ensuring that data collection is carefully matched to the capabilities of the study population (Murtagh *et al.* 2007d).

Cognitive interviewing required specific planning, and careful consideration as to responses necessary to achieve overall validity of the instrument. It could be said that the cognitive interviewing technique which was applied in this study was effective in identifying problems with developing questionnaires for distribution. Cognitive interviewing techniques are most effective if the researcher uses them with other techniques to assure reliability and validity such as a small scale pilot survey, as the combination of techniques will lead to the development of an effective and comprehensive instrument (Drennan 2003).

8.9 Recommendations

As mentioned above, the study population had very specific demographic characteristics and required careful consideration of whether and how the VOICES questionnaire could be applied. Any modification to the instrument as a result of the cognitive interview process impacts validity and reliability as derived from the original validation. The VOICES instrument had been previously used and well validated in a different population. The original

VOICES questionnaire was developed and used in the UK with a number of different populations including heart disease, cancer, stroke and COPD patients. The questionnaire had not been used with older ESRD patients managed without dialysis in Thailand. The validity and reliability of the revised VOICES-ESRD/Thai version will require re-testing in future phases of research.

Although cognitive interviewing is important to minimise problems with questions, reveal the specific thought processes of respondents, make the best use of the data collected from the participants and help the researcher ensure that the data collection is carefully matched to the capability of the respondents, the administration of the questionnaire has not been evaluated. Therefore, the next step of the study is an individual testing a prototype of the ESRD version of the VOICES questionnaire by conducting a small scale pilot survey of the experiences and health care needs of older people with ESRD managed without dialysis in Thailand. This is because a small scale pilot survey could test the method of recruitment and administration, examine response rates, find instances of missing data, identify redundant data items and contribute further refinement of the VOICES questionnaire.

Chapter 9: Methodology of phase III: Small scale pilot survey

9.1 Introduction

This chapter will present the argument for the choice of methodology and methods used in phase 3, the small-scale pilot survey. The study design and objectives are presented, alongside an explanation of how this approach will enable the refinement of the ESRD specific version of VOICES for use in Thailand. Details on the research approach to sampling, sample size, recruitment, data collection and data analysis are provided.

9.2 Design

A small-scale pilot survey was employed in this phase. Before launching any major survey, researchers are encouraged to carry out a pilot study in order to duplicate the study on a small scale and test all the procedures planned for the main study (Knapp 1993). If any serious difficulties are encountered in carrying out the pilot study, the researcher will have the opportunity to change the procedures in the execution of the primary study to avoid difficulties (Knapp 1993). Therefore, this small-scale pilot survey was conducted in a setting similar to that in which the main survey will be carried out, and with subjects similar to those who will participate in the main survey.

9.3 Objective

To test a prototype of the ESRD version of the VOICES questionnaire through conducting a pilot survey of the experiences and health care needs of older people with ESRD managed without dialysis in Thailand. The purpose of this stage was to test the method of recruitment and administration, examine response rates, find instances of missing data, identify redundant data items and further refine the VOICES questionnaire.

9.4 Sample

According to Watson *et al.* (2008), conducting a survey study can be carried out into two steps, namely: 1) testing the feasibility of the questionnaire; and 2) testing the feasibility of the study as a whole. In order to test the questionnaire, a sample can be selected by giving the instrument to a smaller group (10 to 15 people) with the same characteristics as the target sample are assumed to have (Watson *et al.* 2008). The target population in this study was restricted to people who were bereaved relatives of people aged 60 or above who had died from ESRD managed without dialysis, either female or male, who were main carers and who met with the inclusion criteria

9.5 Eligibility criteria

The eligibility criteria for this part of the study are similar to the criteria for phase 1 (see page 54).

9.6 Setting

The setting for this phase was similar to the setting for phase 2 (see pages 102-103).

9.7 Sample size

In order to test the Thai version of the VOICES-ESRD questionnaire resulting from the cognitive interviews, it was planned to approach between twenty and thirty bereaved relatives of older people with ESRD managed without dialysis (the people who register the death at the renal unit, Nakorn Ping Hospital, Chiang Mai Province, Thailand) (see Figure 10). During the period between 1 April and 30 August 2012, the total number of potential participants who registered a death from ESRD five to ten months previously at the renal unit of the Nakorn Ping Hospital was thirty-two cases. The average number of patients who are registered dead each month was between five and six cases (see Figures 10). Therefore, the approximate number of potential participants who could have been recruited 1 April 2012 and 30 August 2012 was 30 cases

which should have been available during the five-month data collection period. According to Watson *et al.* (2008), a good number of participants for a pilot survey should be between twenty and fifty cases: “The size of a sample for a pilot study should be kept small, and depending on how easy/difficult it is to include respondents and whether it is interviews or self-administered questionnaires, something like 20-50 respondents should be recruited” (Watson *et al.* 2008, p. 186). A nonprobability sampling method was used to obtain the sample (Creswell & Plano Clark 2011). Consecutive convenience sampling was used to select potential participants who were available and who met with the inclusion criteria of the study. Twenty bereaved relatives of older ESRD patients managed without dialysis were surveyed around five to ten months after the patients’ deaths.

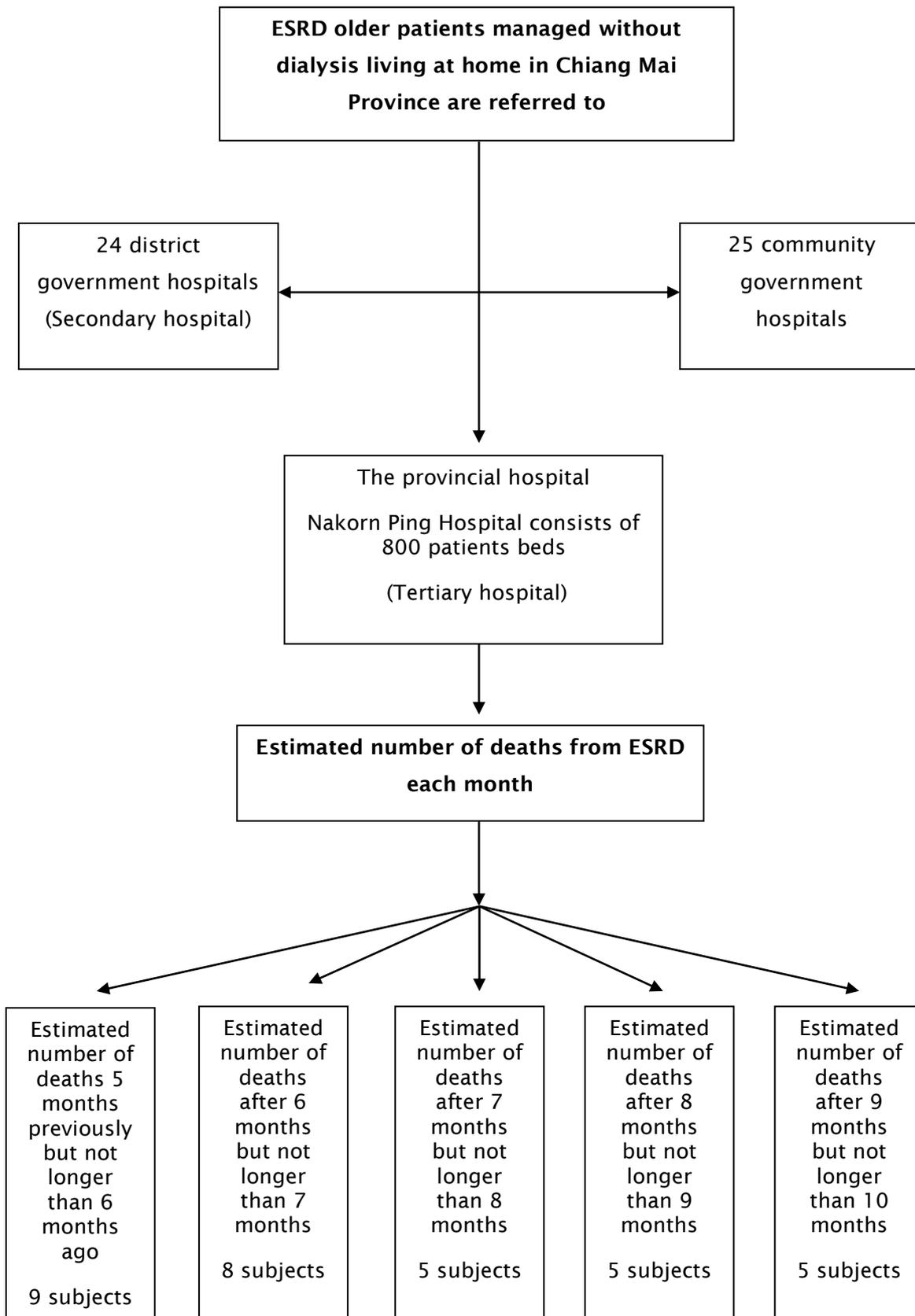


Figure 10 Flowchart of potential participants in phase III

9.8 Recruitment process

The researcher carried out a small-scale pilot survey of the carers for older ESRD patients who managed without dialysis (the person who registered the death) between January and March 2013. The renal unit of Nakorn Ping Hospital holds a database of all registered deaths, which included the underlying cause of death and the name of the person registering the death. It was assumed that the informant would be close to the deceased and involved in caring for them in the last months of life. After initial contact from the researcher, if this proved not to be the case, the informant was asked to forward the questionnaire to whomever they felt would be the most appropriate person and passed their name to the researcher. The recruitment process for this phase was similar to the procedures used in phases 1 and 2 (refer to Chapters 5, 7 and Figure 5).

9.9 Data collection

In this pilot survey, data were collected by an interviewer-administered questionnaire, based on previous experience of cognitive testing and knowledge about how surveys are administered in Thailand. The decision to use interviewer administration was based on the fact that many of the participants were elderly people who may be vulnerable and might have comprehension and language difficulties (many do not know how to read and write fluently). They are likely to need help to complete a questionnaire. The technique of using an interviewer to administer the questionnaire was also chosen because it provides more opportunities for bereaved relatives to discuss their concerns and talk about the deceased than a self-completed postal questionnaire (Addington-Hall *et al.* 1998). High rates of refusal to participate in studies have been related to individuals with functional impairments, poor physical and emotional health, low socioeconomic status and weak social networks (Burns & Grove 2005). The use of an interviewer-administered questionnaire could therefore provide an advantage in reducing the refusal rate (the number or percentage of potential subjects who declined to participate in the study), and in decreasing the sample error by increasing the sample size.

However, Addington-Hall *et al.* (1998) undertook a randomised controlled trial of postal versus interviewer administration of a VOICES questionnaire measuring satisfaction with and use of services received in the year before death. They found that the interview administered questionnaire gave more positive answers about symptom control and satisfaction. This association with positive answers could be a disadvantage of using interviewer administration, since questions might be difficult for respondents to interpret. The interviewers therefore must play a part in helping respondents interpret these questions and formulate their responses, but they must take care not to interpret the questions to respondents (Addington-Hall *et al.* 1998). This technique was applied during the data collection process. In this phase, the prototype of the Views of Internal Carers – Experiences of Services (VOICES) questionnaire version ESRD/Thai was used to collect the data. After participants agreed to participate in the study, an interviewer-administered questionnaire was used to interview people at a mutually convenient time. The procedures for collecting the data are explained below.

9.9.1 Data collection procedures

Following the instructions for renal nurses on how to recruit potential participants (see Appendix E), potential participants were invited by renal nurses to join the study. If potential participants were willing to be interviewed, appointments were made and the interviews were implemented by following the procedures below:

1. The researcher called participants to introduce herself and inform them about the purpose of the study, the process of data collection, human rights protection issues, and the time required for interviews, whether face to face or over the telephone.
2. The researcher provided time for participants to make their own decision and choose the interview method that they preferred.
3. After a brief introduction, the participants were asked to sign a consent form (see Appendix I), and in circumstances where participants could not write they were asked for their verbal consent and use their thumbprint

instead of a signature. The participants who chose telephone interviews provided verbal consent which was audio-recorded.

4. After receiving informed consent, the researcher collected personal data by asking participants for information and completing relevant parts of the demographic data section.
5. The researcher read each item carefully to the participants and let them choose responses by themselves, without any additional clarification. The participants were also allowed to write or explain their answers by themselves for the open-ended questions. The researcher wrote and recorded answers in cases where some participants could not write properly, or where they provided answers over the telephone.
6. The interviews for each participant lasted approximately 45 to 60 minutes to complete all the questions in the VOICES-ESRD/Thai questionnaire. During the interview, the participants could take a break or stop the interview at any time.
7. Finally, the researcher expressed thanks to the participants for their time and participation.

9.9.2 The instrument

The adapted VOICES-ESRD (Thai version) was used to collect the data in this phase. Following the testing in phase 2, the ESRD specific version VOICES-ESRD/Thai questionnaire consisted of ten sections including:

Section 1: Information about the informant (4 items)

Section 2: Information about the deceased (4 items)

Section 3: Help at home (7 items)

Section 4: Urgent Care (out of hours and in the week during office hours) (10 items)

Section 5: Symptom experiences and treatment (8 items)

Section 6: Provincial, district and community nurses (5 items)

Section 7: General doctors and physicians (7 items)

Section 8: Last hospital admission (3 items)

Section 9: The last three days (4 items)

Section 10: Circumstances surrounding the death (17 items)

Male and female versions of the questionnaire were produced. The overall length of the questionnaire was 29 pages, and the total number of questions or items was 69 including closed and open-ended questions. The total time to interview each participant was estimated to be between 30 and 45 minutes. Items were predominantly fixed-response, with the opportunity for further comments. The scores of each section were different.

9.10 Data analysis

The quantitative data were analysed using the Statistical Package for the Social Sciences (SPSS) (version 17). The researcher did hand-coding directly on the paper questionnaire. A numeric code was assigned and dichotomous response choices were scored before entering the data onto the computer. To avoid coding errors, numerical codes were provided for consistency (e.g. Yes = 1 and No = 0). Outlier data were examined using SPSS frequency statistics in order to detect random and systematic errors such as typing or coding errors. Data were carefully recorded, coded, entered and double-checked for any inconsistencies.

Responders and non-responders (age, gender, religion and relationship with the deceased) showed no differences in terms of biographical characteristics. There were two types of missing value in the study, namely: 1) skipped or missing entry: the question was deliberately left blank because it did not apply to individual respondents; and 2) inadequate response: a reply was expected but not given (Bowling 2009b). Inadequate responses were coded as (9s) and does not apply was coded as (8s). Then the researcher identified missing values. The missing values were counted and shown as a percentage, which enables the researcher to check and correct them (Bowling 2009c). Descriptive statistics (means, rates and percentages) were used to describe the

demographic data, the needs and experiences of the subjects within this sample. The questionnaire data were analysed and presented as percentages. The response rate were calculated by comparing the number of potential participants and the number of participants who were interviewed. Then, missing data were calculated and summarized according to questions and sections. Participants were also asked to consider the relevance of items for which they had sufficient information. In addition, they were also asked to give an indication of whether items or topics were “not useful”.

General open-ended questions were also included at the end of the questionnaire. These general questions had the potential to optimise the quality of the data and analysis by enabling respondents to elaborate on their responses to closed questions, and allowing them to identify new issues not captured in the closed questions (Pope & Mays 2006). Content analysis was used to analyse the responses to open-ended questions by devising codes, assigning codes and entering codes into the statistical package (SPSS version 17) (Chathain & Thomas 2004).

9.11 Chapter summary

This chapter has discussed the process of conducting the small-scale pilot survey with 20 participants. The pilot study was required to ensure the questionnaire was acceptable and easy to understand and administer. The results will be reported in the next chapter, including the method of recruitment and administration, an examination of response rates, instances of missing data, the identification of redundant data items, and further refinement of the VOICES questionnaire.

Chapter 10: Findings from phase III

10.1 Introduction

This chapter uses findings from the pilot survey to further evaluate the questionnaire, sampling and administration processes. A summary of response rates achieved is followed by factors affecting the response rate, amount and type of missing data and responses to question. The overall questionnaire structure and responses to, closed and open questions are discussed and evaluated. Recommendations to further refine VOICES-ESRD/Thai prior to conducting a future survey are provided.

As the focus of this phase was on the properties of the questionnaire itself rather than the data generated, the responses to the questionnaire have been summarised and are presented in Appendix Q, rather than in the main body of this chapter.

10.2 Response rate

Data collection took place between 1st January 2013 and 1st April 2013. Details of bereaved relatives of older ESRD patients managed without dialysis in the renal unit at the Nakhorn Ping Hospital, Chiang Mai province, Thailand who met the inclusion criteria were retrieved by clinical staff and these individuals sent an invitation by post. Figure 11 provides a flowchart of how people responded to the invitation.

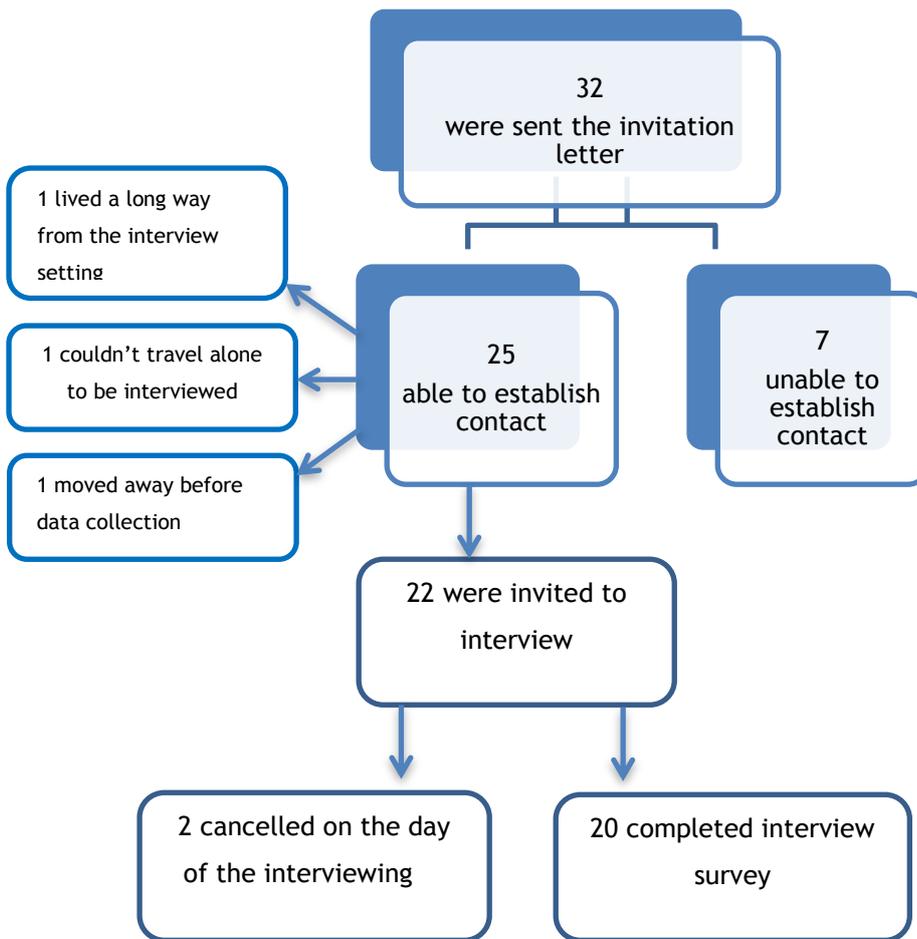


Figure 11 Flowchart of response rates and reasons for non-participation

Of the 32 people sent an invitation, seven informants were later excluded as the researcher was unable to establish contact by telephone. Of the twenty five contactable three declined with reasons including living a long way from the interview setting (1 case) and unable to travel alone (1 case). Another informant was found to have moved away to another province. Therefore, twenty-two potential participants were contacted by the researcher to arrange a date for interview. On the date of interview the researcher was unable to contact two participants either by mobile or land line. Of the first ten participants interviewed, five opted to complete the questionnaire at a hospital near their home, three completed the questionnaire at the renal unit in the Nakorn Ping hospital, and two preferred to complete the questionnaire at home. Half way through the recruitment process, three potential participants suggested they would be happy to complete the survey over the telephone, saving petrol costs and time taken in travelling to and from interview. A further consideration was that it was safer for the researcher than travelling alone to

unfamiliar places. As a consequence, a further ten informants completed the questionnaire over the telephone. In total twenty informants of the original 32 identified from the database completed the questionnaire (69%).

10.3 Demographic characteristics of the informants and the deceased

The majority of informants were either the patients' daughters or sons (50%) (see Table 14). Around 15% of informants were husbands, wives or partners. Most informants were aged between 50 and 59 years (60 %), and there were fewest informants aged between 70 and 79 years (5%). The ratio of genders was equal between males and females at 50%. All twenty informants were Buddhist (100%).

**Table 14 Demographic characteristics of the informants and the deceased
– frequencies (%)**

	Informants		Deceased	
	(N=20)	(%)	(N=20)	(%)
Relationship with deceased				
Husband/Wife/Partner	3	15		
Son/Daughter	11	55		
Brother/Sister	1	5		
Son-in-law/Daughter-in-law	2	10		
Other relative	1	5		
Neighbour	2	10		
Friend	0	0		
Someone else	0	0		
Age				
20–29	2	10		
30–39	3	15		
40–49	2	10		
50–59	12	60	2	10
60–69	0	0	8	40
70–79	1	5	8	40
80–89	0	0	2	10
Gender				
Male	10	50	10	50
Female	10	50	10	50
Religion				

	Informants		Deceased	
	(N=20)	(%)	(N=20)	(%)
Buddhist	20	100	20	100
Duration of illness from diagnosis until death				
Sudden death				
< 24 hours			1	5
1 day but < 1 week				
1 week but < 1 month			2	10
1 month but < 3 months			6	30
3 months but < 6 months			4	20
6 months but < 1 year			5	25
1 year or more			2	10
Time spent at home during last three months				
Yes			20	100
No			0	0

There was an equal distribution of patients in terms of gender. Most patients were aged between 60 and 79 years. The majority (30%) were ill for a period of over 1 month, but less than 3 months. A small number (5%) died within twenty-four hours of receiving their diagnosis of ESRD. 25% of patients died between 6 months and 1 year from diagnosis, 10% died between 1 week and 1 month and another 10% lived for longer than a year. All the patients (100%) spent time at home during the last three months of their life. For more information of the statistical report for the pilot survey please see Appendix Q.

10.4 Factors affecting response rate

The researcher identified two main factors that appeared to affect the response rate: method of recruitment and method of interviews.

10.4.1 Method of recruitment

The researcher couldn't directly approach people to take part in post-bereavement research, because of issues related to data protection and research subject rights. Therefore, the researcher had to contact the relevant hospital administration for ethical approval to conduct the research and permission to make contact with the renal unit which recorded the number of deaths. The number and identity of the deceased was manually recorded by renal nurses. Normally, ESRD patients are divided into two groups – the waiting list (group 1) and those who had refused, or been refused, dialysis (group 2). In the first group, renal nurses routinely ring up patients who are waiting to receive dialysis at home, and if they find a patient has died they note it down. Errors can occur when renal nurses forget to call patients to confirm whether they are still alive. Furthermore, the records of many potential participants were found to contain wrong numbers for mobile phones and land lines. This may have been caused by manual recording errors on the part of the renal nurses. Also, the estimated number of deaths in the group (group 2) who had refused or been refused dialysis treatment remained unclear and a method to identify the bereaved carers of this group was not identified during the pilot; the data recorded through the National Renal Registries in Thailand only relate to those who are on dialysis and does not include those never referred to renal services or those who refuse dialysis. In addition, the precise figures reporting place of death of patients with ESRD are difficult to obtain because death certification often refers to death from sepsis or cardiac complications rather than ESRD (Hobson *et al.* 2011). Therefore, it is difficult to collect a list of people who have died with ESRD in Thailand. The researcher was only able to approach those recorded as having died from the list (i.e. those waiting for dialysis) held by the renal nurses, it was not feasible to refer to death certificates as often the cause of death from ESRD is not recorded. This will affect how a sampling frame might be constructed in any future large scale survey as it is not possible to retrospectively identify bereaved carers of those with ESRD who declined, or were refused, dialysis.

Second, the initial method of contacting informants did appear to influence the response rate. The researcher noted that if the renal nurses contacted informants directly by calling to arrange an interview after sending an invitation letter or calling to invite them to participate in the study, the informants seemed more interested in taking part in an interview, rather than in situations where the researcher phoned to enquire about possible participation. However, the renal nurses were always very busy, and they often declined to do this because they did not have time to call to arrange interviews with the informants. Similarly, Addington-Hall *et al.* (1998) found that the method of contacting potential participants influenced the response rate in their study, since sending questionnaires from local GPs or health authorities was more effective than sending them from university or academic departments.

10.4.2 Method of interview

10.4.2.1 Face to face vs. telephone interviews

A face to face interview (an interviewer-administered questionnaire) was the intended method for survey data collection during the pilot, following the findings from the first phase of the study. Half way through the data collection process, however, participants mentioned they might prefer a telephone interview to complete the questionnaire, for reasons mentioned above. Then, 10 participants who firstly refused a face to face interview were invited and agreed to a telephone interview. Moreover, the response rate differed between the offer of a face to face interview and when telephone was offered later during the study (face to face: 45% – 10 out of 22), telephone: 100% – 10 out of 10). This is in contrast with a comparison of response rates between postal questionnaires and face to face interviews, conducted in UK and reported there to be no statistical difference between response rates between postal (56%) and interview (52%) groups (Addington-Hall *et al.* 1998). A study by Ingleton *et al.* (2004) on satisfaction with end of life care in Powys, Wales reported the response rate of informants required to “opt in” by requesting a copy of the questionnaire (37%) was lower than the response rate of informants who were not required to opt in (48%). There is also evidence to support the idea that

respondents prefer to complete sensitive questions included in the VOICES questionnaire by themselves, rather than being asked face to face by an interviewer (Hunt *et al.* 2011). The difference in response rates observed between face to face and telephone interviews in this study has shown that the offer of a telephone interview could increase the response rate for the VOICES-ESRD/Thai questionnaire.

10.4.2.2 E-mail

Even though in this study e-mail was not used as a method of interviewing, two respondents from the first phase and one respondent from the second phase of the study suggested they would prefer to answer the questionnaire via e-mail as this would have been convenient for them. An e-mail or web-based method should be considered as an alternative way to collect data. However, this is dependent on the geographical area and the level of literacy. The three respondents who preferred to use e-mail lived in Chiang Mai city and had a higher level of literacy than other respondents in the third phase, who mostly lived in rural areas. According to According to Hunt (1986), Hughes et al (2005), and Hughes & Addington-Hall (2005) literacy levels were identified as a potential inhibitor to participation and the success of survey methodologies, as self-completion will ultimately fail if it is applied as a data collection technique in a low literacy population. Therefore, multiple modes of completion are likely to be needed in order to get a good response rate and achieve a representative sample in Thailand.

10.4.2.3 Time

The informants who took part in a face to face interview were more likely to schedule the meeting in the morning (between 8.00 am and 12.00 pm) rather than the afternoon. This might be because the informants had to travel from their own home to the meeting point, i.e. a hospital near their home. The approximate time spent travelling ranged between thirty minutes and three and a half hours. The duration of the interview was normally between thirty and -forty-five minutes, and informants preferred not to travel back to their homes late at night. This contrasted with the telephone group, where

informants preferred to be interviewed in the evening (between 6.00 pm and 8.00 pm). However, both groups preferred to have interviews at the weekend.

10.4.2.4 Location

In this study, many informants preferred to hold the interview in their own home or by telephone for their convenience. This was because many of the informants were farmers in rural areas. They did not want to spend the whole day travelling for an interview. Some informants who lived in the city were happy to hold the interview at the renal unit of the provincial hospital. Some informants who lived in Districts outside Muang Chiang Mai understood that it might be difficult for the researcher to go to their homes, so they were happy to meet at the district hospital near their home.

10.4.2.5 Incentive/ Reimbursement

According to Hughes *et al.* (2005) an incentive, including monetary gifts, may encourage people to participate in the research. The researcher did not provide an incentive to participate in this study, since incentives can raise ethical issues and affect the quality of the data (Huby & Hughes 2001). At the beginning of interviewing, the first two respondents were not asked for paying for reimbursement. However, the researcher realized that it was necessary to pay for respondent's travelling costs (petrol) and some of them had to take time off work on the day of the interview. Eighteen potential participants in this study were therefore informed by the researcher at the first time of the contacting to participate in the study that they will receive the reimbursement for participating in the study. The researcher also asked them "*Which type of the reimbursement would you prefer?*" All the informants, who asked and preferred to receive reimbursement, agreed they would prefer to receive petrol costs only.

10.5 Missing data

Two types of missing data can occur during a survey, inappropriate or missing entries and inadequate responses (don't know and not sure) (Addington-Hall *et al.* 1998); Bowling (2009b). In this study, missing entries firstly occurred when respondents missed a question they were eligible to answer (i.e. the question was left blank). Second, inadequate responses occurred where respondents answered "don't know" or "not sure" to a question (see Table 15).

Table 15 Proportion of missing data, by section and by type of missing

Questionnaire item	Omitted	Don't know	Not sure
	N (%)	N (%)	N (%)
Section 3: Help at home			
<i>Missing data on one or more questions</i>	0	2 (10)	0
Question 12.		2 (10)	
Section 4: Urgent care (out and in the office hours)			
<i>Missing data on one or more questions</i>	8 (40)	9 (45)	3 (15)
Question 18			
Question 19			1 (5)
Question 20		7 (35)	
Question 22	8 (40)		
Question 23	8 (40)		
Question 24			3(15)
Question 25		9 (45)	
Section 5: Symptom experiences and treatment			
<i>Missing data on one or more questions</i>	0	5 (25)	0

Questionnaire item	Omitted N (%)	Don't know N (%)	Not sure N (%)
Question 26			
a) Last 3 months		1 (5)	
Question 27			
a) Last 12 months		3 (15)	
b) Last 3 months		1 (5)	
Question 28			
a) Last 12 months		2 (10)	
b) Last 3 months		1 (5)	
Question 29			
a) Last 12 months		4 (20)	
Question 30			
a) Last 12 months		2 (10)	
b) Last 3 months		1 (5)	
Question 31			
a) Last 12 months		2 (10)	
b) Last 3 months		1 (5)	
Question 32			
a) Last 12 months		5 (25)	
b) Last 3 months		4 (20)	
Question 33			
a) Last 12 months		5 (25)	
b) Last 3 months		2 (10)	

Questionnaire item	Omitted N (%)	Don't know N (%)	Not sure N (%)
Section 6 : Provincial, district and community nurses			
<i>Missing data on one or more questions</i>	11(55)	15(75)	0
Question 35	11 (55)		
Question 36			
Question 37		15 (75)	
Section 7 : General doctors and physicians			
<i>Missing data on one or more questions</i>	0	2(10)	0
Question 42		1 (5)	
Question 43		1 (5)	
Question 44		2 (10)	
Question 45		1 (5)	
Section 8: Last hospital admission			
<i>Missing data on one or more questions</i>	0	2(10)	0
Question 47		2 (10)	
Section 9: The last three days			
<i>Missing data on one or more questions</i>	0	3 (15)	0
Question 52			
a)		3 (15)	
b)		1 (5)	
Section 10: Circumstances surrounding the death			
<i>Missing data on one or more questions</i>	0	2 (10)	4 (20)
Question 53		2 (10)	

Questionnaire item	Omitted	Don't know	Not sure
	N (%)	N (%)	N (%)
Question 59			3 (15)
Question 60			4 (20)
Question 61			1 (5)
Question 63			2 (10)

Table 15 presents the proportion of missing data, by section and type of missing data. Section 6 (Provincial, district and community nurses) had a high proportion of both types of missing data, inadequate “don’t know” responses (75%) and inappropriate response items omitted (55%), while section 10 (Circumstances surrounding the death) there were a high proportion of inappropriate “not sure” responses (20%). Section 4 (Urgent care outside and in office hours) combined three different types of missing data, among which “don’t know” responses formed a proportion at 45%, “omitted” at 40% and “not sure” at 15%. In this study, missing data occurred based on the reasons provided below;

10.5.1 Missing entries

10.5.1.1 “Skip question” or “Filter question”

Missing entries (items omitted) were mostly located in Section 4: Urgent care in relation to question 22 and question 23 and in Section 6: Provincial, district and community nurses in relation to question 35 (see Table 15 and Appendix Q). Potential errors made during face to face interviews include incorrect “skipping question” or “filtering questions”, which are designed to route respondents through specific questions and which may cause confusion (Polit & Beck 2008; Bowling 2009b) if respondents sequentially omit to answer questions. Bowling (2009b) suggested clear signposts should be provided to ensure the interviewer does not make erroneous skips and complex rerouting

of questions should be minimised to reduce extra demands of the interviewer. Polit and Beck (2008) advised this problem can be minimised by using computer-assisted interviewing (or the use of laptop computers which display questionnaires, enabling respondents' replies to be directly keyed in and automatically displaying the next question). Questions No 21, 22 and 35 warrant adjustment by providing instructions to skip to a specific question in the right-hand margin of the filter question and also providing a clear signpost as show in the box below (see Box 4).

Box 4 Instructions to skip to a specific questions

Original format	Revised format
<p>21. In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent during office hours?</p> <p>Tick one only</p> <p><input type="checkbox"/> Not at all in the last 3 months</p> <p><input type="checkbox"/> Yes please tick one only</p>	<p>21. In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent during office hours?</p> <p>Tick one only</p> <p><input type="checkbox"/> Not at all in the last 3 months <i>(Skip to Q 25)</i></p> <p><input type="checkbox"/> Yes please tick one only <i>(Continue to Q 22)</i></p>
<p>22. The last time this happened, who did she contact, or who was contacted on his/her behalf?</p> <p>Tick all that apply</p> <p><input type="checkbox"/> General doctor or physician or the out-of -hours number</p> <p><input type="checkbox"/> Provincial, District or community nurses</p> <p><input type="checkbox"/> Nobody or can't contact</p> <p><input type="checkbox"/> Something else-please write in the space below:.....</p>	<p>22. The last time this happened, who did she contact, or who was contacted on his/her behalf?</p> <p>Tick all that apply</p> <p><input type="checkbox"/> General doctor or physician or the out-of -hours number</p> <p><input type="checkbox"/> Provincial, District or community nurses</p> <p><input type="checkbox"/> Nobody or can't contact <i>(Skip to Q 25)</i></p> <p><input type="checkbox"/> Something else-please write in the space below:.....</p>
<p>35. Did she receive help at home for her renal trouble from the nurses?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p>a) If yes, how often did the nurses visit (at the most frequent time)</p>	<p>35. Did she receive help at home for her renal trouble from the nurses?</p> <p><input type="checkbox"/> Yes <i>(Continues to Q 35a)</i></p> <p><input type="checkbox"/> No <i>(Skip to Q 37)</i> ↓</p> <p>35 a) If yes, how often did the nurses visit (at the most frequent time)</p>

10.5.2 Inadequate responses

10.5.2.1 “The recall (memory) bias”

Table 15 shows that most cases of missing data were due to inadequate responses (“don’t know”) rather than inadequate responses (“not sure”), particularly in Section 5: Symptom experiences and treatment (in relation to questions 26 to 33). This section required the researcher to pay attention as respondents might not have good recall about the patients’ renal symptoms. A recall (memory) bias is always possible in questions asking about the past, and asking about events that occurred longer than six months ago should be avoided, except on topics of terminal care or death where memory is better than for example where the topic is about non-fatal injuries (Bowling 2009, p.332). However, this may depend on the age of respondents (Bowling 2009, p. 332), so that people aged over fifty should be prompted by the interviewer by asking them to check with any documents they may have, or by using assistive questions such as *“Was it more or less than three or twelve months ago?”* and *“Could you tell me more about the patient’s life events during the last three months or the last year?”*

10.5.2.2 “Sensitive items”

In Section 6: Provincial, district and community nurses (question 36 and 37), most of the respondents answered “don’t know” (see Table 15 and Appendix Q). Most of the respondents did not provide ratings about this type of care, perhaps because they hadn’t received that type of care and weren’t clear how they should answer. Alternatively, they might not want to provide a negative answer about the care their relatives received from nurses at home by trying to say *“Please don’t ask me how good or bad it was”*. According to Bowling (2009), telephone interviews have a higher non-response rate than face to face interviews in health surveys, especially for sensitive items, and this method of administration can lead to incomplete information and more “don’t know” responses. Providing open-ended questions for sensitive or complex topics may enable respondents to give an opinion without being forced to answer directly about whether care was good or bad (Bowling 2009b).

10.5.2.3 “Attitude (opinion) questions”

Inadequate responses (not sure) were particularly common in Section 10: Circumstances surrounding the death. Question 59 to 63 asked respondents about health care staff and patients’ attitudes. These questions can be difficult to interpret, and the respondents may not have thought about this topic before (Bowling 2009b). The interviewer might provoke a response by asking questions using the words “Do you think...?” rather than “In your opinion...?” or “Do you feel...?” (see Box 5). These wordings will provide more natural responses and reflect everyday speech (Bowling 2009b) and have been taken into account when suggesting some rewording of particular questions.

Box 5 Rewording of particular questions

Original words	Rewords
<p>59 Did the health care staff have a record or know of this?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Not sure</p>	<p>59 Do you think the health care staff have a record or know of this?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Not sure</p>
<p>62 Do you feel that her religious, beliefs or faith in God were taken into consideration by those caring for her?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Yes, partially</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't sure</p>	<p>62 Do you think that her religious, beliefs or faith in God were taken into consideration by those caring for her?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> Yes, partially</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Don't sure</p>
<p>63 Were you or her family given enough help and support by the healthcare team at the actual time of her death?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes, definitely</p> <p><input type="checkbox"/> Yes, to some extent</p>	<p>63 Do you think/ feel you or her family given enough help and support by the healthcare team at the actual time of her death?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes, definitely</p> <p><input type="checkbox"/> Yes, to some extent</p>

Original words	Rewords
<input type="checkbox"/> No, not at all <input type="checkbox"/> Don't know	<input type="checkbox"/> No, not at all <input type="checkbox"/> Don't know

No missing data were encountered in Section 1: Information about the informants and Section 2: Information about the deceased. On the whole the interviewer-administered approach produced a low level of missing data (Addington-Hall *et al.* 1998), especially in terms of missing entries (omitted). This might be because each respondent completed the questionnaire in a question by question manner. If they did not understand a question they had an opportunity to ask the researcher to explain instead of skipping or omitting it.

In addition, a “don’t know” reply could be interpreted in several ways. This is because “don’t know” and “not sure” were provided as response categories for the questions in this study. According to Bowling (2009, p. 357) it is possible that the respondents may not understand the question clearly and hence they may not want to admit they don’t know answers. Alternatively, the phrase “don’t know” may provide respondents with time to think; the respondents may feel reluctant to answer the question, so they try to avoid answering; or respondents simply may not know the answer. The most important thing is that inappropriate responses (“don’t know” or “not sure”) are not reported as missing entries (omitted in error) (Bowling 2009b). However, the researcher considers the best way to deal with this situation is by repeating the question and providing the respondents with a non-directive-probing question (Bowling 2009) as set out below (see Box 6);

Box 6 Providing the respondents with a non-directive-probing

Directive questions	Non-directive questions
-Are there any other reasons why you feel that way?" -Was it more or less than a year ago? -Which of these comes closest to your ...?	-Repeating the question or writing down -A verbal "mm" or "yes" followed by an expectant pause - A quizzical glance followed by an expectant pause -Neutral comments of questions such as "Any other reason?", "How do you mean?" and "Why do you feel/think that way?"

10.5.3 Response to questions**10.5.3.1 Feedback on structure and format of questionnaire**

Respondents provided some useful suggestions about how to improve the questionnaire, including suggestions about question layout and questionnaire ordering. It is important that any questionnaire should have good structure and format (Bowling 2009, p. 302–303).

10.5.3.2 Questionnaire layout

- Based on feedback Section 4 (Urgent Care out of hours and in the week during office hours) should be rearranged to make it easier to answer instead of being separated into two parts (see Box 7).

Box 7 Questionnaire layout/ rearranged

Question	Out of hours	In the office hours
22.The last time this ...		
23. What happened as a ...		

- Section 5 (Symptom experiences and treatment) should have text highlighted in the headings for each symptom, to make it easy to find the different symptoms.
- Respondents suggested that the structure of the questionnaire should be arranged to make it easy to read and simple to answer.

10.5.3.3 Question order

- The phrase “*Tick one only*” should be stated at the start of the questionnaire on page 2 (where the content of questionnaire begins). The phrase “*Please tick all the boxes which apply*” should be provided for each specific question to which it applies.
- One respondent suggested that the researcher should put the number in front of the response category box to make it easier to know the sequence of the response categories; for example (see Box 8):

Box 8 The sequence of the response categories

1	<input type="checkbox"/>	Excellent
2	<input type="checkbox"/>	Good
3	<input type="checkbox"/>	Fair
4	<input type="checkbox"/>	Poor
5	<input type="checkbox"/>	Don't know

10.5.4 The last three open questions

Sixteen respondents (80%) took the opportunity to provide comments for the last three open questions. Four respondents (20%) didn't want to express their feelings about the quality of care at home because they did not receive the service. Therefore, it was impossible for them to say whether the care was good or bad.

“I didn't receive any help or support at home. So I can't tell you how good or bad it was.”

According to Bowling (2009b) open-ended questions are essential to enable respondents to raise other relevant issues that are not covered by answering the closed questions. However, a disadvantage could be that respondents may not bother to write their replies, and the replies obtained can be distorted by inappropriate categories (Bowling 2009b). In order to avoid this bias, the researcher clarified and compared data captured from open-ended questions in terms of the framework analysis produced during an earlier phase of the research about the symptom experiences and health care needs of older people with ESRD who were managed without dialysis in Thailand (see Figure 6, page 90). This process identified two related issues raised by respondents which need to be added to the VOICES-ESRD/Thai questionnaire, namely health education ("*need to know when back home*"; please see Appendix R) and support with transportation ("*I have no car*"; please see Appendix R).

10.5.4.1 Question 1 "What if anything was good about the care?"

Most respondents provided positive feedback that their relatives were treated with dignity and respect while they were being cared for by the nurses and doctors, even in the case where the respondent felt disappointed with the doctors regarding the overall quality of care in the last three months (see Table 16).

Table 16 Comments on doctors and nurses at provincial hospital (N= 16)

Always polite	Understand/ provide good communication	Better co-ordination
(11/16)	(10/16)	(1/16)
<p>“The doctors were <i>always polite</i> and understood the health problems of my mother.”</p>	<p>“The nurse was not aggressive at all even though she had to care for many patients at the same time. She looked <i>understanding and provided good communication</i> with my father every time we met her in the hospital.”</p>	<p>“The doctors and nurses at the provincial hospital showed <i>better co-ordination</i> with the doctors and nurses at the district hospital, especially when my mother was referred back home.”</p>

10.5.4.2 Question 2 “What, if anything was bad about the care?”

In this question, the negative comments relating to the four categories of care received were mentioned by respondents including, help at home, urgent care out of office hours, district doctors and nurses. Three respondents expressed their thoughts that the quality of care at home is currently not good enough, and needs to improve in order to respond to patients’ needs. The quality of urgent care out of office hours was also seen as a negative aspect by five respondents who focused on the ambulance service. The lack of effective ambulance support, especially for patients who manage without dialysis at home, seems to be a systematic problem among local hospitals in Thailand (see Table 17).

Table 17 Comments on quality of care about help at home and urgent care out of office hours (N=16)

Not good	Disappointed	I have no car
(3/16)	(5/16)	(5/16)
<p>“I think health services at home for patients who manage without dialysis should be improved as it is not good to leave patients at home with their carers who might not understand or be able to help patients properly.”</p>	<p>“I feel very disappointed with the care we received at home. This is because no nurse or doctor came to see my father at all since when my father left the hospital until he died three months later. In addition, I had to work in the daytime and I would have liked someone to help me by taking care of my father when I had to work outside the home.”</p>	<p>“The ambulance car was a problematic service. I mean, my Mom had emergency health problems at home and I have no car. I had to borrow my neighbour’s car to take my Mom to hospital, especially at night.”</p>

One respondent expressed negative feelings about the quality of care provided by general doctors at the district hospital because the doctor neglected to perform a special disease investigation in order to provide the right diagnosis and effective treatment. This resulted in rapid progress of the patient’s complications. This also left the patient and carer unable to prepare for the end of the patient’s life. Two respondents provided negative feedback about the quality of care provided by the provincial nurses. The respondents felt the quality of care was poor, and the way the nurses communicated with the patients and carers was poor (see Table 18).

Table 18 Comments on quality of care provided by district doctors and provincial nurses (N=16)

Why not tell earlier	Not nice at all	I was ignored
(1/16)	(2/16)	(2/16)
<p>“I <i>don’t understand</i> if the doctor didn’t know about the patient’s health problem, why the doctor <i>did not tell us earlier</i> and why he did not refer my father to the provincial hospital which has a renal specialist. The last two months while my father managed without dialysis at home, the doctor never suggested even for regular health check-ups. Sometimes, I observed that the doctor felt annoyed to see me and my father.”</p>	<p>“I don’t want to go back to that hospital again. The nurses were <i>not nice at all</i>, they were not sympathetic about the feelings of patient who felt uncertain about living at the hospital and also were fearful about their death.”</p>	<p>“My personal experience with the hospital nurse at the general ward was bad. The nurse would come to monitor my father’s blood pressure only once a day. Some days no nurse came to see my father. I tried to ask questions about what was going on with my father’s treatment. <i>I was ignored</i> by the nurses since they kept quiet and looked at me like I had done something wrong.”</p>

10.5.4.3 Question 3 “Anything more you would like to say about the care provided?”

Many respondents were not satisfied with the treatment their relative had received from doctors during the end of their life. One respondent thought that his father should receive better treatment and full support before death. Most respondents would like their relatives to receive better end of life care at home, including regular home visiting. Three respondents provided comments about a lack of time for discussion with the nurse about the patients’ health problems, saying that the nurses in the renal unit were always busy (see Table 19).

Table 19 Overall suggestions to improve quality of care (N=16)

Make more effort to help	Having time for visiting at home	Information needed on being sent home
(7/16)	(2/16)	(3/16)
<p>“The last time when I took my father to the provincial hospital, I felt disappointed with the hospital doctors. I used to think the hospital doctor would make a lot of effort to help patients. But the doctor said to me that he thought my father was not getting better and the health condition would get worse very quickly. So he said he couldn’t do anything more. I took my father back home but he died on the way before arriving at home.”</p>	<p>“Everyone normally knows doctors always busy in the hospital and it is impossible to them to see patients at home. However, if doctors think they should see patients at home. I think the doctor could arrange their time for visiting patients at home.”</p>	<p>“I do think the quality of care of the hospital nurses, especially at the renal unit, would be excellent if the nurses were not too busy and had more time to discuss with patients and carers about what the patients or carers need to know when they are back at home. Currently, the nurse is in a hurry to train carers in how to care for the patients at home before patients are discharged, not knowing that the carers and patients may not fully understand what the nurse tried to train.”</p>

10.6 Chapter summary

This small scale pilot survey was conducted to check potential issues which can arise when face to face interviews are used as a method of collecting survey data. Response rates and reasons for non-participation in the study, factors affecting response rates (methods of recruitment and methods of interview) were clarified and explained. Missing data (missing entries and inappropriate responses) were discussed, and solutions to avoid bias explored. Responses to closed and open-ended questions were analysed by linking with the framework analysis conducted in phase I (see Chapter 6, Figure 8, page 98). Two aspects

should be considered as additions to the questionnaire, namely health education and support with transportation. Revisions to the questionnaire that should be considered based on these findings will be presented in the next chapter, alongside a more general discussion of the findings from the three phases of the study.

Chapter 11: General discussion

11.1 Introduction

This study has resulted in the development of a questionnaire based on qualitative data. The use of an exploratory, sequential design has enabled the design of a questionnaire that is sensitive to Thai culture and a valid assessment of the experience of services as the end of life approaches in a Thai health care context. The findings have also furthered our understanding of the needs of older people with ESRD who manage without dialysis in Thailand. This chapter will discuss the outcomes of the research and its strengths and limitations in relation to three particular areas: understanding the experiences and health care needs of older ESRD patients who were managed without dialysis; the development of a culturally acceptable version of the VOICES-ESRD/Thai questionnaire; and how the findings might inform the shape and conduct of any future large-scale survey. The specific clinical implications and research recommendations will also be considered.

11.2 Experiences and health care needs of older ESRD patients managed without dialysis in Thailand

This study fills a research gap and generates new knowledge through developing our understanding and providing evidence about the experiences and health care needs of older Thai ESRD patients who managed without dialysis during the last year of life from the perspective of their bereaved relatives. The numbers of ESRD patients are increasing around the world, including in Thailand (Yodchai *et al.* 2011). It is important to explore their experiences and health care needs, which are key to developing health care services responsive to patients' requirements (Teerawattananon *et al.* 2007). A great deal of research on end-of-life or conservative care for this patient group has been conducted in UK, other European countries and the USA. However, similar evidence has been lacking for Thailand. Because of the differences between health care systems and cultural beliefs in Eastern and

Western countries, research is required into what underpins the preferences and priorities of similar patients in Asian countries in order to provide them with the best end-of-life and supportive care.

Four main themes (symptom experiences, impact, current symptom management and health care needs and utilisation) were explored during the qualitative phase. The qualitative findings suggested that patients experienced a range of negative impacts and for some their suffering was severe, with uncontrolled symptoms and renal complications included physical symptoms (breathlessness, pain and oedema), psychological symptoms (worry and low mood) and spiritual distress during the last year at home. Furthermore, their health care needs such as symptom management at home, psychological and spiritual support, regular home visits, an effective referral system, health education, and financial support were not adequately accessed or provided for. A discussion and reflection on the qualitative findings is presented below.

11.2.1 Symptom experiences

11.2.1.1 Physical symptoms

During the last three months before death, carers explained the intensity of symptoms increased dramatically and reflected a rapid decline in patients' physical health. Carers described that breathlessness caused "***the most suffering***" and created the greatest "***sense of difficulty***". Breathlessness impacted on patients' physical weaknesses, sleep patterns and social isolation, forcing them to become totally dependent on carers for performing activities relating to daily living. Pain was described as "***the main factor***" which made patients feel uncomfortable. Oedema was described as "***in everywhere***", and it resulted in patients feeling "***a lot of pain***" for a long time. Oedema limited patients' mobility, and caused them to experience a lack of confidence in their body image. Noble *et al.* (2010) also found symptoms affected patients' daily living, and some symptoms such as breathlessness become difficult to treat with oedema becoming increasingly difficult to manage with diuretics when death was close. Murtagh *et al.* (2006) have mentioned the intensity of

symptoms such as pain has rarely been studied, perhaps because pain has not been thought to be problematic for renal patients. Many of the common causes of pain in renal patients are associated with long-term chronic diseases, such as ischemic pain from peripheral vascular disease, neuropathic pain from polyneuropathy which is related to diabetes mellitus, bone pain from osteoporosis or muscular-skeletal pains from a variety of causes. This may influence both the patients' attitudes to the pain and the professionals' approach to identifying and addressing it (Murtagh *et al.* 2006). Many symptoms can go unrecognised because doctors were focused on the disease itself and not the symptoms (Murtagh *et al.* 2006). In addition, many patients with renal problems have several co-morbid conditions, and renal teams might consider that management of symptoms unrelated to the renal condition is the responsibility of other health professionals. Also, it is possible that non-renal health professionals may be both unskilled and lacking in confidence in the use of appropriate medicines and non-pharmacological methods in the context of renal disease management.

A picture emerged of a heavy symptom burden experience among the Thai population which is extremely distressing for some, with symptoms such as pain, breathlessness and oedema appearing to be common. These results are consistent with studies in UK. For example, Murtagh *et al.* (2011) demonstrated that the functional status of patients with conservatively managed ESRD, measured using the Karnofsky Performance Scale (KPS), remained stable during the last year of life but declined steeply in the last month of life. According to Murtagh *et al.* (2007c), patients in stage 5 chronic kidney disease who were being managed without dialysis experienced fatigue and lack of energy (76%), pruritus (74%), dyspnoea (61%), oedema (58%), pain (53%), sleep disturbance (41%), restless legs (48%) and poor concentration (44%). Similar findings by (Noble *et al.* 2010) found that the symptoms experienced by patients managed without dialysis were oedema (96%), pain (90%), immobility (60%), breathlessness (50%), pruritus (47%), lethargy and insomnia (53%) and depression (37%).

The findings reveal that the physical symptoms profile, intensity and prevalence in this study are slightly different in comparison with previous studies in the UK. This might be because of limitations in the availability of specific symptom management at home such as oxygen support and pain control, which are currently not well managed in Thailand. In regard to the management of physical symptoms, oxygen support and other respiratory equipment (to manage breathlessness), pain relief medicines and diuretics (to manage oedema) were used, but these were only available in the hospital. Murtagh *et al.* (2008) used quantitative methods and focused on symptom data collection at baseline and a month before death. Noble *et al.* (2010) used qualitative methods to collect information about symptoms at any point in the disease trajectory. There is no other work in Thailand that has applied a retrospective qualitative data collection method to explore symptom experiences and identify patients' needs during their last year of life before their death. The effective identification and management of symptoms, a factor highlighted from the accounts of bereaved relatives in this study are important, and this study has revealed a clear picture of the symptom burden and health care needs in the Thai population.

11.2.1.2 Psychological symptoms and spiritual distress

Little is known about the specific psychological and spiritual needs and relative impact of these aspects on patients. In particular, previous studies in the UK did not mention or explore the issue of worry and spiritual needs of older ESRD patients managed without dialysis. This omission was addressed in this study in the Thai context. Psychological symptoms including worry and low mood were found to be a crucial issue of concern for this group of patients in Thailand. Worry caused patients to feel a "*sense of being useless*" because they were unable to help themselves to perform their daily activities. The severity of breathlessness was considered to be an influencing factor on patients' levels of worry about their lives, particularly in the last months before death, since patients thought they placed a burden on their families. Worry impacted on patients such that they were unable to control their emotions, especially when they suffered severe breathlessness during the last months of life; patients felt panic, and a fear of dying surfaced. The physical changes they

experienced often interfered with the mental and social function of patients (Tallis 2005). At the same time low mood developed and increased in severity during the last few months before a patient's death. This is consistent with the study by Murtagh *et al.* (2006), who reported that depression (27%) was found to be a psychological symptom of ESRD people managed without dialysis. The carers explained that suffering with physical symptoms in the last few months before death resulted in the patients feeling depressed. Noble *et al.* (2010) also observed that some patients experienced depression as a result of the decision that they were not to receive dialysis, and some patients suffered with low mood after overhearing, from the doctor, that nothing more could be done for them.

The findings from the qualitative data suggested that low mood affected the patients in this study, who became less interested in participating in activities with others. Similarly, Noble *et al.* (2010) found that depression affected patients' management of ESRD, as they became unable to do things that they had previously been able to do with ease. Depression also changed patients' personalities, caused them to manifest a lack of concern for themselves as well as encouraging them to give up their treatment. In comparison, Davison (2010) found that patients with depression may not always clearly show the impact of their symptoms, but it could have been an important influence when considering the way some patients respond to treatment. Based on the evidence from previous studies and the findings from this research, psychological symptoms among patients, such as worry and low mood, accompany the experience of managing without dialysis and ineffective control of physical symptoms including breathlessness, pain and oedema appear to contribute. The intensity of worry and low mood increases especially when death is approaching. According to these findings, psychological support is needed in order to improve the patients' quality of life during the end-of-life phase.

In patients with CKD it can be difficult to distinguish between the symptoms of uraemia, psychosocial factors (unemployment, low income, social withdrawal, low social support, lack of adjustment to the hardships of dialysis) and the

somatic symptoms of depression (Zalai & Novak 2008). The concept of “depression” is sometimes defined in terms of “depressive affect” and may be classified according to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) (Zalai & Novak 2008). According to DSM-IV, a major depressive episode involves the presentation of five or more symptoms during the same 2 weeks period and represent a change from the patients’ previous functioning; at least one of the symptoms is either depressed mood or loss interest or pleasure;

- depressed mood
- markedly diminished interest or pleasure in (almost) all activities
- significant weight loss when not dieting or weight gain, or decrease or increase appetite
- insomnia or hypersomnia
- psychomotor agitation or retardation
- fatigue or loss of energy
- feeling of worthlessness or excessive or inappropriate guilt
- diminished ability to think or concentrate, or indecisiveness
- recurrent thoughts of death, recurrent suicidal ideation, or a suicide.

Depression might also be defined on the basis of a high score on a self-report questionnaire designed to measure mood disorder. The terms depression and depressive disorder are often used interchangeably (Zalai & Novak 2008). In the study by Murtagh *et al.* (2006) and Noble *et al.* (2010) the term “depression” was used on the basis of self-report questionnaires and report of depressed mood during interviews. This terminology most accurately represents the study findings as portrayed by the authors. For example Noble *et al.* (2010) explained that “depression was attributed to an inability to do the things that patients had previously been able to do with ease, but others were depressed due to the decision not to have dialysis”. In the current study the term “low mood” rather than depression has been used as this more accurately represents the accounts given by study participants, and there was no attempt to apply any diagnostic criteria to the variations in mood reported or assess this symptom using standardised instruments.

At the end of the patients' lives, spiritual beliefs were shown to be an important factor among this group. These findings concur with other studies in Thailand. When patients are faced with uncertainty in their lives, the religious and spiritual beliefs of Thai people become more important because they are the part of their inherent belief system and daily lives (Chinnawong 2007). Buddhism influences many parts of the Thai culture as well as health care beliefs and practice, as Thai Buddhists apply Buddhist Dhamma and supernatural beliefs to cope with various kinds of suffering including crises and illness. This coping strategy helps patients feel comfortable with and accepting of their health conditions (Yodchai *et al.* 2011). In this study, praying to Lord Buddha was performed by the patients and their carers at home in order to help the patients feel peaceful and fulfil their spiritual beliefs during the last stage of their life. Yodchai *et al.* (2011) found that ESRD Thai patients being managed with haemodialysis (HD) applied Dhamma (the Buddha's teachings) to cope with the adverse effects of HD. In order to provide a holistic end-of-life approach to meet the spiritual needs of Thai people, understanding, respecting and planning interventions to facilitate patients' spiritual and religious beliefs and practices is recommended.

11.2.2 Health care needs and utilisation

This research has indicated that many of the patients' physical, psychological and spiritual needs that developed during the last year of the patients' lives, which often dramatically increased in severity in the last few months before death, were not addressed effectively by the health services. Health service provision that includes a referral system, early investigation by a specialist, health education, support at the end of life and care with dignity (effective symptom and pain management, oxygen, psychological and spiritual support at home), would be required to best suit their needs. Hobson *et al.* (2011) reported that patients with ESRD experience a significant symptom burden and have complex needs. Particularly, home visiting was described by bereaved carers as the main service which should be provided regularly in order to monitor and control patients' symptoms. This support was needed because patients had physical conditions which caused them to struggle to cope in their daily lives. Also they were unable to access anything beyond basic health

services, and this often precluded oxygen support and advanced pain management, as these were only available at hospital. Carers explained that they and the patient needed doctors and nurses to visit the patients at home to monitor and control patients' symptoms, as well as support patients emotionally. Finally, financial support (regarding transportation costs) was also required because it is a barrier to accessing the health services and necessary for patients to attend their physical health check-ups with the doctors at the hospital. Many carers explained that patients should have been provided with a better quality of health care when they were being managed without dialysis. Unfortunately, however, the lack of holistic care and proactive management by medical professionals when they were required to deal with patients' physical, psychological, spiritual and financial issues at home caused the patients to feel that their needs had not been met.

The health care needs and service utilisation addressed in this study are strongly supported by previous studies, including Murtagh *et al.* (2009b) who suggested that basic care should be a fundamental response to the needs of ESRD older patients managed without dialysis. Particularly, health services need to be able to rapidly respond to the steep functional decline of these patients in their last months of life. Also, it has been suggested that clinical staff should be required to undertake specific training on ESRD and end-of-life care (Noble *et al.* 2010). Similarly, Davison (2010) suggested that emotional, social and spiritual support should be integrated with medical support. Moreover, health care professionals need to define the role that various members of the multidisciplinary team will play in the provision of end-of-life care, such as symptom management and psychological and spiritual support (Davison 2010). Finally, Hobson *et al.* (2011) also recommended that the high quality holistic care delivered by specialised palliative care teams is an important element for improving the quality of life of patients and their carers.

There is a clear need for further research to provide corroborative evidence, using a large-scale survey to quantify the problem and see if the findings generalise to other services across the country. In addition, assessment of the quality of end-of-life care is not only focused on the patients, but also on those

caring for the person with limited life expectancy (World Health Organization, 2002). Future research is required about carers' perspectives, including their information needs associated with the patients' prognoses, treatment options, and appropriate communication to support patients at the end of life. Concurrently, more research is needed to explore and understand the attitudes to the needs of this group among healthcare professionals and assess what education and training needs they have.

11.3 Strengths and limitations of the qualitative phase of this study

The researcher learned about the advantages and limitations of this phase of data collection. These considerations will be useful for other researchers, and they impinge on the degree of confidence that can be placed in the findings because the strengths and limitations impact on validity and reliability.

11.3.1 Qualitative data analysis

The use of framework analysis demonstrated that it suited and was able to analyse the qualitative data generated by the study to answer the research questions. The framework analysis method is a matrix-based analytic method which facilitates rigorous and transparent data management, and all the stages involved in the analytical hierarchy can be systematically conducted (Creswell & Plano Clark 2011). Framework analysis was an effective analysis process in this study, enabling the researcher to analyse large quantities of data from the first phase into categories, and then to use the categorised data to develop the VOICES-ESRD/Thai instrument. The framework analysis also provided an effective and economical form of analysis for this study where the main purpose was to generate data for revisions to the instrument, rather than a more in-depth and labour-intensive method such as thematic analysis.

11.3.2 Ethics permission

The researcher received comments from the chair of the ethics committee noting that this study was considered to be addressing a very sensitive issue, particularly with regards to interviewing persons who had recently lost a loved one in the family. Moreover, the information from the interviews may have a negative impact on health services in Thailand, and therefore the information should not be disclosed to other countries. There is no tradition of conducting research with bereaved relatives in Thailand. This challenge to obtaining permission to conduct end-of-life research, especially regarding health service officers, should be taken into account in the future large survey. In this study, the researcher had to very carefully explain the reasons behind using a retrospective approach to data collection in which carers' accounts were used as proxies for the deceased patients' experiences; this is a well-established method for gathering information about the last year of the life in the UK.

11.3.3 Reaching a representative sample

A second challenge was dealing with health care professionals, especially the renal nurses who were the main supporters of the research since they recruited the participants. This impacted on reaching a representative sample. The researcher mitigated this issue by building good relationships with renal nurses, which was facilitated by the fact that the researcher had previously trained as a haemodialysis nurse and had already conducted some research with renal nurses in clinical settings. Therefore, the strategy of understanding their personalities, creating good relationships and working as a colleague was used throughout the research process. These strategies will also be applied when conducting the large survey.

11.3.4 The number of potential participants declining

The researcher noticed that the proportion of carer informants who agreed to be interviewed in the first phase was less than 50% (12) of the total number of carers who were contacted (25). The reasons for declining to participate in the

study, as explained by those declining, included the fact that many of them had to deal with flooding during the rainy season in Thailand, and some of them said that they had moved house from rural areas in Chiang Mai province to urban areas in Bangkok in order to get a job. A few said that they were busy as they had to work seven days a week and therefore would have no time available when the researcher could interview them. This refusal to engage in face-to-face interviews may be reduced by offering telephone interviews for these participants, and this would be another choice for mode of administration for the large-scale survey.

The small number of potential participants in this study should not be considered to imply a reduction in the credibility and transferability of the qualitative data (Ritchie & Lewis 2011b). Conversely, there may be a high degree of confidence placed in the internal validity or credibility of the data, since the data have captured real phenomena and provided a clear picture to help with understanding the symptom experiences and health care needs of the patients involved. The study allowed participants to express themselves in their own words, encouraging them to report what and how symptoms and health care needs were expressed by the patients. The findings are strongly supported by previous evidence, and generated specific characteristics such as symptom intensity and prevalence and the types of supportive care that are needed among the Thai population.

11.4 Developing a culturally acceptable end of life survey (the VOICES-ESRD/Thai questionnaire)

Generating a culturally specific questionnaire and generating information to refine and develop a robust VOICES questionnaire were the two successful outcomes of the second phase. Several strengths and limitations to developing a culturally acceptable end of life survey (the VOICES-ESRD/Thai questionnaire) and apply the cognitive interviewing technique were encountered during the study.

11.4.1 Generating a culturally specific questionnaire

The stage began by applying the themes and sub-themes which emerged in the first phase to develop the prototype of the VOICES-ESRD/Thai questionnaire. The research referred to four versions of the VOICES survey questionnaire (VOICES-SF, VOICES-COPD, VOICES-Cancer and VOICES-Stroke) (Hunt & Addington-Hall 2011; Hunt *et al.* 2011; Department of Health 2012) and to the items on these questionnaires and selected the most relevant questions and adapted them with reference to the framework analysis of older ESRD patients who managed without dialysis in Thailand (see Figure 8, page 98). Questions and response categories were created, and the objectives and reasons for changes were provided (please see Appendix M). The researcher applied the five steps for developing an instrument recommended by DeVellis (1991, cited in Creswell & Plano Clark 2011, p. 189). The original VOICES questionnaire was developed and used in the United Kingdom (UK) and had not been used in Thailand. There are clear cultural differences and sensitive issues surrounding end-of-life ESRD patients between the United Kingdom and Thailand. The adapting of an instrument for cross-cultural use is necessary to reflect the cultural norms of the new context (in this case, Thailand). A consideration of the translation method and types of equivalence (such as content, experiences, semantic and conceptual equivalence) in evaluating the appropriateness of the measures when administered in different cultures are also required (Meadows *et al.* 1997). In this study, the development of the culturally acceptable VOICES-ESRD/Thai questionnaire involved rigorous methods of translation for cultural equivalence, the instrument was reassessed in relation to the specific population of interest, and experts in the specific area of the study were consulted. Items described phenomena relevant to the experiences of Thai older ESRD patients who managed without dialysis during the last year of life, based on the qualitative finding of the study.

The questionnaire was reviewed by the experts who developed the original version of the VOICES questionnaire, as well as by experts in the field of the study and by bilingual translators (see Appendix T). Tests of content validity, cultural equivalence, congruent values and careful use of colloquialisms with sensitivity to cultural concerns and the selection of appropriate words are an

important part of adapting an instrument for cross-cultural use (Meadows *et al.* 1997; Bowling 2009c). Language barriers between service users and health care professionals can also hinder the provision of palliative care (Randhawa *et al.* 2003). This can lead to problems with the quality of care when discussing diagnoses, patients' symptoms and the provision of end-of-life care (Hughes *et al.* 2005). There is a need for the researcher to be sensitive to the needs of people from all ethnic and cultural groups when developing end-of-life survey questionnaires (Firth 2001; Papadopoulos & Lee 2002). Careful approaches and methods such as bilingual consultation and the translation of existing practice and research materials into the first languages of the people from ethnic and cultural communities (Dunckley *et al.* 2003) were undertaken in this study to assess the cultural acceptability and appropriateness of the VOICES-ESRD/Thai questionnaire before its administration.

VOICES is a well-established questionnaire, completed by bereaved relatives, that has been shown to be valid in the evaluation of health services provided for patients at the end of life (Hunt & Addington-Hall 2011; Hunt *et al.* 2011; Department of Health 2012). The VOICES instrument has been used successfully to assess the quality of care given to patients dying from a range of conditions (e.g. cancer, strokes, heart failure and chronic obstructive pulmonary disease) but not for patients with end stage renal disease (ESRD). Testing of the specific content validity of the VOICES-ESRD/Thai version was required to ensure it was an effective tool to evaluate the cognitive processes and understanding of respondents to the questionnaire. In this study, cognitive interviewing was used as a diagnostic tool for pre-testing the survey instrument by focusing on the questionnaire design, paying attention to the mental process of respondents and testing the understanding of respondents of specific symptom experiences and health services related to end stage renal disease among the Thai population.

11.4.2 Generating information to refine and develop robust VOICE questionnaire

The VOICES-ESRD/Thai version was checked for misunderstanding, incomplete concept coverage and inconsistent interpretations by respondents in answering the questionnaire. The cognitive interviews informed revisions to the questionnaire to ensure a better fit to the target population while maintaining the objective and structure of the original VOICES instrument. The overall findings from the successive cycles of cognitive interviewing concluded that five problems of the questionnaire design were 1) difficulties relating to the appearance or formatting of the questionnaire; 2) difficulties with specific wording (medical terms) or phrasing; 3) difficulties with specific questions; 4) difficulties regarding the response categories (lack of some categories, too many response categories and the response categories were too complicated); and 5) difficulties with interpreting response categories. The response problems that occurred during questionnaire completion in the study could be classified into five categories, including: 1) lexical problems; 2) inclusion/exclusion problems; 3) temporal problems; 4) logical problems; and 5) computational problems (Conrad & Blair 1996, cited in Drennan 2003). At the end of this phase a number of solutions and modifications to the questionnaire were provided including addressed, minimised or revised (please see Appendices N, O and P). Therefore, it could be stated that two cycles of cognitive interviewing successfully provided the researcher with information which was used to modify the questions and validate the instrument specifically for ESRD patients before its use in the pilot survey.

However, conducting cognitive interviews needs to be weighed according to the advantages and disadvantages. So whilst the cognitive interviewing phase was really important, the process of cognitive interviewing was time-consuming and burdensome. This increased the burden for the researcher as well as respondents because the interview took a maximum of approximately one hour to complete, while actual completion of the questionnaire without cognitive interviewing took a maximum of approximately thirty minutes. The researcher also realised early on that the particular population in this study was unique and had specific characteristics that needed to be taken into

account during the questionnaire design and administration. The researcher encountered some challenges during the cognitive interviewing process. For example, the participants could not always give full information because they were unable to remember exactly what the researcher had asked them. Many of them only had a primary school education level. Furthermore, it is frequently in the nature of Thai respondents that they prefer to keep quiet, or they are more likely to answer with a short sentence than provide a long explanation. In order to mitigate against these problems, the researcher required careful consideration when conducting the interviews by providing respondents with time for thinking or recalling, applying prompt questions and reading or explaining each question to respondents who couldn't properly read or clearly understand the questions on their own.

11.5 Refining the VOICES-ESRD/Thai questionnaire for the large survey

The evaluation of the questionnaire in the final phase specifically reflected the purpose of instrument development, which was to examine methods of recruitment and administration, examine response rates, classify instances of missing data, identify redundant data items and further refine the VOICES questionnaire. It was necessary to pilot the modified VOICES-ESRD/Thai questionnaire by administering it to a small group of people who would be similar in characteristics to the intended respondents. This is because the best and most effective way to ensure the quality of a questionnaire's development is to test or pilot the instrument (Parahoo 2006). The main findings and recommendations for applying the refined VOICES-ESRD/Thai questionnaire in the large survey are summarised (see Figure 12) below.

11.5.1 Response rate

The response rate for this study was 69%, calculated from the number of eligible respondents who participated in this phase (twenty from thirty-two participants). In comparison with previous research studies of VOICES questionnaire the response rate was at 41.6% (Burt *et al.* 2009), 48%

(Addington-Hall & O'Callaghan 2009), 37% (Hunt *et al.* 2011) and 45.7% (Department of Health 2012) the response rate was higher in this study. There is no standard agreement on what constitutes a minimum response rate, but it is generally accepted that a response rate below 60% is sub-optimal, and 75% and above is good (Bowling 2009c). The findings from the pilot survey show that two main factors affected the response rate: the method of recruitment and interview method. The strategies to respond to these issues in the context of a future survey are discussed.

11.5.1.1 Method of interviews (face to face vs. telephone)

The researcher realised in the first phase that within Thailand people are unfamiliar with receiving and responding to questionnaires by post. This might be because most of the Thai population, especially in the rural areas, have to work day by day and the majority of them lack the higher levels of education that would have at least enabled them to understand, if not respond to, a questionnaire. In particular, the participants may need someone to help them to answer some specific questions during the interview situation. According to limitations concerning the unfamiliarity of postal questionnaires and low levels of literacy among rural Thai people explained in the first phase, two interview methods were found to be effective in increasing the response rate in the study. Firstly, the researcher found that face-to-face interviews provided more complex and detailed answers from the respondents. This method had no literacy requirement on the part of the respondents. The researcher could gain more information from respondents using this method. Unfortunately, the researcher also found that face-to-face interviews were expensive and time-consuming. Addington-Hall *et al.* (1998) suggested that face-to-face interviews could provide higher response rates than postal questionnaires or telephone interviews (Bowling 2009c; Polit & Beck 2012), but this advantage was not realized in this study.

In order to increase the response rate, telephone interviews are the method of choice because this method was associated with a high response rate and it is economic in terms of time and resources (Bowling 2009c). However, the

disadvantage of telephone interviewing is that it is best used for short, straightforward questions and non-sensitive topics. In this study, many respondents preferred to have telephone interviews than face-to-face interviews because it was more convenient. The accuracy of information from telephone interviews appeared to be equal to that from face-to-face interviews (Bowling 2009c). Furthermore, open-ended questions in the VOICES-ESRD/Thai questionnaire encouraged respondents to provide their opinions in full for more complex issues. Therefore, telephone interviewing should be selected as the best method for administering the VOICES-ESRD/Thai questionnaire in the large survey. The researcher also realised that interviews should be arranged at the right time and in the right place to encourage people to accept invitations to interviews. In addition, reimbursement should be considered as a factor to encourage people to participate in the study.

11.5.1.2 Method of recruitment to the survey

According to the first phase, the researcher found that when the information sheet and consent form were posted to the potential participants, after one month no one had replied. The researcher and renal nurses decided that the researcher had to call them directly and ask them to participate in the study. During the first meeting, the participants were informed in some detail about the research and asked to sign the consent form. From this experience and in the future survey, potential participants should initially be contacted by the service or renal nurses and followed up by contact from the researcher to confirm the date, time and location of the interview.

The method used to identify the sample population in this study was limited by the number of older ESRD patients who were registered at renal units at the time of their death, including older ESRD patients who were waiting for dialysis, who had refused it or who had been refused it. There was also a proportion of non-registered (unidentified) persons that the researcher could not characterise or identify. This might also affect the construction of the sample frame for the future large scale survey. In quantitative research a large number of participants is needed to ascertain the characteristics and be representative of the population (Creswell & Plano Clark 2011). A large sample

size is required for a rigorous quantitative study, in order to be large enough to meet the requirements of statistical tests (Creswell & Plano Clark 2011). In order to obtain a large enough sample size in the survey, the sample size specification should be considered and a power analysis performed to estimate the necessary number of participants (Polit & Beck 2012). However, the different experiences and outlooks of the three registered groups (those on waiting lists, those refusing dialysis or those who were not suitable to receive dialysis) will have to be taken into account in estimates of the sample size in the survey.

Another limitation of records kept at renal units is that it can be difficult to identify the main carer or the individual most suitable to complete the questionnaire. Also, the registered contact details might not be accurate since the names and addresses are manually recorded by renal nurses. Therefore, resources need to be built into any future survey to source correct details.

11.5.1.3 Questionnaire structure and format

The pilot testing of the VOICES-ESRD/Thai questionnaire demonstrated that on the whole respondents understood the questions and provided appropriate answers with regard to the aims of each question. A few respondents provided suggestions, including a recommendation that the length of questionnaire should not be too extensive, and that the questionnaire layout should be altered to make the questions easier to read and simpler to answer.

11.5.2 Missing data

Two types of missing data were found, including missing entries (answers omitted) and inadequate responses (don't know and not sure). In missing entries, "skipped questions" or "filter questions" were found in questions 22, 23 and 35. Inadequate responses in the form of a "recall bias" were found in question 26 and 23, "sensitive items" were seen in questions 36 and 37, and "attitude (opinion) questions" were presented in questions 53 to 69. It has been suggested by Hughes *et al.* (2005) that the proportion of missing data in a VOICES type questionnaire should be kept between 10-20%, but in the Thai

pilot version it was between 5-75%. Therefore, careful revision to some questions and possible elimination of other questions that produced higher proportions of missing data than this is required. A revised version of the questionnaire is presented in (Appendix P and R) describes the revisions undertaken in response to particular issues.

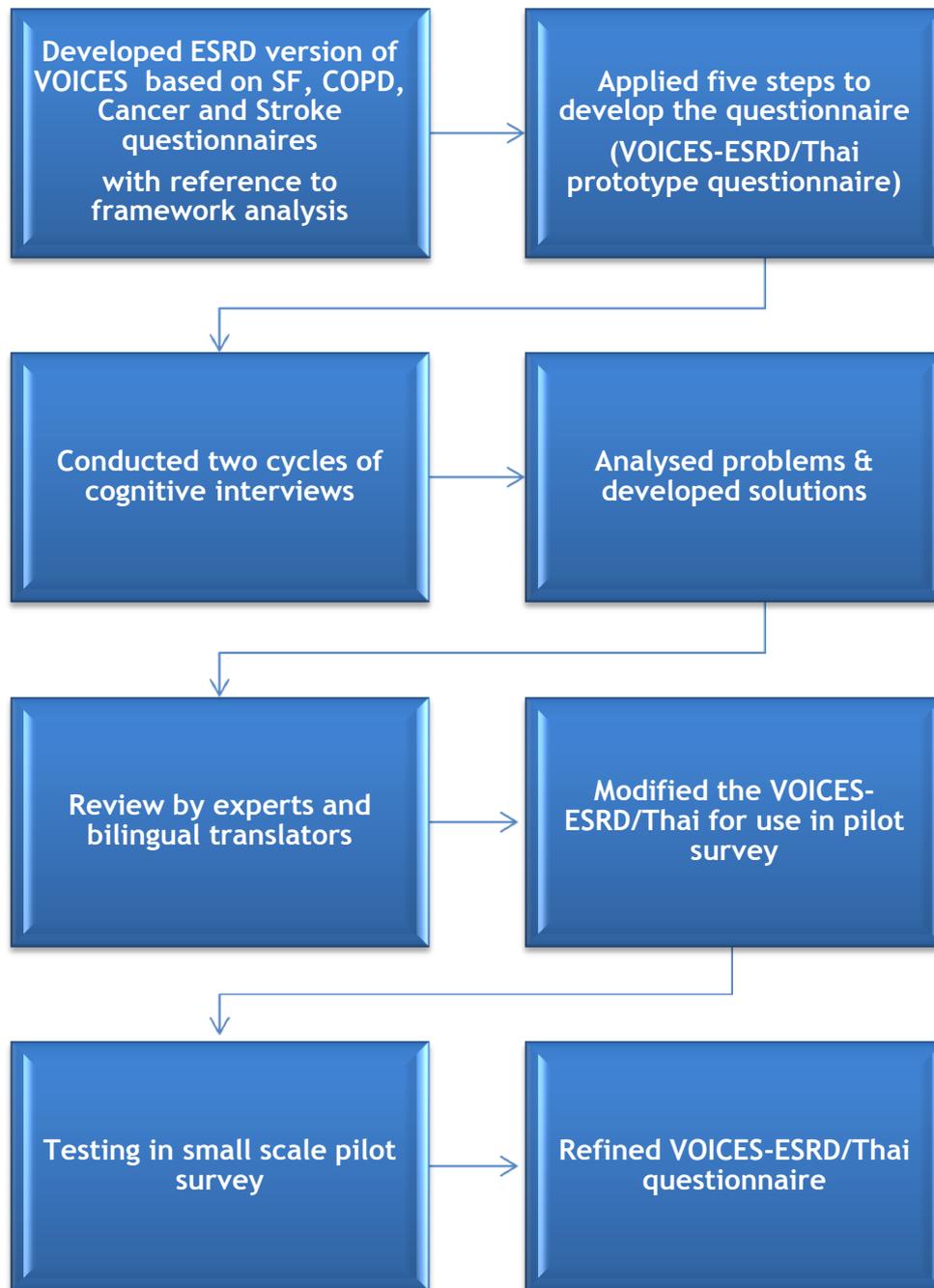


Figure 12 Summary process involved in developing VOICES-ESRD/Thai questionnaire

11.6 Application of a mixed-method exploratory sequential design

Mixed methods are a valuable methodology since “mixed method research is focused on collecting, analysing, and mixing both quantitative and qualitative data in a single study. The central concept is that using quantitative and qualitative approaches, in combination, provides a better understanding of research problems than either approach alone” (Creswell & Plano Clark 2011) (p. 5). In this study, the mixed-method exploratory sequential design began qualitatively; it was conducted to explore a phenomenon, and the qualitative design was particularly useful to develop and test an instrument. In addition, the exploratory, sequential design used sequential timing by beginning with and prioritizing the collection and analysis of qualitative data in the first phase. Building from the exploratory findings of the first phase, the researcher was then able to perform the second and third phase by focusing on developing the VOICES-ESRD/Thai version of the questionnaire to gather quantitative data. The sequential mixed methods study design in this study used three types of triangulation, including theoretical, methodological and data source (Thurmond 2001). Theoretical triangulation is important to the researcher to conceptualise and develop a diagram about how the overall design fits together and at different levels (Burns *et al.* 2011).

In this study, the study design, procedures of data collection and analysis from both qualitative and quantitative methods were created (see Figure 1 and 5). Sequential multiple methods provided effective controls at each stage of the study because each stage was treated as an independent study in its own right (Mafuba & Gates 2012). In terms of methodological triangulation, combining methods from different paradigms provides a clearer picture of a phenomenon than would be available from qualitative and quantitative data alone because of the potential for the strengths of one method to compensate for the weakness of the other (Morse 1991). The data source triangulation, achieved by increasing the volume of data especially in the context of the participants, has the potential to enhance the confidence levels of the data and the findings (Banik 1993). Mafuba and Gates (2012) suggested that using sequential multiple-method approaches is more likely to generate valid and reliable

knowledge than a single method, because this approach allows the researcher to make adjustments and refine each subsequent stage following the findings from the earlier stages. The use of sequential mixed methods is therefore essential to capture the context and social complexities associated with the experiences and health care needs of the population in the study and to develop the VOICES-ESRD/Thai questionnaire.

11.7 Clinical implications

Through the conduct of interviews with bereaved carers and applying the ESRD Thai version of VOICES prototype it has been possible to gather data on the experiences of patient as end of life approaches, including the symptoms they experience and type of support available. The findings suggest, albeit based on one geographical area in Thailand, that health services are not currently meeting patients' needs. Based on resources available, and taking into account the organisation of the Thai health care system, four main clinical implications are put forward here.

11.7.1 Symptom management at home

There was clearly insufficient health care provision at home for patients to manage their symptoms such as pain and breathlessness. This is a priority need.

11.7.1.1 Pain management

Pain management for this group of patients needs to be fully evaluated. In Thailand, medicines for pain for groups other than cancer patients are not readily accessible and only available through prescriptions written by doctors at district or provincial hospitals. Specific pain management guidelines for older ESRD patients managed without dialysis at home are needed. Moreover, regular pain assessment and monitoring are required from renal nurses or health care staff and training developed to ensure a more pro-active

management approach, especially at home. Non-pharmacological methods of pain control should also be considered especially as medicines such as morphine and diamorphine are not recommended for use with ESRD patients because of metabolite accumulation (Murtagh *et al.* 2006). In addition, alternative treatments such as music therapy, massage, guided imaginary, meditation and acupuncture should be explored with the added benefit that these types of approaches have the added benefit of engaging patients in an active approach to pain management.

11.7.1.2 Breathlessness

The management of breathlessness needs to be more effectively addressed. Breathlessness was a great source of anxiety for patients and their informal carers. The provision of oxygen needs to be examined and protocols developed to make it available through local healthcare facilities. Similarly to pain, the contribution of non-pharmacological approaches to breathlessness management should also be considered.

11.7.2 Telephone counselling and information support

Most of the patients managed without dialysis, as well as their relatives, lived in rural areas, were on a low income and had no car of their own. Transportation and referral systems were found to be barriers to accessing help and support. Access to health professionals through telephone consultation, for example with one of the specialist nurses at the centre might help patients and carers live independently whilst at the same time provide regular health monitoring in order to evaluate progression and management of patients' symptoms at home. Through such a service carers would be able to access information and support in order to help them in their efforts to care for a person at home and cope with the many physical and psychological symptoms. Furthermore, this type of service could reduce the cost of transportation for patients and their families.

11.7.3 Developing training programmes

Interviews and questionnaire responses indicated that health education was required by patients and carers in this study. To understand disease' prognosis, treatments, patients' symptoms, three different programmes are recommended. Firstly, developing training programmes to enhance knowledge, and understanding of the natural history of ESRD and problems experienced by patients and their families is required for all health professionals. Secondly, training in approaches to symptom management, communication skills and responding to patients and carers' emotional and spiritual distress should be established for community health staff, health volunteers and religious leaders. Improving the knowledge, skills, attitudes as end of life approaches of health professionals such as renal specialists and generalists or community nurses and doctors are essential elements of developing effective end of life care and planning to provide end of life support. Finally, technical information on consulting and coordinating between stakeholders should also be included in the training, to establish effective team support in order to develop proactive end of life care for patients.

11.7.4 Raising awareness amongst policy makers

The level of unmet needs suggested by the findings among older ESRD patients managed without dialysis (including long waiting lists, inability to afford expensive treatments and being judged not suitable to receive dialysis), as well as inadequate health service provision, suggests there is an urgent need to change the current Thai health care system for this patient group. Using the collaboration developed between the researcher and renal nurses during the course of the study, the findings from this study need to be presented and discussed with regional health policy makers such as administrators or directors of community, district and provincial hospitals in the Chiang Mai Province, to raise their awareness and convince them that the needs of this group should be incorporated into future policy planning at their hospitals.

The findings of the study could prove influential in improving palliative and end-of-life care for ESRD patients managed without dialysis in Thailand by driving change in Thai health care policy for the management of chronic kidney disease. The findings can be used to underpin awareness raising activities with health policy makers to underline the fact that patients' needs are not being met. The data point to the need to develop approaches to symptom management such as pain control and management of breathlessness at home, and establish systems to provide health education for patients and carers at home. Whilst this will demand investment, one place to start would be to focus on development of skills and knowledge of informal carers with respect to simple techniques to relieve symptoms. Attention should also be given to influencing the curriculum that underpins the education and training offered to nurses and doctors with respect to palliative care and core competencies required for all patients as they approach end of life, irrespective of diagnosis.

11.8 Research recommendations

The evidence from this study indicates four major areas for research moving forward.

11.8.1 Conduct of a large survey using the VOICES instrument with older ESRD patients managed without dialysis in Thailand

The credibility and transferability of the findings in this study lay in the combined mixed methods approach, using qualitative and quantitative methods to explore experiences and health care needs and to refine the VOICES-ESRD/Thai instrument. However, the size of the sample was small and the instrument has only been pilot tested. Robust information from a large scale survey with a representative sample would generate a wider picture of the issues and data collected have the potential to drive positive changes in health care policy at both local and national levels in order to improve the quality of care at the end of the patients' lives.

11.8.2 Perspectives of caregivers of older ESRD patients managed without dialysis in Thailand

Whilst interviewing bereaved carers it became clear that carers themselves experience considerable needs. It is important to develop a study to explore carers' experiences of providing care for their relatives, what kind of burden and suffering they faced when caring for dying relatives, and what type of support they need. Moreover, the different characteristics of carers need to be taken into account when planning a study of this kind to reflect the three different groups of older ESRD patients managed without dialysis in Thailand, namely those on a waiting list, those unable to afford expensive treatment and those judged not suitable to receive dialysis. Identification of the coping strategies of these different groups of carers would yield important findings and contribute to guidelines designed to support both patients and carers.

11.8.3 Perspectives of health care staff of older ESRD patients who managed without dialysis in Thailand

Further research exploring the perspectives of health care staff should be a key element in understanding the context of health care provision for older ESRD patients who manage without dialysis at home. The findings of such research would describe the knowledge, skills, attitudes and experiences of healthcare professionals who care for this group and inform education and training initiatives

11.9 Conclusion

This study aimed to explore the experiences and health care needs of older ESRD patients managed without dialysis in Thailand, and develop the VOICES-ESRD/Thai questionnaire. The study has achieved its aims. The findings have generated significant new knowledge about the symptoms, experiences and health care needs of older ESRD patients in Thailand. A rigorous high-quality instrument has been developed to evaluate symptom experiences and health care services in a Thai context which can now be applied in a large scale

national survey to reveal the experiences of patients across Thailand. A wealth of information has been collected and analysed, which will inform clinical practice, policy and research in the area of ESRD and end of life care.

Appendices

Appendix A: Appraisal tools:

- 1) 10 questions to help you make sense of qualitative research
- 2) 10 questions to help you make sense of randomised controlled trials

Critical Appraisal Skills Programme (CASP)

making sense of evidence

10 questions to help you make sense of qualitative research

This assessment tool has been developed for those unfamiliar with qualitative research and its theoretical perspectives. This tool presents a number of questions that deal very broadly with some of the principles or assumptions that characterise qualitative research. It is *not a definitive guide* and extensive further reading is recommended.

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of qualitative research:

- **Rigour:** has a thorough and appropriate approach been applied to key research methods in the study?
- **Credibility:** are the findings well presented and meaningful?
- **Relevance:** how useful are the findings to you and your organisation?

The 10 questions on the following pages are designed to help you think about these issues systematically.

The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

The 10 questions have been developed by the national CASP collaboration for qualitative methodologies.

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Screening Questions

1. Was there a clear statement of the aims of the research? Yes No

Consider:

- what the goal of the research was
- why it is important
- its relevance

2. Is a qualitative methodology appropriate? Yes No

Consider:

- if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants

Is it worth continuing?

Detailed questions

Appropriate research design

3. Was the research design appropriate to address the aims of the research? Write comments here

Consider:

- if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)

Sampling

4. Was the recruitment strategy appropriate to the aims of the research? Write comments here

Consider:

- if the researcher has explained how the participants were selected
- if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- if there are any discussions around recruitment (e.g. why some people chose not to take part)

.....
Data collection

5. Were the data collected in a way that addressed the research issue?

Write comments here

Consider:

- if the setting for data collection was justified
- if it is clear how data were collected (e.g. focus group, semi-structured interview etc)
- if the researcher has justified the methods chosen
- if the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)
- if methods were modified during the study. If so, has the researcher explained how and why?
- if the form of data is clear (e.g. tape recordings, video material, notes etc)
- if the researcher has discussed saturation of data

.....
Reflexivity (research partnership relations/recognition of researcher bias)

6. Has the relationship between researcher and participants been adequately considered?

Write comments here

Consider whether it is clear:

- if the researcher critically examined their own role, potential bias and influence during:
 - formulation of research questions
 - data collection, including sample recruitment and choice of location
- how the researcher responded to events during the study and whether they considered the implications of any changes in the research design

.....
Ethical Issues

7. Have ethical issues been taken into consideration?

Write comments here

Consider:

- if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- if the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- if approval has been sought from the ethics committee

.....
Data Analysis

8. Was the data analysis sufficiently rigorous?

Write comments here

Consider:

- if there is an in-depth description of the analysis process
- if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- if sufficient data are presented to support the findings
- to what extent contradictory data are taken into account
- whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

.....
Findings

9. Is there a clear statement of findings?

Write comments here

Consider:

- if the findings are explicit
- if there is adequate discussion of the evidence both for and against the researcher's arguments
- if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)
- if the findings are discussed in relation to the original research questions

.....
Value of the research

10. How valuable is the research?

Write comments here

Consider:

- if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)
- if they identify new areas where research is necessary
- if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

CRITICAL APPRAISAL SKILLS PROGRAMME (CASP): Making Sense of Evidence

10 Questions to Help You Make Sense of
Randomised Controlled Trials**How to Use This Appraisal Tool**

- Three broad issues need to be considered when appraising the report of a randomised controlled trial:
 - Is the trial valid?
 - What are the results?
 - Will the results help locally?
- The 10 questions on the following pages are designed to help you think about these issues systematically.
- The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions.
- You are asked to record a "yes", "no" or "can't tell" to most of the questions.
- A number of hints are given after each question. These are designed to remind you why the question is important. There may not be time in the small groups to answer them all in detail!

A. Are the results of the study valid?**Screening Questions**

1. Did the study ask a clearly-focused question?

Yes Can't Tell No

HINT: Consider if the question is 'focused' in terms of:

- the population studied
- the intervention given
- the outcomes considered

2. Was this a randomised controlled trial (RCT) and was it appropriately so?

Yes Can't Tell No

HINT: Consider:

- why this study was carried out as an RCT
- if this was the right research approach for the question being asked

Is it worth continuing?**Detailed Questions**

3. Were participants appropriately allocated to intervention and control groups?

Yes Can't Tell No

HINT: Consider:

- how participants were allocated to intervention and control groups. Was the process truly random?
- whether the method of allocation was described. Was a method used to balance the randomization, e.g. stratification?
- how the randomization schedule was generated and how a participant was allocated to a study group

- if the groups were well balanced. Are any differences between the groups at entry to the trial reported?
- if there were differences reported that might have explained any outcome(s) (confounding)

4. Were participants, staff and study personnel 'blind' to participants' study group?

Yes Can't Tell No

HINT: Consider:

- the fact that blinding is not always possible
- if every effort was made to achieve blinding
- if you think it matters in this study
- the fact that we are looking for 'observer bias'

5. Were all of the participants who entered the trial accounted for at its conclusion?

Yes Can't Tell No

HINT: Consider:

- if any intervention-group participants got a control-group option or vice versa
- if all participants were followed up in each study group (was there loss-to-follow-up?)
- if all the participants' outcomes were analysed by the groups to which they were originally allocated (intention-to-treat analysis)
- what additional information would you like to have seen to make you feel better about this

6. Were the participants in all groups followed up and data collected in the same way?

Yes Can't Tell No

HINT: Consider:

- if, for example, they were reviewed at the same time intervals and if they received the same amount of attention from researchers and health workers. Any differences may introduce performance bias.

7. Did the study have enough participants to minimise the play of chance?

- Yes Can't Tell No

HINT: Consider:

if there is a power calculation. This will estimate how many participants are needed to be reasonably sure of finding something important (if it really exists and for a given level of uncertainty about the final result).

B. What are the results?

8. How are the results presented and what is the main result?

HINT: Consider:

- o if, for example, the results are presented as a proportion of people experiencing an outcome, such as risks, or as a measurement, such as mean or median differences, or as survival curves and hazards
- o how large this size of result is and how meaningful it is
- o how you would sum up the bottom-line result of the trial in one sentence

9. How precise are these results?

HINT: Consider:

- o if the result is precise enough to make a decision
- o if a confidence interval were reported. Would your decision about whether or not to use this intervention be the same at the upper confidence limit as at the lower confidence limit?
- o if a p-value is reported where confidence intervals are unavailable

10. Were all important outcomes considered so the results can be applied?

- Yes Can't Tell No

HINT: Consider whether:

- o the people included in the trial could be different from your population in ways that would produce different results
- o your local setting differs much from that of the trial
- o you can provide the same treatment in your setting
- o Consider outcomes from the point of view of the:
 - o individual
 - o policy maker and professionals
 - o family/carers – wider community
- o Consider whether:
 - o any benefit reported outweighs any harm and/or cost. If this information is not reported can it be filled in from elsewhere?
 - o policy or practice should change as a result of the evidence contained in this trial

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APPENDIX B: Reviewed and evaluated the strengths and weaknesses of articles in Thailand

Table 20 Review of research evidences about older people with ESRD managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/ impacts
<p>1. Economic evaluation of palliative management versus peritoneal dialysis and hemodialysis for end-stage renal disease: evidence for coverage decisions in Thailand</p> <p><u>(Teerawattananon, Mugford & Tangcharoensathien, 2007)</u></p>	To examine the value for money of palliative care, peritoneal dialysis (PD) or hemodialysis (HD) in the Thai universal health insurance scheme	Longitudinal survey/ secondary data analysis	A probabilistic Markov model was applied to examine the incremental cost-effectiveness ratio (ICER) of participants	<p>The data were collected from input parameters of 6,272 ESRD patients aged 20 to 70 years, extracted from a national cohort, the Thailand Renal Replacement Therapy Registry.</p> <p>The nonparametric Kaplan-Meier approach was used to analyse the data and to indicate that the Weibull survival model would adequately fit the data.</p>	The results suggest that offering PD as an initial treatment was a better choice than offering HD. However, providing treatments for younger ESRD patients resulted in a significant improvement of survival and gain in QALYs compared with the older aged group. The total programme cost of palliative care for an older ESRD population from a social perspective was evaluated to be the most cost effective implementation.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/outcome measurements	Data collection/analysis	Results/impacts
2. The implications of benefit package design: the impact on poor Thai households of excluding renal replacement therapy. (Prakongsai <i>et al.</i> 2009)	To assess the economic impact of RRT costs on Thai households of different economic status, focusing on three issues: (1) the use of RRT; (2) the financial burden of health care payments; and (3) household strategies for coping with RRT costs.	Qualitative research – A case study design	Open-ended interviewing guide	In-depth case studies of 20 households covered by the UC scheme and having ESRD patients were undertaken using three qualitative data collection approaches: semi-structured and in-depth interviews, and direct observation. The study was conducted in early 2005 and households were visited every 2 weeks for 3 months. Interviews were transcribed and analysed using a thematic approach.	The decision to exclude RRT from the UC benefit package created financial barriers to RRT and had a substantial economic impact on poorer ESRD patients. Inadequate dialyses and erythropoietin injections to correct anaemia appeared to be a major cause of death for poorer patients. Various coping strategies were employed by poorer patients; these included reducing frequency of dialyses, reducing food consumption, using public transportation to hospitals and taking high interest loans. The RRT cost burden not only impacted patients but also their relatives who provided financial support.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
<p>3. Prevalence of chronic kidney disease in Thai adults: a national health survey</p> <p>(Ong-ajyooth, Vareesangthip, Khonputsas & Aekplakorn 2009)</p>	To determine the prevalence of CKD in Thai adults in a National Health Examination	A descriptive cross sectional study	Physical examination and blood samples. Serum creatinine was measured using the Jaffé method. GFR was estimated using the Chinese Modification	A multistage stratified cluster sampling technique was used to recruit study participants. Data from a nationally representative sample of 3,117 individuals aged 15 years and older was collected. Logistic regression was used to measure the association between major risk factors and CRF (GFR < 60 mL/min).	Compared to non-CKD individuals, patients with CKD were older, had a higher level of cholesterol, and higher blood pressure. Those with cardiovascular risk factors were more likely to have CKD (stage 3–5) than those without, including hypertension (OR 1.6, 95%CI 1.1, 3.4), diabetes (OR 1.87, 95%CI 1.0, 3.4). The findings of this study may offer a potential opportunity for earlier therapeutic interventions to reduce the rate of disease progression and incidence of ESRD.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
4. Effect of the Self-efficacy and Social Support Enhancement Program on Exercise Behaviour Among the Elderly with Chronic Renal Failure (Yowaphui 2008)	The purpose of this study was to examine the effect of the Self-efficacy and Social Support Enhancement Program on exercise behaviour among elderly patients with chronic renal failure.	Quasi-experimental research	The instruments used in this study consisted of the Self-efficacy and Social Support Enhancement Program, the Perceived Self-Efficacy Questionnaire, the Social Support Questionnaire, a videotape showing exercise role modelling, the Self Care Manual, the Social Support for Exercise Manual and the Exercise Behaviour Questionnaire.	The subjects were 30 elderly ESRD patients from the renal unit who were randomly assigned equally into experimental and control groups considering similarity in gender, exercise behaviour score, self-efficacy score and social support score. The experimental group received the Self-Efficacy Enhancement Program provided by the researcher and received social support from family members, while the control group received routine nursing care. Data were analysed using descriptive statistics and t-tests.	The findings revealed that the exercise behaviour among the elderly patients with chronic renal failure who received the program was significantly higher than those in the control group ($p < 0.001$), and the exercise behaviour of elderly patients with chronic renal failure after participating in the program was significantly higher than before participating ($p < 0.001$). The study findings indicate the effectiveness of the Self-efficacy and Social Support Enhancement Program in enhancing exercise behaviour of elderly patients with chronic renal failure.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
5. High prevalence of chronic kidney disease in Thailand (Perkovic <i>et al.</i> 2008)	To describe the prevalence of stage III and IV chronic kidney disease in Thailand.	A descriptive cross-section study	Glomerular filtration rates were estimated from serum creatinine using the Cockcroft-Gault and the simplified Modification of Diet in Renal Disease (MDRD) formulae.	The population aged 35 years and above was stratified into eight demographic groups, defined by age (35–44, 45–54, 55–64, and ≥65 years) and gender. A stratified, multistage, cluster-sampling method was used to select the sample (N= 5,303). Population estimates were calculated by applying sampling weights from the 2000 Thai census. The STATA 8.0 statistical software package, estimates of means and proportions using <i>t</i> -tests, analysis of variance derived from linear regression models for continuous variables, and Chi ² tests were used to analyze the data.	The prevalence of chronic kidney disease in the Thai patients was significantly higher than that reported in individuals age over 40 years old from the United States for both stage III and IV disease, and higher than the reported incidence in Taiwan and Australia. This high prevalence of chronic kidney disease in Thailand has obvious implications for the health of its citizens and for the allocation of health-care resources.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
6. Prevalence of chronic kidney disease in type 2 diabetes in primary health care units of Udon Thani province, Thailand (Narenpitak & Narenpitak 2008).	To determine the prevalence of chronic kidney disease (CKD) and risk factors of decreased kidney function in Type 2 diabetes at primary health care units in Udon Thani province	A descriptive cross-sectional study	The definition and classification of CKD were classified according to K/DOQI guidelines 2002. Medical histories, physical examinations, and blood tests for glucose, creatinine, total cholesterol, and triglyceride after 9-12 hours fasting were measured.	A cluster random sampling method was conducted from April to August 2007. 716 patients were recruited. Logistic regression analysis was used to analyse the data.	The mean age of the diabetic patients was 58.70 +/- 9.83 years, ranging from 30 to 92 years old. The mean duration of diabetes was 5.53 +/- 4.62 years, the majority (82.41%) had suffered from diabetes for less than 10 years. More than half the patients (51.82%) were obese (BMI > or = 25 kg/m ²). Most of them (89.39%) had universal coverage health assurance. The prevalence of CKD stages 3 to 5 was 27.09% and 25.28% using C-G and MDRD formulae respectively. The duration of diabetes, diabetes with history of hypertension, triglyceride level, and diabetic retinopathy were significant independent risk factors for decreased kidney function.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
7. The development of a program for promoting quality of life of ESRD patients receiving haemodialysis (Pungchompoo <i>et al.</i> 2010)	The purpose of this study was to examine the effect of an exercise program on quadricep muscle strength and functional capacity among end-stage renal disease patients receiving haemodialysis.	Quasi-experimental research (two groups pre- and post-test design)	Research instruments included 1) 12 week Exercise Program developed by the researcher, consisting of walking and leg exercise programs; 2) Demographic Data Form; 3) Six Minute Walk Test Tools; 4) Borg's Scale (1994); and 5) Recording form for weight using quadriceps. 6) Self-Efficacy Questionnaire 7) A videotape showing self-management role modelling, the 8) Self-management questionnaire 9) SF 36 version 2	The sample consisted of 40 ESRD patients who met the inclusion criteria. Subjects were randomly assigned equally into experimental and control groups. The experimental group received the program consisting of 3 consecutive weekly sessions, advice, and skill training for self-management pertaining to food, water, medication and exercise, followed by monthly individual monitoring and counselling for 5 months. The control group received routine nursing care. Data were collected at baseline, and 3 months and 6 months after the intervention. Data were analysed using descriptive statistics, t-test and one-way repeated measured ANOVA.	The overall self-management and vitality quality of life were significantly higher in the group receiving the program only at 6 months after the intervention ($p < .05$). It was also found that the 6-minute walking distance and quadriceps strength among the group receiving the program were significantly higher at both 3 months and 6 months after the intervention ($p < .05$). There was no significant difference in adequacy of haemodialysis as measured by Kt/V and haemodialysis cost between the two groups.

Table 20. (cont.) Review of research evidence about older people with ESRD who managed without dialysis in Thailand

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
8. How do Thai patients with End Stage Renal Disease adapt to being dependent on haemodialysis? A pilot study (Yodchai <i>et al.</i> 2011)	To conduct a pilot study to explore how HD affects Thai patients with end stage renal disease (ESRD) and understand HD patients' perspective about adapting to being dependent on HD.	Grounded Theory	1) The open ended interviews guide 2) Standard demographic data questionnaire 3) Semi-structured interviews	Five patients (age range 24–66 years; mean 45.40 years; mode=24) participated in the study. Data were collected in the Thai language using that focused on problems, feelings, thoughts, attitudes and ways of adapting to HD. Field notes, audio tape recordings and transcripts were used to collect the data. Grounded theory (GT) was selected as a method to guide data collection and analysis including three level, open, axial and selective coding.	Four main coping processes emerged during analysis: planning, adjustment and avoidance; belief in religion and superstition; and living with hope. Patients reported a range of adverse effects of HD including restriction, fatigue, effects on sexual activity, altered body image, fear of dying, stress and depression and suicide. Thai patients with ESRD felt treatment, including HD, adversely affected their lives and required physical, psychological and social changes to enable them to cope by using a range of strategies to deal with it.

Table 21 Evaluation of strengths and weakness of review articles in Thailand

Authors	Years	Major strengths	Major weaknesses
Perkovic <i>et al.</i>	2008	<ul style="list-style-type: none"> • The study provided a clear problem statement and objectives for this cross-sectional study. • The research design, population, sample, data collection process and statistical methods were described in sufficient detail. • The research staff members were trained to administer the questionnaire, perform a brief physical examination and collect blood sample from participants. • The participant's ethical concerns about data disclosure were clearly addressed. • The data analysis was addressed to the research question and the statistical methods were used appropriately. • The number of participants was big enough to yield results from a descriptive survey. • The information about statistical significance was presented and the findings were adequately summarised using appropriate tables and figures. • A recommendation is made for further study about the health implications of ESRD. • There is a balanced presentation of the limitations and strengths of the study 	<ul style="list-style-type: none"> • The outcome measurements, such as GFRs, were estimated using the MDRD formula which has not been validated within the Thai population. This may affect the accuracy of the results. • The study did not contain any attempt to prevent potential biases in data collection and analysis. • Inclusion and exclusion criteria in the sample selection process were not explained.
Ong-ajyooth <i>et al.</i>	2009	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study, including background, method, results and conclusion. • The purpose and literature review of this study were clearly described. • The multistage stratified cluster sampling technique and probability random sampling were explained. • The reason for choosing specific statistical analyses and outcome measurements were sufficiently provided and appropriated. • The results answered and reflected the research purpose. 	<ul style="list-style-type: none"> • Outcome measurements such as GFRs were estimated by using the MDRD formula, which has not been validated within the Thai population. This may affect the accuracy of results. • The study did not make any attempt to prevent potential biases in data collection and analysis. • Information about ethical approval, participant protection and data disclosure were not

Authors	Years	Major strengths	Major weaknesses
		<ul style="list-style-type: none"> • The discussion was clearly explained with sufficient evidence. • The findings offered a potential opportunity for earlier therapeutic interventions to reduce the rate of disease progression and the incidence of ESRD. • The limitations of the study were clearly described. 	<p>described in the study.</p> <ul style="list-style-type: none"> • The inclusion and exclusion criteria used during sample selection were not explained.
Narenpitak & Narenpitak	2008	<ul style="list-style-type: none"> • The abstract provided the objectives of this descriptive cross-sectional study, the method, results and conclusion. • The background and purpose of this study were clearly described. • The research design, inclusion and exclusion criteria and definition of CKD were described. • Details of the sample size, data collection technique, specific statistical analysis methods and types of outcome measurements were sufficiently provided. • The results answered and reflected the research purpose by focusing on the prevalence and independence of risk factors of ESRD. • The information about statistical significance was presented and the findings were adequately summarized using appropriate tables and figures. • The discussion was interpreted within the context of prior research. 	<ul style="list-style-type: none"> • Outcome measurements such as GFRs were estimated using the MDRD formula, which has not been validated within the Thai population. This may affect the accuracy of the results. • The study did not address any attempt to prevent potential bias in the data collection and analysis. • Information about ethical approval, participant protection and data disclosure were not described in the study. • The sample size was not large enough to yield accurate results of the survey.
Yodchai <i>et al.</i>	2011	<ul style="list-style-type: none"> • The abstract clearly and concisely summarised the main features of the report, including the background, aims, method, findings and conclusion. • The problem was stated unambiguously, and was easy to identify. • The purpose and aim of the study were explicitly stated. • The literature reported adequately summarised the existing body of knowledge related to the objectives of the study. • The concept of coping was adequately defined, explained and appropriate for application to the study. • The study provided appropriate information about the procedures used to protect the rights of participants. The ethics approval 	<ul style="list-style-type: none"> • The sample size was small (N = 5) and did not represent a broad range of demographic characteristics. • Limited details were reported about the sample population and sample decisions. • The strategies to prevent bias in the purposive sampling and data collection were not clearly explained. • The participants' setting was in one tertiary hospital in Thailand (out of a total of 76 tertiary hospitals); this affected the

Authors	Years	Major strengths	Major weaknesses
		<p>process was described and participant informed consent was obtained.</p> <ul style="list-style-type: none"> • The research method, document, procedures and decision process were sufficient to enhance trustworthiness. • The data management and analysis were sufficiently described. • The findings were discussed and interpreted with appropriate Thai social context and sufficient reference to prior studies. • The limitations and implications of the study were provided and further inquiry was recommended. 	<p>generalizability of the findings.</p>
Teerawattananon <i>et al.</i>	2007	<ul style="list-style-type: none"> • The abstract clearly provided the main features of the report, including objectives, methods, results and conclusions. • The problem was stated unambiguously and is easy to identify. • The processes of data analysis and outcome measurement were adequately described. • The information about statistical significance was presented, and the results were adequately summarized using appropriate tables and figures. • The discussion was fully explained with sufficient supporting evidence. • The limitations of the study were clearly explained. • Recommendations and implications for further study were provided. 	<ul style="list-style-type: none"> • The design and methods of the study were not clearly explained. • No information about ethical issues. • Limited details were reported regarding data collection, sample decisions, participants recruitment, sampling methods and sample size. • Limited focus on potential biases that may occur in the study.
Prakongsai <i>et al.</i>	2009	<ul style="list-style-type: none"> • The problem statement and literature review were reported adequately, with the existing body of knowledge clearly related to the problem. • The research design, method, population, sample selection, sample size and recruitment process were described. • Data collection tools and data analysis (thematic analysis) and procedures were adequately explained. • Ethical concerns about data disclosure were clearly taken into account. • Thematic analysis captured the meaning of data and provided 	<ul style="list-style-type: none"> • The abstract did not clearly provide the main features of the report, including objectives, methods, results and conclusions. • The objective was not stated unambiguously and was difficult to identify. • The reason for conducting a case study was not clearly explained. Other types of qualitative study, such as phenomenology, ethnography or grounded theory, might also have been able to capture similar data.

Authors	Years	Major strengths	Major weaknesses
		<p>appropriate findings according to the objective of the study.</p> <ul style="list-style-type: none"> • The findings were adequately summarised, and good use was made of supporting arguments. • The discussion was adequate in the context of prior studies. • The interpretations were consistent with the study's limitations. • Implications, recommendations and conclusions were provided for further study. 	
Pungchompoo <i>et al.</i>	2010	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study, including background, method, results and conclusion. • The purpose and literature review of the study were clearly described. • The reason for conducting a quasi-experimental study with pre-post design was fully explained. • Sample size, selection and technique, recruitment process, inclusion and exclusion criteria were explained. • The reason for choosing the specific statistical analysis was provided. • Outcome measurements were tested for validity and reliability before being used to collect data. • The information about statistical significance was presented and the findings were adequately summarised using the appropriate tables and figures. The results could answered reflected the research purpose. • The demographic data showing that the experimental and control groups were homogenous was presented. • The discussion was clearly explained and sufficient evidence was provided. • Ethical approval information and participant protection information were provided. 	<ul style="list-style-type: none"> • Actions taken to prevent bias in the study were not clearly explained. • Small size and unrepresentative sample (N=40) • The programme may be limited to CKD patients at stages 1 to3, and might not be applicable to ESRD patients.
Yowaphui	2008	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study. • The problem statement, objectives and literature review of this 	<ul style="list-style-type: none"> • Actions taken to prevent bias in the study were not clearly explained. • Small size and unrepresentative sample (N =

Authors	Years	Major strengths	Major weaknesses
		<p>study were clearly described.</p> <ul style="list-style-type: none"> • The reason for conducting a quasi-experimental study with a pre-post design was fully explained. • Data collection, sample size, selection technique, recruitment process, inclusion and exclusion criteria were explained. • Data analysis and reasons for choosing the specific statistical analysis were provided. • Outcome measurements were tested for validity and reliability before being used to collect the data. • Information about statistical significance was presented and the findings were adequately summarized using appropriate tables and figures. The results answered and reflected the research purpose. • The homogenous sample demographic data between experimental and control groups was presented. • The discussion was clearly explained in the context of prior studies. • Ethical approval information and participant protection information were provided. 	<p>40)</p> <ul style="list-style-type: none"> • The researchers were not blind to the participants' allocation to groups. • Limited short follow-up time (4 months) may not be enough to show changes in behavior.

APPENDIX C: Reviewed and evaluated the strengths and weaknesses of articles Worldwide

Table 22 Review of research evidence about older people with ESRD managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
<p>1. Dialysis or not? A comparative survival study of patients over 75 years</p> <p>(Murtagh <i>et al.</i> 2007)</p>	<p>To describe and compare the survival of CKD patients over 75 years of age managed with dialysis and those managed conservatively. To identify several key variables that might be independently associated with survival.</p>	<p>Quantitative research/ retrospective analysis</p>	<ul style="list-style-type: none"> - Demographic data and data from individual comorbid factor questionnaire - Renal registry categories - The Modification of Diet in Renal Disease Formula (MDRD) was used to calculate glomerular filtration rate (eGFR). 	<p>Sample n=129 (52 dialysis patients and 77 conservatively-managed patients). Statistical analyses were performed using SPSS version 12. Mann Whitney U-tests and X² were used to test the differences between the two groups. A Cox proportional hazard regression model was used to investigate the impact of the relationships between the variables.</p>	<p>The patients who chose dialysis had improved survival compared to those who chose conservative management. However, the survival advantage was lost in those with high comorbidity. Identified modality choice, age and comorbidity were identified as being the most strongly associated with survival. For CKD stage 5 patients over 75 years of age who received special nephrological care early, and who followed a planned management pathway, the survival advantage of dialysis was substantially reduced by comorbidity and ischaemic heart disease in particular. Comorbidity should be a major consideration when advising elderly patients in favour of or against dialysis.</p>

Table 22 (cont.) Review of research evidence about older people with ESRD who managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/ impacts
<p>2. National survey of palliative care in end-stage renal disease in the UK</p> <p>(Gunda, Mark & Smith 2005)</p>	To establish the current pattern of provision of palliative care for ESRD in UK	- Quantitative research/ a cross-sectional study	The palliative care provision questionnaire	<p>An anonymous but numbered questionnaire concerning local palliative care provision was sent to clinical directors of all 69 UK renal units (N= 69). 100% response was obtained.</p> <p>The data were analysed by using descriptive statistic (percentage).</p>	<p>Only 27 (39%) units employ nursing or Professional Allied to Medicine (PAM) staff with palliative care for ESRD patients as a specified part of their role. Fifty-five (80%) units do not have a written protocol for palliative care. There is a significant variation in provision of palliative care services across the UK. In some areas access to palliative care is restricted to patients with malignant disease, and ESRD patients are excluded.</p>

Table 22 (cont.) Review of research evidence about older people with ESRD who managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
3. Factors affecting survival in advanced chronic kidney disease patients who choose not to receive dialysis (Wong <i>et al.</i> 2007)	1) To evaluate the prognosis factors influencing the survival of non-dialysis treatment (NDT) patients. 2) To evaluate the hospitalization rates and the survival rates among NDT patients and the clinical risk factors for these. 3) To evaluate if the Renal Association Standard (RAS) for renal anemia, renal biochemical parameters, and blood pressure are reached in practice in this population.	-A perspective observational study	-The Stoke Comorbidity Grade (SCG) (The SCG was an independent prognosis factor in predicting survival The SCG also provides a potentially useful indication of expected prognosis.)	30 ESRD patients who chose not to dialyze were recruited from the renal unit. The study group was classified according to age (<70 years, 71–80 years, and >80 years), estimated glomerular filtration rate (eGFR) (<10 ml/min, 11–20 ml/min, and >20 ml/min) according to the SCG. Cox regression multivariate analysis was used and STATA version 8 was used to analyse all statistical data.	The most common primary cause of kidney disease in NDT (non-dialysis treatment) was diabetic nephropathy and the most common comorbidity was ischemic heart disease. The median age was 79 years. There is likely to be increasing number of elderly patients who will tolerate dialysis badly and be very dependent on others. The overall median survival was 1.95 years; one year mortality was 35%. Over a three-year period, 60% of patients had no admissions at all, and more than 70% of the patients died at home. A multidisciplinary approach, an advanced care plan, integrated services with primary care, community nurses, a palliative care team for carrying out the patients' treatment at home and spiritual care to allow a dignified death need to be implemented in this area.

Table 22 (cont.) Review of research evidence about older people with ESRD managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
4. Exploring symptoms in patients managed without dialysis; a qualitative research study (Noble <i>et al.</i> 2010)	To explore experiences of ESRD patients who managed without dialysis and their trajectories to death	Qualitative research exploratory design	In-depth open-ended guide	The subjects were explored their experiences by interviewing and observation. The qualitative data were analysed related to symptoms specific. during naturally occurring consultations with patients and/or carers(30 ESRD patients and 17 carers)	Findings indicate that as symptoms escalate and death approaches, some symptoms such as fluid overload and lethargy become difficult to treat, indicating that death is close. This new knowledge can help staff as they attempt to determine when the end of life is approaching in order to support and care for patients appropriately. The paper highlights a need for effective identification and management of symptoms as they arise and further exploration of the effects of those symptoms on daily living.

Table 22 (cont.) Review of research evidence about older people with ESRD managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
5. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care (Yong <i>et al.</i> 2009)	To explore the symptom burden and quality of life (QOL) of ESRD patients on chronic dialysis and in palliative care	A prospective cross-sectional study	<ul style="list-style-type: none"> - Demographics and socioeconomic status questionnaire - Modified Charlson Comorbidity Index (CCI) - Prevalence and intensity of 23 ESRD-related symptoms , - Brief Pain Inventory and QOL by MOS SF-36. 	The data were collected from 1 January 2006 to 31 April 2007. A total of 179 ESRD patients completed the study; 45 patients (25.1%) were in the palliative care group and 134 patients (74.9%) were in the dialysis group. SPSS-PC 10 was used for the analysis. One-way ANOVA was used for comparison between groups. Relationships among the measures were analysed using Pearson correlation coefficients. A P-value of less than 0.05 was taken as statistically significant. All probabilities were two-tailed.	The palliative care group were older (73.1 ± 7.1 vs 58.2 ± 11.4 years, $P < 0.001$), had marginally higher modified CCI (8.5 ± 1.9 vs 6.1 ± 2.4 , $P = 0.05$), had more diabetics (62.2 vs 35.8% , $P < 0.001$) and were of poorer socioeconomic status than the dialysis group. The mean number of symptoms was 8.2 ± 3.9 and 9.3 ± 4.7 in the palliative care and the dialysis group, respectively ($P = \text{NS}$). Fatigue, cold aversion, pruritus, lower torso weakness and difficulty sleeping were the five most prevalent symptoms in both groups, and were also among the most intense symptoms. QOL was significantly impaired in both groups. Scores for all QOL domains correlated negatively with the number of symptoms ($P < 0.001$). The patients under palliative care and dialysis had overlapping symptom prevalence, intensity, significant symptom burdens and impaired QOL.

Table 22 (cont.) Review of research evidence about older people with ESRD managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/impacts
6. Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill haemodialysis patients (Weisbord <i>et al.</i> 2003)	To assess the data collection instruments to determine their suitability for palliative care, and to assess the acceptability of palliative care to such patients and health nephrologists	Quantitative research survey & pre- and post-test quasi experimental study	- the Memorial Symptom Assessment Scale Short Form (MSAS-SF) - the Functional Assessment of Chronic Illness Therapy - Spirituality Scale (FACIT-Sp) - the Dialysis Patient Choices at the End-of-Life Questionnaire (DPCELQ)	19 haemodialysis patients with modified Charlson co-morbidity scores of ≥ 8 were recruited. Each completed surveys to assess symptom burden, HRQOL and prior advance care planning. Palliative care specialists then visited patients twice and generated recommendations. Patients again completed the surveys, and dialysis charts were reviewed to assess nephrologists' (i) compliance with recommendations, and (ii) documentation of symptoms reported by patients on the symptom assessment survey. Patients and nephrologists then completed surveys assessing their satisfaction with palliative care. Data analysis was analyzed data by using the Wilcoxon sign-rank test for non-parametric data and the paired student's t-test for normally distributed data.	Dialysis patients have marked symptom burdens, considerably impaired HRQOL and frequently lack advance directives, making them appropriate candidates for palliative care. Patients and nephrologists perceive palliative care favourably despite its lack of effect in this study. A more sustained palliative care intervention with a larger sample size should be attempted to determine its effects on the care of the population

Table 22 (cont.) Review of research evidence about older people with ESRD managed without dialysis worldwide

Research title and authors	Aims of study	Research type/design	Instruments/ outcome measurements	Data collection/ analysis	Results/ impacts
7. Evidence for improving palliative care at the end of life: A systematic review (Lorenz <i>et al.</i> 2008)	To assess evidence about interventions to improve palliative and end of life care	Systematic review	Synthesized evidence by using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) classification	Single reviewers screened 24,423 titles to find 6,381 relevant abstracts and reviewed 1,274 articles in detail to identify 33 high-quality systematic reviews and 89 relevant intervention studies. They synthesized the evidence by using the Grading of Recommendations, Assessment, Development, and Evaluation (GRADE) classification.	Strong to moderate evidence supports interventions to improve important end-of-life care. Future research should quantify these effects and address the generalizability of insights across the conditions and settings in the last stage of life. Many clinical issues lack high-quality evidence.

Table 23 Evaluation of strengths and weakness of reviewed articles worldwide

Authors	Years	Major strengths	Major weaknesses
Murtagh <i>et al.</i>	UK/ 2007	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study including background, method, results and conclusions. • The study provided a clear problem statement and the objectives of the study. • The research design, population, sample, data collection process and statistical methods were described in sufficient detail. • The participants' ethical rights concerning data disclosure were clearly addressed. • The data analysis was addressed to the research question, and the statistical methods were appropriately used. • Information about statistical significance was presented and the findings were adequately summarized using appropriate tables and figures. • Employed balance of limitations and the strengths of the study • Recommendations are provided for further prospective survey studies about differences in survival between dialysis and non-dialysis groups. 	<ul style="list-style-type: none"> • The outcome measurement GFRs was estimated using the MDRD formulae which has not been validated within the Thai population. This may affect the accuracy of the results. • The study did not attempt to prevent potential biases in data collection and analysis. • The number of participants (N=129) was not big enough to yield accurate results for the descriptive survey.
Gunda <i>et al.</i>	UK/ 2005	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study including background, method, results and conclusions. • An introduction and the objectives of the study were provided. • The reasons for choosing specific statistical analysis and outcome measures were sufficiently provided and appropriated. • The results answered and reflected the research purpose. • The discussion was clearly explained with sufficient evidence. • The limitations of the study were clearly described. 	<ul style="list-style-type: none"> • The research design, the method of data collection (the validity and reliability of the instrument) and analysis were not clearly described. • The study did not address any attempt to prevent potential biases in data collection and analysis. • The recruitment process and demographic characteristics of the participants were not explained. • Furthermore, as the participants were clinical directors of renal units, they might have tried to

Authors	Years	Major strengths	Major weaknesses
			<p>present positive portrayals of their roles, reducing the quality of the data collected.</p> <ul style="list-style-type: none"> • The number of participants (N=69) was not big enough to yield accurate results from the survey. • Inclusion and exclusion criteria used in the sample selection procedure were not explained.
Wong <i>et al.</i>	UK/ 2007	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study including background, method, results and conclusions. • The study provided a clear problem statement and objectives for the cross-sectional study. • The research design, population, sample, data collection process and statistical methods were described in sufficient detail. • Statistical methods were used appropriately. • Information about statistical significance was presented and the findings were adequately summarized using appropriate tables and figures. • The discussion was fully explained with sufficient supporting evidence • The conclusions and implications provided a useful indication of expected prognosis factors in predicting the survival of non-dialysis patients. 	<ul style="list-style-type: none"> • The process used to validate the instrument was not provided in the article. • The study did not address any attempt to prevent potential biases in data collection and analysis. • Information about ethical approval, participant protection and data disclosure were not described in the study. • The sample size was not large enough to yield accurate results. • There was no discussion of the limitations and strengths of the study
Noble <i>et al.</i>	UK/ 2010	<ul style="list-style-type: none"> • The background, purpose and aim of the study were clearly stated and easy to identify. • The literature review adequately summarised the existing body of knowledge related to the objectives of the study. • The study provided appropriate procedures used to protect the rights of participants. The ethical approval process was described and participants' informed consent was obtained. • The findings were discussed and interpreted in the light of appropriate social context and sufficient prior studies. • The discussions, limitations and implications of the study were 	<ul style="list-style-type: none"> • The research design, method and procedures were not sufficiently described to enhance the trustworthiness of the study. • The process of qualitative data collection and analysis were not clearly explained. This might influence the credibility of the results. • The abstract clearly provided the main features of the report. • The strategies employed to prevent bias in the purposive sampling and data collection stages

Authors	Years	Major strengths	Major weaknesses
		provided and further inquiry was recommended.	were not clearly explained.
Yong <i>et al.</i>	China/ 2009	<ul style="list-style-type: none"> • The background, literature review and objectives of the study were clearly provided. • The research method, the data collection procedure, the process of data analysis and the outcome measures were adequately provided. • Information about ethical approval, participant protection and data disclosure were provided in the study. • Information about statistical significance was presented and the results were adequately summarised using appropriate tables. • The discussion was fully explained with sufficient supporting evidence • The limitations of the study were clearly explained. • Recommendations and implications for further study were provided. 	<ul style="list-style-type: none"> • The abstract did not clearly provide the main features of the report including objectives, methods, results and conclusions. • A limitation of this study was the representativeness of the results, as the study was conducted in one hospital in Hong Kong. • The cross-sectional design could not illustrate how symptom burden and quality of life might change over time based on the trajectory of ESRD until death. • The sample size was not large enough to yield accurate results. • Limited focus on potential biases that may occur in the study.
Weisbord <i>et al.</i>	USA/ 2003	<ul style="list-style-type: none"> • The abstract provided a concise summary of the main features of the study including background, methods, results and conclusions. • The problem statement and aims of the study were reported adequately. • The research design, method, population, sample selection, sample size and recruitment process were described. • The data collection, survey instruments, data analysis and procedures were adequately explained. • Statistical methods were used appropriately. • The participants' rights concerning ethical issues and data disclosure were clearly provided. • The results and information about statistical significance were presented and the findings were adequately summarised using appropriate tables and figures. • The discussion was fully explained in the context of prior studies. • The interpretations were consistent with the study's limitations. 	<ul style="list-style-type: none"> • The small sample might not be representative of the whole population, and it could influence the generalizability of the results. • The validity and reliability of the instruments was limited as they not been used with ESRD patients. • Recall bias by nephrologists is also a possibility. • Limited focus on potential biases that may have occurred in the study.

Authors	Years	Major strengths	Major weaknesses
Lorenz <i>et al.</i>	USA/ 2008	<ul style="list-style-type: none"> • Implications, recommendations and conclusions were provided to guide further study. • The abstract provided a concise summary of the main features of the systematic review, including background, purpose, data sources, study selection, data extraction, data synthesis, limitations and conclusion. • The problem statement, research questions, method of reviews, objectives, literature search and data analysis were clearly described. • Sample size, selection technique, recruitment process, inclusion and exclusion criteria were explained. • The reason for choosing the specific statistical analysis (Grading of Recommendation, Assessment, Development, and Evaluation (GRADE) system) was sufficiently explained. • The discussion, clinical implication and limitations of the study were clearly provided with sufficient evidence. 	<ul style="list-style-type: none"> • Limitations of using non-specific search terms in domains of spiritual support and bereavement. • End-of-life and palliative care of ESRD patients managed without dialysis was not addressed in the study. • Results for improving palliative care at the end of life cannot be directly transferred to these patients. • Ethical approval information and data protection issues were inadequately identified.

APPENDIX D: Ethics approval letters

**Ethics approval letter from the Faculty of Nursing,
Chiang Mai University, Thailand**



No.165/2011

CERTIFICATE OF ETHICAL CLEARANCE
Research Ethics Review Committee
Faculty of Nursing, Chiang Mai University

The Research Ethics Review Committee of the Faculty of Nursing,
Chiang Mai University declares approval of

Research Project Title : Experiences and health care needs during the last
year of life of older people with End Stage Renal Disease (ESRD) managed
without dialysis in Thailand

Principal Investigator : Assistant Professor Wanicha Pungchompoo

Participating Institution : Doctoral in Clinical Practice Candidate, School of
Health Science, University of Southampton, UK.

The above research project does not violate rights, well being, and/or
endanger human subjects and is justified to conduct the research procedures as
proposed.

This clearance is valid from the date of approval to November 17, 2012

Date of approval November 18, 2011

.....
(Professor Dr.Wichit Srisuphan)
Chair, Research Ethics Review Committee
Faculty of Nursing, Chiang Mai University

.....
(Associate Professor Dr.Thanaruk Suwanprapisa)
Dean of Faculty of Nursing, Chiang Mai University

Ethics approval letter form Nakorping Hospital, Thailand



Nakorping Hospital
Donkaew, Maerim, Chiangmai 50180
Tel : 0-5399-9200 # 1175
Fax : 0-5399-9200 # 1174

8 December , 2011

TO WHOM IT MAY CONCERN :

This is to confirm that Miss Wanicha Pungchompoo's thesis entitled "Experiences and health care needs during the last year of life of older people with End Stage Renal Disease (ESRD) managed without dialysis in Thailand.

I would like to inform you that Nakorping Hospital allowed her to contact and collect data in this thesis work.

Yours sincerely,

(Dr. Siripoj Sribunditkul)
Deputy Director of Nakorping Hospital

Ethics approval letter form Chiang Mai Ram Hospital, Thailand

S/F-032-MCI



โรงพยาบาลเชียงใหม่ ราม
CHIANGMAI RAM HOSPITAL

www.chiangmairam.com
e-mail : chiangmairam@chiangmairam.com

8 Boonuangrit Rd. Tel. 053-920300
Chiang Mai, 50200 Fax. 053-224880
THAILAND

No. CMR-CRD 0312/2554

November 07, 2011

RE : Assistance for research participation
To Assistant Professor Vanicha Puengchomphu,

Regarding the letter from the Nursing Faculty of Chiangmai University, No.๙๖.0515 (04.12)/4626 dated on August 16, 2011.

Concerning the research of Asst.Prof.Vanicha Puengchomphu, professor of Internal medicine of the Nursing Faculty of Chiangmai University about **“The Experience and Medical Need of the End Stage Renal Disease Patients Who have not Gotten the Renal Replacement Therapy in their last year before Death, from the Perspective of Relatives in Thailand”**

Chiangmai Ram Hospital is very pleased to hear that you have kindly accepted to participate with this research. If you have any questions or need more information please do not hesitate to contact our hospital, Khun Supaporn Laohapoonrungsri, manager of customer relations department (tel.053-920300 ext.4474 fax.053-224044 or e-mail: chiangmairam@chiangmairam.com)

Sincerely yours,

Varaphan Unachak, M.D.
Chief Executive Officer
Chiangmai Ram Hospital

โรงพยาบาลเชียงใหม่ ราม ผู้นับถือและเป็นโรงพยาบาลชั้นนำระดับโลก
CHIANGMAI RAM HOSPITAL

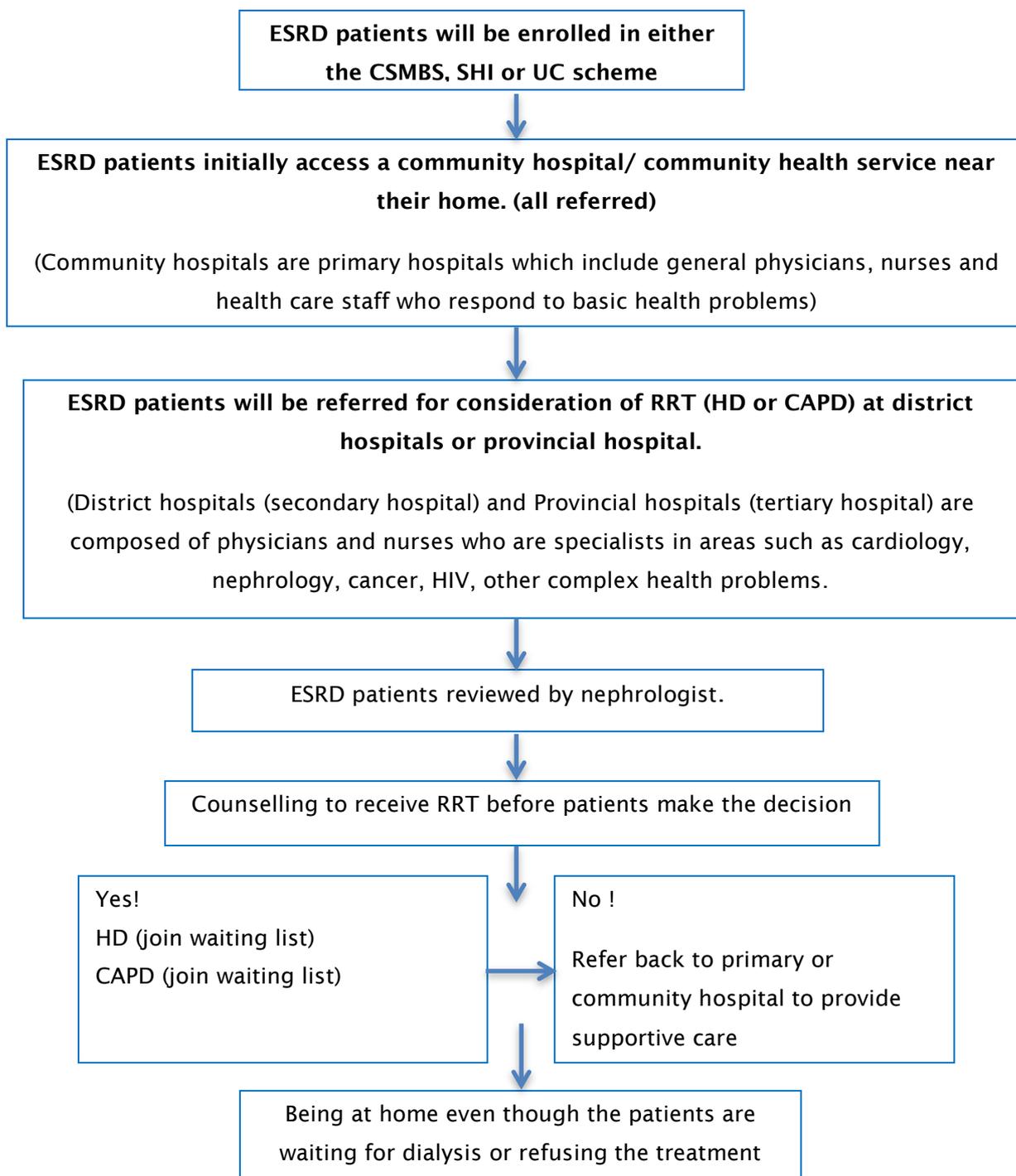
APPENDIX E: The instructions for renal nurses to recruit potential participants

Dear... Renal nurses

**Could you please read and follow this guideline in order to help you
recruit potential participants?**

1. The participants of the study will consider are the bereaved relatives of older people aged 60 or above with ESRD managed without dialysis.
2. The participants are persons who are involved in the caring of patients in the last three months of life.
3. The participants are persons who are able to participate in this study (including being able to read and write in the Thai language).
4. The participants are persons who are capable of providing informed consent (not cognitively impaired).
5. The participants are those who are willing to participate in this study.
6. The participants are those who have experienced the death of a person with ESRD managed without dialysis 5-10 months previously.
7. The potential participants will be recruited to the study via the medical history record system of the renal unit by the renal nurses.
8. The potential participants will be asked to identify the informal carer who provided the most care to the older ESRD patients. (If they are not this person they will be asked to identify the person who provided the direct care to the dying ESRD patients managed without dialysis.)
9. The renal nurse will phone to inform about the study and then send an invitation letter to the potential participants.
10. The reply slip with name and contact details of participants will be returned to the researcher.
11. The researcher will send the information pack to potential participant, providing time for them to read and decide.
12. The researcher will phone to confirm for willingness in taking part of the study. (If the potential participants have not received the information pack for joining the research project, they will be given further information and an invitation to join the study over the phone by the researcher.

APPENDIX F: The process of accessing health services for ESRD patients in Thailand



APPENDIX G: Contact letters for three phases

Contact Letter for the qualitative interview data

(English translation of form from Faculty of Nursing, Chiang Mai University)

Dear...

I am currently a doctoral student in clinical practice (DClinP.) at the School of Health Science, University of Southampton. I am beginning a study of “experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life”. Therefore, I would like to interview about your experiences and your relative’s health care needs during the time that you cared for your relative in the last year of life before he/she died. Your information will be used to develop a questionnaire survey.

If you are interested in this study, please provide your name and address at the end of this letter and return it directly to me by post to address below;

Faculty of Nursing, Chiang Mai University 110 Inthawaroros Rd., SriPhum, Chiang Mai 50200
--

Replying to this letter does not obligate you to take PART BUT I WILL SEND YOU FURTHER INFORMATION AND THE QUESTIONNAIRE TO LOOK AT AND THEN YOU CAN DECIDE. I would like to thank you for taking the time to read this letter. If you have any questions, please feel free to call me at 053- 949093 or 0845038871.

Sincerely,
Wanicha Pungchompoo,
Doctoral in Clinical Practice Candidate,
School of Health Science,
University of Southampton, UK.

Name and address of perspective participate:

.....
.....

Contact Letter for the developing questionnaire

(English translation of form from Faculty of Nursing, Chiang Mai University)

Dear...

I am currently a doctoral student in clinical practice (DClinP) at the School of Health Science, University of Southampton. I am in the process of designing the questionnaire that will be used in a survey of carers who have cared for older people managed without dialysis. I would like to invite you to read and think about the questionnaire in order to explore how easy or difficult the questions are to understand, so that we will be able to further develop questionnaire based on your feedback for use in a larger survey in Thailand.

If you are interested in this study, please provide your name and address at the end of this letter and return it directly to me by post to address below;

Faculty of Nursing, Chiang Mai University

110 Inthawaroros Rd., SriPhum, Chiang Mai 50200

Replying to this letter does not obligate you to take PART BUT I WILL SEND YOU FURTHER INFORMATION AND THE QUESTIONNAIRE TO LOOK AT AND THEN YOU CAN DECIDE. I would like to thank you for taking the time to read this letter. If you have any questions, please feel free to call me at 053- 949093 or 0845038871.

Sincerely,

Wanicha Pungchompoo,

Doctoral in Clinical Practice Candidate,

School of Health Science,

University of Southampton, UK.

Name and address of perspective participate:

.....
.....
.....

Contact Letter for the pilot testing the instrument

(English translation of form from Faculty of Nursing, Chiang Mai University)

Dear...

I am currently a doctoral student in clinical practice (DClinP) at the School of Health Science, University of Southampton. I would like to invite you to take part in a research study about the experiences and health care needs during the last year of life of older people with End State Renal Disease managed without dialysis from the perspective of their bereaved relatives. I have designed an interviewer administered questionnaire survey about the symptoms experienced and symptom control and health care needs of older people with End State Renal Disease managed without dialysis from the perspective of bereaved relatives. I like to test this survey on 20-30 people before it is used in a much larger study.

Therefore, I would like invite you to be part in my study. If you are interested, please provide your name and address at the end of this letter and return it directly to me by post to address below:

Faculty of Nursing, Chiang Mai University 110 Inthawaroros Rd., SriPhum, Chiang Mai 50200
--

Replying to this letter does not obligate you to take PART BUT I WILL SEND YOU FURTHER INFORMATION AND THE QUESTIONNAIRE TO LOOK AT AND THEN YOU CAN DECIDE. I would like to thank you for taking the time to read this letter. If you have any questions, please feel free to call me at 053- 949093 or 0845038871.

Sincerely,
Wanicha Pungchompoo,
Doctoral in Clinical Practice Candidate,
School of Health Science,
University of Southampton, UK.

Name and address of perspective particiapate:
.....
.....

APPENDIX H: Participant Information Sheets for three phases

Participant Information Sheet: Phase 1 Collecting Qualitative data

(English translation of form from Faculty of Nursing, Chiang Mai University)

Title of Project: Experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life.

Principal Investigator: Ms. Wanicha Pungchompoo

Ethics number:

**Please read this information carefully before deciding to take part in this research.
If you are happy to participate you will be asked to sign a consent form.**

Research brief summary: The first phase of the study will be to explore the experiences and health care needs of older people with End Stage Renal Disease (ESRD) managed without dialysis. The data will be collected from bereaved relatives of older people with ESRD managed without dialysis by using the interview topic guide. You have been selected from the patients' medical history records at the renal unit of Nakhon Ping Hospital, Chiang Mai Province, Thailand.

Research Procedures: You will be asked to take part in a face-to-face interview to explore the last year of life of End Stage Renal Disease (ESRD) older patients managed without dialysis from your own perspective, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death. With your permission, we would like to audiotape from you to get information regarding your ideas and experiences. At the end of this study, a brief summary of the study results will be shared with you. The interviewing process will take approximately one hour.

Benefit and risks: The information provided by you will contribute towards the development of questionnaire which will use to assess the needs of the end of life care for older people with End Stage Renal Disease (ESRD) managed without dialysis in Thailand. Importantly, the renal nurse at the renal unit of Nakorn Ping Hospital and I are happy to assist you to deal with your problems or any emotional distress resulting from participation in this study. Completing the interview process will not pose a risk to your physical health and you are free to refuse to answer the question or to withdraw from this study at any time without penalty.

Support for research participants: If you feel emotionally distressed during the data collection process, I will observe closely and provide information or telephone numbers for you to contact the renal nurse for support at the renal unit. If I feel you might be severely distressed after participation in the data collection process and feel you might be in need treatment or care, I will (with your permission) refer you directly to general physician (GP) at the emergency department of the Nakhon Ping Hospital or discuss the issue with the renal nurse and the general physician they are able to refer you to receive specific treatment.

Confidentiality of Research Data: Results of this study will be reported as a group and no individuals will be identifiable. Data will be kept confidentially in line with the data protection policy developed by the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University and the School of Health Science, University of Southampton. The principle investigator will be the only person eligible to access the data stored on a password protected computer. Moreover, your name, address, and telephone numbers will not be retained for a period of longer than 10 years in line with the data protection policy at the Faculty of Health Sciences, University of Southampton.

Contact person: If you have any questions or need more information, please feel free to contact me at the Faculty of Nursing, Chiang Mai University or my nursing colleagues at the renal unit by following

Faculty of Nursing, Chiang Mai University:
Ms.WanichaPungchompoo
(053-940993), 0845038871
Nakon Ping Hospital Renal Unit: Ms WatchareeNakapa
(053-940993),

If you have any concerns or are anxious about your participation in this study, you feel free to contact the chairman of the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand, on telephone number provided b

Institutional Review Board of Faculty of Nursing (IRB),
Chiang Mai University, Thailand
Tel: 053-221-142 (available on official time).

Participant Information Sheet: Phase 2 Developing the questionnaire

(English translation of form from Faculty of Nursing, Chiang Mai University)

Title of Project: Experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life.

Principal Investigator: MsWanicha Pungchompoo

Ethics number:

Please read this information carefully before deciding to take part in this research.

If you are happy to participate you will be asked to sign a consent form.

Research brief summary: This study will develop a questionnaire for use in the pilot surveys of the study. A cognitive interviewing will be used to ask you to read and think about your understanding of the questions in the questionnaire. You have been selected from the medical history record at the renal unit of Nakhon Ping Hospital, Chiang Mai Province, Thailand.

ResearchProcedures: You will be asked to take part in a face-to-face interview to ask your opinion and understanding of the questionnaire. The questions will associated with the last year of life of End Stage Renal Disease (ESRD) older patients managed without dialysis from your own perspective, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death. During the checking process, we would like to take note record and audiotape from you to get information regarding your understanding and interpreting on the questionnaire. The interviewing process will take approximately one hour.

Benefit and risks: The information provided by you will contribute towards the development of the prototype questionnaire which will be modified and made ready for use for pilot testing in the phase 3 of the study. Importantly, the renal nurse at the renal unit of Nakorn Ping Hospital and I are happy to assist you to deal with your problems or any emotional distress resulting from participation in this study. Completing the interviewing process will not a pose risk to your physical health, but you are free to refuse to answer any questions or to withdraw from this study at any time without penalty.

Support for research participants: If you feel emotionally distressed during the data collection process, I will observe closely and provide information or telephone numbers for you to contact the renal nurse for support at the renal unit. If I feel you might be severely distressed after participation in the data collection process and feel you might be in need treatment or care, I will (with your permission) refer you directly to general physician (GP) at the emergency department of the Nakhon Ping Hospital or discuss the issue with the renal nurse and the general physician they are able to refer you to receive specific treatment.

Confidentiality of Research Data: Results of this study will be reported as a group and no individuals will be identifiable. Data will be kept confidentially in line with the data protection policy developed by the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University and the School of Health Science, University of Southampton. The principle investigator will be the only person eligible to access the data stored on a password protected computer. Moreover, your name, address, and telephone numbers will not be retained for a period of longer than 10 years in line with the data protection policy at the Faculty of Health Sciences, University of Southampton.

Contact person: If you have any questions or need more information, please feel free to contact me at the Faculty of Nursing, Chiang Mai University or my nursing colleagues at the renal unit by following

Faculty of Nursing, Chiang Mai University:
Ms.WanichaPungchompoo
(053-940993), 0845038871
Nakon Ping Hospital Renal Unit: Ms WatchareeNakapa
(053-940993), 0865860122 or
Ms.KesronKumdee(053- 224861), 0818850562

If you have any concerns or are anxious about your participation in this study, you feel free to contact the chairman of the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand, on telephone number provided below;

Institutional Review Board of Faculty of Nursing (IRB),
Chiang Mai University, Thailand
Tel: 053-221-142 (available on official time).

Participant Information Sheet: Phase 3 the pilot testing of the instrument

(English translation of form from Faculty of Nursing, Chiang Mai University)

Title of Project: Experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life.

Principal Investigator: Ms. Wanicha Pungchompoo

Ethics number:

**Please read this information carefully before deciding to take part in this research.
If you are happy to participate you will be asked to sign a consent form.**

Research brief summary: A pilot survey is being conducted to test a questionnaire designed to survey the experiences and health care needs of older people with End Stage Renal Disease (ESRD) managed without dialysis in Thailand from the perspective of bereaved relatives. You have been identified from patients' health history records by health care professionals at the renal unit of Nakhon Ping Hospital, Chiang Mai Province, Thailand.

Research Procedures: You will be received an information related to symptom experiences and health care needs of older people with End Stage Renal Disease (ESRD) managed without dialysis. The questionnaire will be administered as an interview. At the data collection process, you will be asked to express your idea and experiences. The questions will relate to your opinions about the last year of life of End State Renal Disease (ESRD) older patients managed without dialysis, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death. The questionnaire will take approximately one hour.

Benefit and risks: The information provided by you will contribute towards testing the prototype of VOICES questionnaire in views of bereaved relatives of older people with End Stage Renal Disease (ESRD) managed without dialysis in Thailand. Importantly, the renal nurse at the renal unit of Nakorn Ping Hospital and I are happy to help with any issues or any emotion distress that arises for you as a result of taking part in the study. Completing the interview process, it will not a pose risk to your physical health, but you

Appendix H

are free to refuse to answer any questions or to withdraw from the study at any time without penalty.

Support for research participants: If you feel emotionally distressed during the data collection process, I will observe closely and provide information or telephone numbers for you to contact the renal nurse for support at the renal unit. If I feel you might be severely distressed after participation in the data collection process and feel you might be in need treatment or care, I will (with your permission) refer you directly to general physician (GP) at the emergency department of the Nakhon Ping Hospital or discuss the issue with the renal nurse and the general physician they are able to refer you to receive specific treatment.

Confidentiality of Research Data: Results of this study will be reported as a group and no individuals will be identifiable. Data will be kept confidentially in line with the data protection policy developed by the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University and the School of Health Science, University of Southampton. The principle investigator will be the only person eligible to access the data stored on a password protected computer. Moreover, your name, address, and telephone numbers will not be retained for a period of longer than 10 years in line with the data protection policy at the Faculty of Health Sciences, University of Southampton.

Contact person: If you have any questions or need more information, please feel free to contact me at the Faculty of Nursing, Chiang Mai University or my nursing colleagues at the renal unit by following

Faculty of Nursing, Chiang Mai University:
Ms.WanichaPungchompoo(053-940993), 0845038871)

Nakon Ping Hospital Renal Unit: Ms WatchareeNakapa
(053-940993), 0865860122 or
Ms.KesronKumdee(053- 224861), 0818850562

If you have any concerns or are anxious about your participation in this study, you feel free to contact the chairman of the Institutional Review Board of Faculty of Nursing (IRB), Chiang Mai University, Thailand, on telephone number provided below;

Institutional Review Board of Faculty of Nursing (IRB),
Chiang Mai University, Thailand
Tel: 053-221-142 (available during office hours).

APPENDIX I: Consent Form

--	--	--

Date: ___/___/___ Setting___ Study ID

Title of Project: Experiences and health care needs of older people with End Stage Renal Disease managed without dialysis in Thailand during the last year of life.

Principle Investigator: Ms.Wanicha Pungchompoo

Participant’s name:.....Age.....

Address.....

Participant Informed Consent:

I have received all the information and read the participant information sheet about this study.

I clearly understand and are willing to participate in this study.

I agree to be interviewed and audiotaped.

I understand that I can ask the investigator whenever I have any question.

I understand that I am free to withdraw from this study at any time without giving a reason

I understand that the investigator will protect my personal identifying information against disclosure to anybody else. The data will be used for research only.

Signature.....(Participant)

.....(Witness)

.....(Witness)

Date.....

Investigator’s Declaration:

I have clearly explained all details of the procedures conducted in this study plus potential risks and benefits to the participation.

Signature.....(Investigator)

APPENDIX J: Example of the Framework analysis

Example of Framework analysis: *Symptoms experiences*

	A	B	C	D	E	F	G	H	I
	1. Physical symptoms		1.1 Pain	1.2 Breathlessness	1.3 Edema	1.4 weak	1.5 Weight loss	1.6 Dependency	2. Psychological symptoms
01: Daur in law	Physical symptoms were showed into six types including pain, breathlessness, edema, weigh loss and dependency.	He always complained about the back pain and bone pain. He said "I feel very painful." "Please help me or do something for me to release it" "Sometime, he asked us to provide a massage on his body. "Please pressure or massage on my back". He had severe pain. He was quite suffered with severe pain.	At first, he felt nothing since he still believed that he quite strong and could do everything. "He realized that he was unhealthy when he had problem about breathing, which caused him readmitted to hospital more often". He couldn't breath properly. "He also had problem about breathing at 3-5 months	none-mentioned	He looked really weak. When he wish to move, we had to carry him for sitting or walking.	He suffered with serious weight loss and his skeleton could be seentrough the skin. He wouldn't able to take any foods, water or medicines. In fact, one week before the patient died, he couldn't eat or drink.	He was depended on us since he couldn't do any activities by himself. He had no energy, when he wish to move, we had to carry him for sitting or walking. We had to make the house suitable for him by putting a hand rail in the toilet and in the room of the house.	Psychological symptoms were described into three types including depress, angry/aggressive and stress.	"He rested word with u oried. Durin died, he qui slept on the
02: Niece		As she had edema on both legs, she could work as same as she was healthy. (Edema was related to unable to work and made atient felt very painful)"When she walked out from her room, she felt very painful on her legs."	"When she walked out from her room, she felt very tired and difficult to breath." Her abdomen was expanded too much, (the expansion of abdomen) This caused her felt very tired and difficult to breath. "6 months before her died, the difficult to breath is the main symptom which was the most her of suffering." "During the last 2-3 days before patient died, her was outstred I think the problem about breathing was that it made him feel exhausted and couldn't breath properly since he seemed to lack energy and was unable to help himself. "2-3 weeks before he was admitted to the hospital, he felt exhausted and couldn't do anything. He felt he quite weak and needed help".	She had edema in both legs. She couldn't walk much less than when she was healthy. She was suffering with edema in her both legs. 2-3 days before she died, she had severe edema and didn't have energy to do the activities of daily living.	"She felt that she got weaker and weaker. She felt exhausted, she couldn't do any activities and she laid down on her bed."	She slept all day. She lost her appetite when she ate something it was always in small portions. "One month before her died, she couldn't eat any food or water."	She couldn't walk outside the room or the house by herself. She could not work or do some activities on her own. She felt down easily. One day, she felt down in front of her room when nobody was in the house. My husband had to drive a car or take her to the market. I always prepared or cooked foods and took her to the hospital for leaving. "Following her admission 2 weeks before he was admitted to hospital, he was really weak and depended on us since he couldn't work or do activities of daily life by himself such as taking bath, walking to toilet etc.		"1 month be quite depre eat any food
03: Wife		During 2-3 weeks before he died, "He really suffered with ESRD especially as he felt severe pain in both legs as he had edema."	The breathlessness was the main symptom which caused the most suffering for the patient during the last days of his life. He couldn't sleep or lie down on the bed, he had to sit on the bed for the whole day. "Sometimes, he said 'I can't sleep / can't sleep'. His breathlessness made him couldn't has enough breathing. This also made him really	Edema made him couldn't walk and it made he felt very painful when he stood or started a walking.	2 months before he died, he quite weak and couldn't breath properly. He always complained "I feel exhausted during works".	none-mentioned			"He was re depressed, worried abo he couldn't activities of himself." "S cried in the had never s before. Hev and he was Normally, h man. He ha humor. His to talk with "EST, and "breathless he changed before the breathless screamed
04: Daughter		During 3 days before he died, he get pain around both legs and abdomen. "Both legs were edema and were painful when he walked or moved. "The abdomen was swollen and expanded". This made him felt painful around his chest and affected his breathing as he couldn't breathe properly.	The breathlessness was the most suffering to him during his days without dialysis. Since, he couldn't stop smoking which caused him had severe breathlessness. While he managed without dialysis, the breathlessness was the important symptom that caused him readmitted to the hospital many times until he died	"During 3 days before he died Both legs were edema and very painful when he walked or moved. He had abdomen swelling and edema on both legs. The abdomen was swollen and expanded.	Last 3 days before he died, he felt really weak. "He said 'I feel really weak and unable to breath properly since take me to the hospital". I took him to the district hospital, and a physician and the nurses provided him with oxygen by using a respiratory machine to support his breathing. "His	none-mentioned	I think symptoms affected to the patient's body a lot, especially last 2-3 days before he died, he couldn't do all activity of daily life by himself such as walking and doing his job".		"The face to used to be the window used to be she too too more time
05: Wife		"While he managed without dialysis, the back and his pain caused suffering to him. When he was that pain he cried and asked for the medicines to relief the pain. "Sometimes, he cried 'I can't tolerate with this pain let me die."	"The breathlessness was the most suffering to him during his days without dialysis. Since, he couldn't stop smoking which caused him had severe breathlessness. While he managed without dialysis, the breathlessness was the important symptom that caused him readmitted to the hospital many times until he died	none-mentioned	"Since, he would lack of energy and was really weak.	He couldn't do anything by himself when he had breathlessness. Sometimes, he wanted to eat the food that he liked and he wanted to cooked that food by himself but he couldn't since he couldn't had energy to do that.	When he was at home as he couldn't perform his job and depended on me. "He couldn't work and depended on me more	"The face to used to be the window used to be she too too more time	
06: Husband		She was very weak and just laid down on the bed. She sometimes cried when he had abdominal pain and requested nurse for giving her with the pain release medicine	"At the last 2 months, she had swollen about her abdomen which caused her couldn't breathe properly and needed the oxygen support in the hospital	"The edema on her legs and back made her couldn't walk as usual. She depended on nurse or her son when she wanted to move or went to the	"She was really weak at that time. I meaned the last 2 months before her died.	"She couldn't eat any food" I meaned the last 2 months before her died.	At that time, the patient was really weak. She couldn't make her own decision. She allowed me and my son to make decision on her health problem.	"She looked like she was really weak. She couldn't make her own decision. She allowed me and my son to make decision on her health problem.	

Example of Framework analysis: Health service utilization

	A2	B	C	D	E	F	G	H	I	J
	1. Health service utilization	1.130 Baht scheme	1.1.1 Provincial/district hospital	1.1.2 Community health	1.1.3 Home visiting	1.1.4 Private clinic	2. Possibility to receive	2.1 Free for HD's cost	3. End of life care for	
01: Daut her in law		The health insurance of the patient (BKK) is not cover for receiving broad range. We was care him at home during illness before he was transfer to the hospital. Home still was provided during the end of patient's life such as basic check up, vital sign and health assessment.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.
02: Niece		Current had bring patient to the hospital to receive the treatment related to the patient's illness. 30 Baht scheme is included with community health insurance and the insurance process of assessment health status when patient have complete health condition in district or provincial hospital. More about health insurance of home was not provided for the.	Home of the community hospital will transfer the patient to the district hospital or the provincial hospital if the patient has more complex health condition than general case or available in the community hospital was cover.	We had to go to the community hospital provided by the government and free of charge in order to receive the medicine when the patient get health problem. He was not had health insurance.	"However, there were some the home staff or health workers to take care the patient at home." "These patients have more complications after rejected the treatment. However, if their conditions don't know about the illness and how to care for patients at home. Patients will do what they can best."	He visited the private clinic in the village by himself. The physician was like with some medicines. The physician might be like about his illness related to ESRD. However, we didn't know him and he didn't know anything about his illness when I asked.	This should have better to provide enough HD treatment for some ESRD patients.	There were patients should not pay for the treatment. If this is possible, many patients' condition may be another unit for longer.	Full option of care was not provided for the ESRD receiving dialysis.	
03: Wife		We also used the health insurance of 30 baht scheme which is not cover for the home dialysis treatment. This made him worse about the end of treatment when he had to go to hospital. He also don't want to take any medicine for the dialysis.	He had hypertension and cholesterol than 5 years. The patient always visited the district hospital for follow up and receiving the medicines. We know him in the district hospital. The physician repeated that he might had the problem about several follow up. He was referred and admitted for receiving the medical treatment at the provincial hospital. 5 days before the patient's death, he was admitted to the provincial hospital. There 3 days later, he was refer to the provincial hospital.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.
04: Daughter		The patient was covered by the 30 Baht scheme and had the right card for other people's health insurance provided by the Thai government. The patient was covered by the 30 Baht scheme and had the right card for other people's health insurance provided by the Thai government. The patient was covered by the 30 Baht scheme and had the right card for other people's health insurance provided by the Thai government.	I took him to the district hospital, and a physician and the nurse provided him with oxygen by using a respiratory machine to support his breathing. The physician also provided him with oxygen by using a respiratory machine to support his breathing. The physician also provided him with oxygen by using a respiratory machine to support his breathing.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.
05: Wife		The physician explained to me the benefit of receiving HD. However, the patient didn't follow the doctor's advice and he continued to have HD using three tubes for once a day by the physician. She always, he said that "don't take me to the hospital if I don't help". I don't like to hear that.	The physician and nurse explained that the home care of ESRD patients. The physician and nurse explained that the home care of ESRD patients. The physician and nurse explained that the home care of ESRD patients.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.
06: Husband		In the last 3 months before he died, I took her to the provincial hospital. The provincial hospital was not able to receive him. He was transferred to the provincial hospital. The provincial hospital was not able to receive him. He was transferred to the provincial hospital.	However, the physician and nurse in the provincial hospital were not able to receive him. He was transferred to the provincial hospital. The provincial hospital was not able to receive him. He was transferred to the provincial hospital.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.
07: Wife		He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.	He was well served with service after discharge. He also had problem about receiving of 80 months before he die. Since, we not had health insurance for receiving an air condition and oxygen.

Case No.	01	02	03	04	05	06	07	08	09	10
Physical symptoms: <u>Pain</u>	<p>He always complained about the back pain and bone pain. He said <i>"I feel very painful."</i> <i>"Please help me or do something for me to release it"</i></p> <p>Sometime, he asked us to <i>"Please pressure or massage on my back"</i>.</p> <p>He had severe pain. He was quite suffering with severe pain for long time.</p>	<p>As she had edema on both legs, she could work the same as when she was healthy. (Edema was related to being unable to work and made patient felt very painful) "When she walked out from her room, she felt very painful on her legs."</p>	<p>2-3 weeks before he died, "He really suffered with ESRD especially as he felt severe pain in both legs as he had edema."</p>	<p>3 days before he died, he <i>got pain around both legs and abdomen. Both legs were edema and very painful when he walked or moved. The abdomen was swollen and expanded.</i> This made <i>him felt pain around his chest and affected this breathing as</i> he couldn't breathe properly.</p>	<p>...<i>While he managed without dialysis, the back and hip pain caused him to suffer.</i> When he was in pain he cried and asked for the medicines to relieve the pain. <i>Sometimes, he cried 'I can't tolerate with this pain let me die'.</i></p>	<p>She was very weak and just laid down on the bed. She sometimes cried when she <i>had abdominal pain and requested nurse for give her the pain release medicine.</i></p>	<p>Edema made him <i>felt painful and uncomfortable.</i></p>	<p>He did not complain about pain symptom as his sensory organs were not responding to the pain stimulations. The physician said that this was caused from the DM. He felt nothing from his hands and legs even if that areas was made to feel pain.</p>	<p>She had bone pain for a long time (3-5 months) about her body.</p>	<p><i>The patient sometime complained about chest pain</i> and felt tired very easily.</p>

Case No.	01	02	03	04	05	06	07	08	09	10
Physical symptoms:	none-mentioned	She had edema in both legs. She could walk much less than when she was healthy. She was suffering with edema in both legs. 2-3 days before she died, she had severe edema and didn't have energy to do the activities of daily living.	Edema meant he couldn't walk and it made him feel very painful when he stood or started a walking.	<u>3 days before he died, Both legs were edema and very painful when he walked or moved. He had abdominal swelling and edema on both legs.</u> The abdomen was swollen and expanded.	none-mentioned	<u>The edema on her legs and body meant she couldn't walk as usual.</u> She depended on nurse or her son when she wanted to move or went to the toilet. My son and his wife had to prepare foods and cook the food that she like for making her felt appetite to eat.	<u>He had an edema on his face, arms and legs and both feet. He also had edema around his face. This made him felt painful and uncomfortable.</u>	He suffered with the edema especially on his face. The last day before he died, I saw his face was very swollen. He looked really suffered too much.	she got edema on her face and legs.	2 months before she died, he couldn't do anything and <u>had many signs and symptoms which related to ESRD such as edema on her legs and body.</u>
<u>Edema</u>										

Case No.	01	02	03	04	05	06	07	08	09	10
Physical symptoms: <u>Breathlessness</u>	At first, he felt nothing since he still believed that he was quite strong and could do everything "He realized that he was unhealthy when he had problems breathin. He couldn't breathe properly. "He also had problems' breathing at 3-5 months before he died." We brought him to the emergency unit at hospital frequently to receive an air nebulizer and oxygen.	"When she walked out from her room, she felt very tired and found it difficult to breathe." Her abdomen was expanded too much. This caused her to feel very tired and difficult to breathe. "6 months before she died, the breathing difficulties are the main symptom which was the most her of suffering." "During the last 2-3 days before patient died, she suffered breathlessness , edema and no energy to do anything."	I think the problem about breathing was that it made him feel exhausted and couldn't breathe properly since he seemed to lack energy and was unable to help himself. "2-3 weeks before he was admitted to the hospital, he felt exhausted and couldn't do anything. He felt he quite weak and needed help".	The breathlessness was the main symptom which caused the most suffering for the patient during the last days of his life. He couldn't sleep or lie down on the bed, he had to sit on the bed <u>for the whole day. Sometimes, he said 'I can't sleep, I can't sleep'</u> . His breathlessness made him couldn't has enough breathing. This also made him really <u>weak and no had energy to perform daily activities. He said 'I feel really weak and unable to breath properly, please take me to the hospital'</u> .	<u>The breathlessness was the most suffering to him during managed without dialysis. Since, he couldn't stop smoking which caused him had severe breathlessness. While he managed without dialysis, the breathlessness was the important symptom that caused him readmitted to the hospital many times until he died</u>	<u>At the last 2 months, she had problem about breathlessness which caused her couldn't breathe properly and needed the oxygen support in the hospital.</u>	<u>He was suffered with breathlessness. He couldn't breathe properly and felt very exhausted when did jobs or did some works on farms. During 2 months before he died, the patient was suffered with breathlessness. He felt every exhausted and lack of energy to do anything.</u>	He had problems about fluid overload which caused him had severe breathlessness. I had to take him to the hospital many times for getting the diuretic medicine in order to release water out of his body.	The breathlessness caused the most suffering to her as she couldn't do anything and felt very exhausted. This symptom made her lack energy and depended on me or my brother to help her at home	2 months before her died, he couldn't <u>do anything and had many signs and symptoms which related to ESRD such as breathlessness.</u>

Case No.	01	02	03	04	05	06	07	08	09	10
Psychological symptoms: <u>Low mood</u>	<p>"He rested and slept all day. He didn't want to say any word with us. He sometime cried. During 1 week before he died, he quite depress and slept on the bed all day."</p>	<p>"1 month before her died, she quite low mood and couldn't eat any food."</p>	<p>"He was really weak and low mood. He seemed more worried about his health since he couldn't work or do the activities of daily living by himself." Sometime, I saw he cried in the bedroom and I had never seen him crying before. He was quite strong and he was the leader of the family.</p>	<p>Normally, he was a friendly man. He had a good sense of humor. His friends really liked <u>to talk with him. When he got ESRD and managed without dialysis,</u> his mood was really changed. During last 3 days before <u>the death, he got the breathlessness; he screamed</u> and cried 'I can't breathe', <u>'anybody please help me'. The time he was admitted in the hospital, he cried and said ' please take me back home'. 'I want to die at home'.</u></p>	<p><u>His face looked really sad and he always looked out the window and cried. He used to say that 'I may not live too long. I have not more time to live.'</u></p>	<p><u>She looked really low mood after having the breathlessness and was needed to retained ET tube with respiratory machine. She was provided with the suction for reducing secretion on her trachea. This made her was very painful and she cried every time when nurse came to provide the suction to her.</u></p>	<p>none-mentioned</p>	<p>During <u>waiting for the HD, he said that he felt bore about his body. He said that 'I wanted to die'. 'Sometime, he wanted to make a suicide', 'he wanted to take some medicines to make him die, but he was worry that, if he died at home, it was not a good thing. His children might fear to live in the house.</u></p>	<p>non-mentioned</p>	<p>non-mentioned</p>

Case No.	01	02	03	04	05	06	07	08	09	10
<p>Psychological symptoms:</p> <p><u>Worry</u></p>	<p>"He quite stress and worry with his illness, since he got illness more than 2 years. He was worry about his illness since it makes the negative impact to his family. He taught he made problem to his family which he don't want to. He always complained "I want to die. I am very old. I live too long."</p>	<p>She kept her feeling very well. She didn't show she was worry about her health problem. However, she often said that "I want to live as long as possible".</p>	<p>When my husband (the patient) came back after meeting with the doctor, I saw him looked stress and when I asked about what the doctor had said. He said "nothing". I thought he was quite worried about his illness but he didn't tell me how much he was worried about it. This meant that I wouldn't ask nor aware much of his health problems. However, after he was admitted to the hospital and the doctor told him, he needed to receive hemodialysis treatment, he used to say that "if I receive dialysis I will die, I will also die if I don't receiving hemodialysis."</p>	<p>non-mentioned</p>	<p>He <i>got breathlessnes quite often. This symptom made him worry as he couldn't breathe properly. Sometimes, I saw him looked outside the window</i> by not said any word.</p>	<p><i>She was worry about her severe diarrhea which mad her no have energy to do anything.</i></p>	<p><i>He felt worry as he couldn't work</i> or do anything as usual. He could walk but he couldn't do hard jobs as working in the farm. He asked me sometimes about the time that he had to go to see the doctor at the hospital. Sometime, he wanted to go to see the doctor before the date of appointment. He was normally didn't feel stress or worry. However, he felt fear and didn't want to die. <i>He would like to live as long as he could.</i></p>	<p>He was worry about he couldn't do anything by his own. He felt bore with his health problems. He bored his life as he had hypertension , DM, pulmonary edema, edema of the body and anemia.</p>	<p>She felt worry as she felt exhausted more easily. She complained often about she felt headache and felt weak easily even thought she didn't do any activities.</p>	<p><i>She felt very worry about her health. 'Sometime, she complained that I want to die, I want to die.' Yes, she felt really worry and stress with her illness.</i></p>

Case No.	01	02	03	04	05	06	07	08	09	10
<p>Spiritual aspects:</p> <p>Spiritual distress</p>	<p>Normally, he loved to go to the temples. He used to pray to the monks and receive blessing at each Buddhist event. When he got ill, he never went to the temple.</p>	<p><i>She normally liked to go to the temple on every Buddhist events like many Thai elderly people. When she was ill, she loved to put fresh flowers and small portion of food in front of Lord Buddha's image by herself at home since she couldn't walk out of her room. As you know, this is the spiritual belief and to show respect for Buddhists by putting fresh flowers, water and food in front of Lord Buddha's picture at home when you can not go to pray respect at the temple. This would also make her feel happier and release her tension</i></p>	<p><i>He normally like to drive his car go to the temple. He always helped monks prepare or clean the temple for Buddhist holy day. He told me he loves to do this. During his difficult time about ESRD, he couldn't do it.</i></p>	<p><i>He liked to go to the temple. He still went to the temple when he could walk by himself. During the time he died, we invited monks for coming to visit and giving the blessing to him. He tried to hold his hands to pay respect to monks, even if, He didn't have energy to help himself. 2-3 hours after that, he died. During he was dying. He wasn't suffered and he died very smoothly. We thought that the last time he received the blessing from monks, this would help him fulfill on his spiritual needs, especially for the dying time.</i></p>	<p>He normally went to the temple every Buddha events. When he got ESRD, if he had energy to walk he would went to the temple for paying the Buddha activities.</p>	<p>She was normally love to go to the temple but when she got ill she couldn't do what she wanted.</p>	<p>He loved to go to the temple and join Buddha events more often. During his illness, if he could he would go to join Buddha events at the temple but if he felt tried or exhausted he wouldn't go but he would donate money to that Buddha's events at the temple (07).</p>	<p>He was normally not like to go to the temple. So, this was his normal life he never went to the temple. He said that 'I would go to the temple when I died.'</p>	<p><i>She was normally like to go to the temple but during the last year of her life she didn't go. This was because she felt weak and no had energy to walk or perform any activities (09).</i></p>	<p>2 months before she died, she couldn't go to the temple. This was because she no had energy to walk or do anything by her own. Normally, she loved to go to the temple.</p>

APPENDIX K: The semi-structured interview schedule

The semi-structured interview schedule



Date: ___/___/___ Setting___ Study ID

Interviewer's name

1. Introduction

- Introduce study: I will ask you a number of questions about your views and experiences but please feel free to tell me anything you want me to know. Don't feel that you have to limit what you want to say because of what I ask.
- Clarify the objective of the interview: to explore the last year of life of ESRD older patients managed without dialysis from the perspective of bereaved relatives, focusing on symptoms, symptom control, access to health and social services, information about the illness, and circumstances surrounding death.
- Obtain/ verify consent

2. Background information

The following questions are to help the interviewer:

- The interviewees' views of experiences and health care needs during the last year of life of older people with ESRD managed without dialysis in Thailand
- Relationship to the patient

3. *The perspectives of bereaved relatives on ESRD patient managed without dialysis*

Moving on to thinking about their experiences of ESRD patient managed without dialysis

- How did the patient decide to manage without dialysis?
- How did the patient feel during managed without dialysis?
- How the treatment decision will be made?
 - Who helped the patient make the decision?
 - What was the reason/information that the patients used to make the decision? Why?
- What factors affected the decision in managing without dialysis?
 - Personal factors: (e.g. patient or family's burden)
 - Socioeconomic factors: (e.g. doctors, nurses, family circumstances, support network/caring system and economic/financial circumstances)
- What is the main concern of the patients after being management without dialysis?
 - How?

4. *Symptoms and symptom control*

- How did patient feel about his/her health during the period of being managed without dialysis?

- Did patient suffer from symptoms or complications which relate to management without dialysis such as pain? (How?)
- What symptoms did they experience?
- What type of symptoms caused the most suffering to the patient, especially when the patient was close to death? and How?
- How did this suffering affect patient? Please describe the following:
 - Physical aspects
 - Emotional aspects
 - Spiritual aspects
 - Social aspects
 - Financial aspects

5. Access to health and social services, information about the illness, and circumstances surrounding death.

- What information was the patient provided with about the treatment by health care professionals?
 - How did the patient find that information?
 - Had the patient found that information by himself/herself? How?
 - Had the patient found the information from anyone else? How?
- Did the patient receive any support/treatment during the period of being managed without dialysis by health care professionals? -
 - If no why not?
 - If yes what type of care did the patient receive during managed without dialysis?
- What type of care did patient receive toward the end of life?

-If none why not?

-If yes what special care (pain and symptom management, relief and anticipation of symptoms, comfort care, spiritual or religious support, end of life care, and bereavement care) had been provided to the patient toward the end of their life?

- What else can health care professional do to make it better/easier for the patient to access care when being managed without dialysis during the last year of his/her life?

Many thanks for your time in answering these questions. Your information is valuable to us. Before we finish is there anything else you would like to add? Anything that I've not asked but you think I should have?

Again thank you very much.

APPENDIX L: Guideline for conducting the cognitive interview

Guideline for conducting the cognitive interview



Date: ___/___/___ Setting___ Study ID
Interviewer's name

Part 1: Principles for researcher conducting the cognitive interview

Aims

Comprehension of the question

Question intent- What does the respondent believe the question to be asking?

Meaning of terms- What do specific words and phrases in the question mean to the respondent?

Retrieval of relevant information from memory

Recalling of the information- What types of information does the respondent need to recall in order to answer the question?

Recall strategy- What type of strategies are used to recall the information? For example, does the respondent tend to recount events by recalling each one individually, or does she/he use an estimation strategy?

Decision processes

Social desirability- Does the respondents want to tell the truth? Does she say something that might make his/her look better?

Response process

Mapping the response- Can the respondent match his/her internally generated answer to the response categories given by the survey question?

Part 2: Interview Schedule for using with the cognitive interview

Schedule

The researcher will help the respondent to practise the 'think aloud' technique by using the some following questions for example:

"Try to visualise the place where you live, and think about how many windows there are in that place. As you count up the windows, tell me what you are seeing and thinking about."

Introduction

The researcher will explain to the respondent that a cognitive interview is a type of interviewing technique in which respondents are asked to read and think about their understanding of the questions in the questionnaire, so that researcher will be able to further develop the questionnaire.

Responding to the questionnaire:

Researcher to read aloud each question in turn and ask respondent to answer using the 'think aloud' technique (the answer can then be analysed in terms of how it fits with the Aims).

Researcher will provide some probes for each question:

1. Can you repeat the question in your own words?
2. What, to you, is a "GP/ Nephrologist/ out-of-hours care/ Accident and Emergency Department/ Renal Nurse Specialist/?" Or, what, to you, is meant by "dignity and respect/ help and support/ religious or spiritual care?"
3. How sure are you that your relative got that type of service?
4. How did you get to that answer?
5. How well do you remember this?
6. How hard was this to answer?
7. Why do you believe this?

Part 3: The Cognitive Interview Testing Protocol

A: Instructions for cognitive interviewer

1. Review the questionnaire to make sure the researcher can “get through it” and to determine probes to ask.
2. To start the interview, the researcher will read the **instructions to subject** either verbatim or paraphrased.
3. When the researcher starts, make sure to enter the **start time**.
4. Make sure the subject isn’t reading the questionnaire as the researcher administer it (i.e., make sure the subject is only listening).
5. Go for up to one hour. If the researcher doesn’t get done, just mark where the researcher ended. If something is difficult to administer or the researcher can’t figure out exactly how to read a question, make a comment to the effect that this is a problem, and ask the subject what is the best that the researcher can do.
6. Use the suggested probes that are written in and other probes the researcher can think of. Don’t feel that the researcher needs to probe every question extensively.
7. Enter comments, under each question, about problems or issues that come up. Try to make the subjects readable because (they are data for the project).
8. When the researcher finished the interview, enter the **end time**.
9. Look back over the questionnaire and other comments as appropriate.
10. Save each commented protocol so that later the researcher can pool these into one version that covers all interviews which the researcher conducts.

B: Instructions to be read to subject

Notes to Interviewer

(A) Either read the instructions in their entirety or paraphrase them (but make sure to include elements 1-7).

(B) Note that this form is set up to be administered after subjects have signed the **Consent Form**.

Thanks for coming in, Let me tell you a little more about what we will doing today.

1. We are testing a new questionnaire with the help of people such as yourself.
2. I will ask you question and you answer them, just like a regular survey.

3. However, our goal here is to get a better idea of how the questions are working. So, I would like you to **think aloud** as you answer the questions-just tell me everything you are thinking about as you go about answering them.
4. At times, I will also stop and ask you more questions about the terms or phrases in the questions and what you think a question is asking about. I will also take notes.
5. Please keep in mind that I really want to hear all of your opinions and reactions. Don't hesitate to speak up whenever something seems unclear, is hard to answer, or doesn't seem to apply to you.
6. Finally, we will do this for an hour, unless I run out of things to ask you before then.
7. Do you have any questions before we start?

Optional Think-Aloud Practice

Let's begin with a couple of practice question. Remember to try to think aloud as you answer.

Practice question 1: How many times are the patient go to the hospital during the last three months?

(Probe as necessary): How did you come up with that answer?

Practice question 2: How difficult was it for the patient to go to the hospital each time: very difficult, somewhat difficult, a little difficult, or not at all difficult?

(Probe as necessary): Tell me more about that. Why do you say (answer)?

OK, now let's turn to the questions that we are testing.

Part 4: Sample cognitive interviewing protocol

Date.....Interview No.....Interviewer initials.....

Enter start time of interview:.....

VOICES-ESRD/THAI

Views of Informal Carers-Evaluation of Services

Note for interviewer (not to be read to subjects): This questionnaire asks to obtain the data about the care and services provided in the last months of life to people with ESRD and their family and friends. (It is one component of the research on the experiences and health care needs of older people with ESRD who managed without dialysis in Thailand during the last year of life.)

1. How long had the she/ he been ill before she/he died?

Tick one only

- She/he was not ill-she/he died suddenly
- Less than 24 hours
- One day or more, but less than one week
- One week or more, but less than one month
- One month or more, but less than three months
- Three months or more, but less than six months
- Six months or more, but less than one year
- One year or more

Probe:

In your own words, what is this question asking?

How did you arrive at your answer?

What time period are you thinking of?

Enter interview

Notes:.....

.....

.....
.....
.....

2. Did she/he spend any time at home during the last three months of life?

Tick one only

- Yes- go to Q 3
- No go to Q 30

Probe:

In your own words, what is this question asking?

How did you arrive at your answer?

What does the term “the last three months of life” mean to you in this question?

What time period are you thinking of?

Enter interview

Notes:.....
.....
.....
.....
.....

Section 1: Help at home

1. When she/he was at home in the last three months of life, did she get any help at home from any of the services listed below?

- A district or community nurse
- Renal nurse specialist
- Community health volunteer
- Social worker/support worker
- Counsellor
- Religious leader
- Occupational therapist (OT)

- Rapid response team (a team of nurses and home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)
- She did not receive any care
- Don't know
- Something else-please write in the space below:

.....

.....

.....

.....

Probe:

In your own words, what is this question asking?

How did you arrive at your answer?

What does the term "help at home" mean to you in this question?

How many types of services are you thinking of?

Enter interview

Notes:.....

.....

.....

.....

.....

.....

2. When she/he was at home in the last three months of life, did all these services work well together?

Tick one only

- Yes, definitely
- Yes, to some extent
- No, they did not work well together
- She did not receive any care
- Don't know

Please feel free to make comments in the space below:

.....

.....

.....
.....

Probe:

In your own words, what is this question asking?
How did you arrive at your answer?
What does the term “work well together” mean to you in this question?
How sure are you of your answer?

Enter interview

Notes:.....
.....
.....
.....
.....

3. Did he/her have any special equipment to help him, or those looking after him? (for example, oxygen support, wheelchair etc.)

Yes.....No.....Don't know.....

If Yes:

a) Please state what equipment he had

.....
.....

Probe:

In your own words, what is this question asking?
How did you arrive at your answer?
What does the term “special equipment” mean to you in this question?
How sure are you of your answer?

Enter interview

Notes:.....
.....

.....
.....
.....

4. Would it have helped to have had other special equipment?

At least one a week.....

At least once a month, but not every week.....

Less than once a month.....

If No (he did not have any special equipment):

c) Would it have helped to have had some of this type of equipment?

Yes.....

No.....

Probe:

In your own words, what is this question asking?

How did you arrive at your answer?

How sure are you of your answer?

Enter interview

Notes:.....
.....
.....
.....
.....
.....

5. Did he/she get help from family and friends (including yourself) with any of the following? (please tick one box for each type of help he got

Yes.....No.....Don't know.....

Personal care (e.g. bathing dressing).....

Household tasks (e.g. shopping, cleaning).....

Night time care.....

Taking of medicines.....

If you answer YES in question 5:

a) How much time did family and friend (including yourself) spend on these tasks?

- Less than 5 hours per week.....
- 5-10 hours per week.....
- 11-19 hours per week.....
- 20-39 hours per week.....
- 40 or more hours per week.....

Probe:

- In your own words, what is this question asking?
- How did you arrive at your answer?
- What types of care are you think of?
- How many hours you spend for each task?
- How many hours you spend per week?
- How did you decide how many hours should be reported per week?
- How sure are you of your answer?

Enter interview

Notes:.....

6. Did you get help from health services with any of the following? (please tick one box for each type of help he got)

Yes.....No.....Don't know.....

- Personal care (e.g. bathing dressing).....
- Household tasks (e.g. shopping, cleaning).....
- Night time care.....
- Taking of medicines.....

If you answer YES in question 6:

a) How often did he or you get help from the health services?

- At least one a day.....
- At least one a week.....

At least once a month, but not every week.....

Less than once a month.....

Probe:

In your own words, what is this question asking?

What does the term “health services” mean to you in this question?

What types of helping from health services are you think of?

How did you decide how many times are you get help from health services?

How sure are you of your answer?

Enter interview

Notes:.....
.....
.....
.....

7. Overall, do you feel that you and your family got as much help and support from health services as you needed when caring for her/him?

- Yes, we got as much support as we wanted
- Yes, we got some support but not as much as we wanted
- No, although we tried to get more help
- No, but we did not ask for more help
- We did not need help

Please feel free to make comments in the space below:

.....
.....
.....
.....

Probe:

In your own words, what is this question asking?

How did you arrive at your answer?

How sure are you of your answer?

Enter interview

Notes:.....
.....
.....
.....
.....

If you would like to, please add any comments about your experiences of caring for him

.....
.....
.....
.....
.....

Until finish at Question 61

Enter end time of interview:.....

Notes:

1. This instruction is appropriate for interviewer-administered questionnaires.
2. This form is set up to be administered after appropriate consent form has been signed.
3. This instruction assumes a one-hour interview. However, it is sometimes useful to repeat the agreed-upon duration of participation to head off any subject tendency to “speed up” the interview based on the expectation that the researcher need to accomplish a certain amount. The researcher wants the subjects to be thoughtful and certainly don’t want them to hurry their answer.
4. This cognitive interview testing protocol is applied from the cognitive interview protocol of Willis (2005, pp. 273-286).
5. Question objectives are developed and provided separately (Appendix P) to give the interviewer a summary of the intent of the questions. These are notes, and are not to be read to subjects.

APPENDIX M: Details of specific question notification whist developing the VOICES-ESRD/Thai questionnaire

Section 1: Information about the informant

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –SF Q 53 What was your relationship to her/him?</p> <p>Were you her/him: Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> Husband/Partner <input type="radio"/> Son/Daughter <input type="radio"/> Brother/Sister <input type="radio"/> Son-in-law/Daughter-in-law <input type="radio"/> Parent <input type="radio"/> Other relative <input type="radio"/> Friend <input type="radio"/> Neighbour <input type="radio"/> Staff in care home <input type="radio"/> Warden (sheltered accommodation) <input type="radio"/> Other official <input type="radio"/> Someone else <p>VOICES –SF:Q .54 What is your age? Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> 18-19 <input type="radio"/> 20-29 <input type="radio"/> 30-39 <input type="radio"/> 40-49 <input type="radio"/> 50-59 <input type="radio"/> 60-69 <input type="radio"/> 70-79 <input type="radio"/> 80-89 <input type="radio"/> 90+ 	<p>This question remained the same as the VOICES-SF. Little is changed according to the result of the demographic characteristic of the informants from the first phase of the study and the different types of caregivers in Thailand. The most direct and indirect carers who take care of ESRD older patients are the patients' relatives. A close friend, neighbour and someone else might be found but are quite rare in Thailand. However, the patients do not have staff in care homes, warden or other official for taking care of them.</p> <p>Therefore, this question the researcher deleted few choices including <i>Staff in care home, Warden (sheltered accommodation), Other official</i></p> <p>This question remained the same as the VOICES-SF. Even though, the result of the demographic characteristic of the informants from the first phase of the study showed that the age of the informant is divided into 4 levels including 30-39, 40-49, 50-59 and 60-69.</p> <p>The research thinks that it will be better to have more levels of the age of the informant as the VOICES-ESRD/Thai might be applied to use in difference areas or settings. This is also to help researchers get more subjects and understand different point of views according to the different</p>	<p>Q 1 What was your relationship to her/him?</p> <p>Were you her/his: Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> Husband/Partner <input type="radio"/> Son/Daughter <input type="radio"/> Brother/Sister <input type="radio"/> Son-in-law/Daughter-in-law <input type="radio"/> Parent <input type="radio"/> Other relative <input type="radio"/> Friend <input type="radio"/> Neighbour <input type="radio"/> Someone else <p>Q 2 What is your age? Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> 18-19 <input type="radio"/> 20-29 <input type="radio"/> 30-39 <input type="radio"/> 40-49 <input type="radio"/> 50-59 <input type="radio"/> 60-69 <input type="radio"/> 70-79 <input type="radio"/> 80-89 <input type="radio"/> 90+ 	<p>To ask about the relationship between carer and the patient.</p> <p>To know the age of informants.</p>

of age of the informants.			
VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
VOICES –SF: Q 55 Are you <ul style="list-style-type: none"> ○ Male ○ Female 	This question remained the same as the VOICES-SF.	Q 3 Are you <ul style="list-style-type: none"> ○ Male ○ Female 	To know the carers' gender.
VOICES –SF: Q 59 What are your religion? <ul style="list-style-type: none"> ○ No religion ○ Buddhist ○ Muslim ○ Christian Any other religion-please write in the space below:.....	This question remained the same as the VOICES-SF.	Q 4 What are your religion? <ul style="list-style-type: none"> ○ No religion ○ Buddhist ○ Muslim ○ Christian Any other religion-please write in the space below:.....	To know the carers' religion.

Section 2 Information about the deceased

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –SF: Q .58 What was her/his age when she/he died? Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> 18-19 <input type="radio"/> 20-29 <input type="radio"/> 30-39 <input type="radio"/> 40-49 <input type="radio"/> 50-59 <input type="radio"/> 60-69 <input type="radio"/> 70-79 <input type="radio"/> 80-89 90+ 	<p>This question is remained the same as the VOICES-SF. The researcher deleted some choices.</p> <p>The result of the demographic characteristic of the deceased from the first phase of the study showed that the age of the deceased is divided into 4 levels including 60-65, 66-70, 71-75 and 75+</p> <p>Moreover this research is focusing on ESRD older patients who managed without dialysis at home.</p> <p>Therefore the age of the deceased should be started and related to the age of the patient group</p>	<p>Q 5 What was her/his age when she/he died? Tick one only</p> <ul style="list-style-type: none"> <input type="radio"/> 50-59 <input type="radio"/> 60-69 <input type="radio"/> 70-79 <input type="radio"/> 80-89 <input type="radio"/> 90+ 	<p>To age of patients.</p>
<p>VOICES –SF: Q 59 What was her/his religion?</p> <ul style="list-style-type: none"> <input type="radio"/> No religion <input type="radio"/> Buddhist <input type="radio"/> Muslim <input type="radio"/> Christian <p>Any other religion-please write in the space below:.....</p>	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 6 What was her/his religion</p> <ul style="list-style-type: none"> <input type="radio"/> No religion <input type="radio"/> Buddhist <input type="radio"/> Muslim <input type="radio"/> Christian <p>Any other religion-please write in the space below:.....</p>	<p>To know the patients' religion.</p>

Section 3: Help at home/ Care at Home *(These questions ask about care at home-not in a care home)*

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES -SF: Q 1 How long had she been ill before she died?</p> <p><i>Tick one only</i></p> <ul style="list-style-type: none"> • She/he was not ill-she/he died suddenly • Less than 24 hours • One day or more, but less than one week • One week or more, but less than one month • One month or more, but less than three months • Six months or more, but less than one year • One year or more 	<p>1. This question is chosen and changed as the VOICE-SF was developed and used separately between the sex (female or male) of the deceased.</p> <p>But, the adapted VOICES mainly planned to focus on the ageing population not mainly focus on the sex of the deceased. Therefore the word</p> <p>- “She” changed to “She/he”</p> <p>2. The number of choices is changed. According to the results of demographic characteristic of the deceased in the phase I of the study showed that the duration of being managing without dialysis was divided in to 6 levels including 1 month, 3 months , 6 months, 12 months, 24 months and 36 months</p>	<p>Q 7 How long had she/he been ill before she/he died?</p> <p><i>Tick one only</i></p> <ul style="list-style-type: none"> • One week or more, but less than one month • One month or more, but less than three months • Three months or more, but less than six months • Six months or more, but less than one year • One year or more, but less than two years • Two years or more 	<p>To know about the duration of managing without dialysis before she/he died.</p>
<p>VOICES -SF: Q 2. Did she spend any time at home during the last three months of life? <i>Tick one only</i></p> <ul style="list-style-type: none"> • Yes- go to Q 3 • She was in a care home for the whole 3 months - go to Q 12 	<p>This question remained the same as the VOICES-SF. The reason to ask about the last three months is related to the normal definition of the duration at the end of the patients’ life which the duration should not be</p>	<p>Q 8. Did she/he spend any time at home during the last three months of life? <i>Tick one only</i></p> <ul style="list-style-type: none"> • Yes- go to Q 9 • She was in a care home for the whole 3 months - go to Q 53 	<p>To know where/place to live during the last three months of patients’ life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> No go to Q 24 	<p>longer than three months.</p> <p>Word "she" is changed to "she/he" (same reason with Q 1)</p>	<ul style="list-style-type: none"> No go to Q 30 	
<p>VOICES -SF: Q 3. When she was at home in the last three months of life, did she get any help at home from any of the services listed below? <i>Tick all that apply</i></p> <p>(These may be provided by different organisations such voluntary organisations, a private agency or social services)</p> <ul style="list-style-type: none"> A district or community nurse (a nurse in uniform who comes to the house) A Macmillan nurse, hospice home care nurse or specialist (a palliative care nurse who visit or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform) A Marie Curie nurse(someone who comes to the house for a few hours or overnight to care for the patient) Any other nurse at home Home care worker, home care aide or home help Social worker/support worker Counsellor Religious leader Meal-on-wheel or other home delivered meals Hospice at home Occupational therapist (OT) Rapid response team (a team of nurses and 	<p>The question is designed to delete and add some choices regarding to the types of health services which relevant with health services in Thailand.</p> <p>Choices' are removed;</p> <ul style="list-style-type: none"> A Macmillan nurse, hospice home care nurse or specialist (a palliative care nurse who visit or telephones to talk and advise on medications and other aspects of care. They do not wear a uniform). A Marie Curie nurse(someone who comes to the house for a few hours or overnight to care for the patient). Any other nurse at home Home care worker, home care aide or home help Meal-on-wheel or other home delivered meals Hospice at home <p>Choices' are added;</p> <ul style="list-style-type: none"> Renal nurse specialist (from the renal unit of the government provincial 	<p>Q 9. When she/he was at home in the last three months of life, did she/he get any help at home from any of the services listed below?</p> <p>These may be provided by different organisations such voluntary organisations, a private agency or social services</p> <p><i>Tick all that apply</i></p> <ul style="list-style-type: none"> A district or community nurse (a nurse in uniform who comes to the house) this is incorrect in Thailand. Renal nurse specialist (from the renal unit of the government provincial hospital or private hospital) Community health volunteer Social worker/support worker Counsellor Religious leader Occupational therapist (OT) Narentorn Life - Rescue Team She did not receive any care Don't know Something else-please write in the space below: 	<p>To find out services or types of helping at home that the patient received during the last three months.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>home care workers who provide care over the short term to allow someone to remain at home and prevent hospital admission)</p> <ul style="list-style-type: none"> • She did not receive any care • Don't know • Something else-please write in the space below:..... 	<p>hospital or private hospital)</p> <ul style="list-style-type: none"> • Community health volunteer • Narentorn Life – Rescue Team <p>Word “she” is changed to “she/he” (same reason with Q 1)</p>		
<p>VOICES –SF: Q 4 When she was at home in the last three months of life, did all these services work well together?</p> <p><i>Tick one only</i></p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, they did not work well together • She did not receive any care • Don't know • Please feel free to make comments in the space below:..... 	<p>This question remained the same as the VOICES-SF. The reason to ask about the last three months is related to the normal definition term of the duration at the end of the patients' life.</p> <p>Word “she” is changed to “she/he” (same reason with Q 1)</p>	<p>Q 10 When she/he was at home in the last three months of life, did all these services work well together?</p> <p><i>Tick one only</i></p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, they did not work well together • She did not receive any care • Don't know • Please feel free to make comments in the space below:..... 	<p>To evaluate the co-ordination of health services which patients received during the last three months of their life.</p>
<p>VOICES version of COPD: Q 4 Did he has any special equipment to help him, or those looking after him? (for example, oxygen support, wheelchair etc.)</p> <p>Yes.....No.....Don't know.....</p> <p>If Yes:</p> <p>a) Please state what equipment she/he had</p> <p>b) Would it have helped to have had other special equipment?</p>	<p>This question is added. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The health care needs and utilization theme, especially in the aspect of home visiting (home oxygen support), showed that the special medical equipment supporting at home is now lacking</p>	<p>Q.11 Did she/he have any special equipment to help him, or those looking after him? (for example, oxygen support, wheelchair etc.)</p> <p>Yes.....No.....Don't know.....</p> <p>If Yes:</p> <p>a) Please state what equipment she/he had</p> <p>.....</p>	<p>To evaluate about special medical equipment support at home.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>Very easy..... Quite easy..... Quite difficult..... Very difficult.....</p> <p>If NO (he did not have any special equipment): c) Would it have helped to have had some of this type of equipment?</p> <p>Yes..... No.....</p>	<p>and mainly required by the patients.</p> <p>The VOICES-SF does not have this question. Therefore, the research tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail remained the same as the VOICES version of COPD</p>	<p>Q 12 Would it have helped to have had other special equipment?</p> <p>Very easy..... Quite easy..... Quite difficult..... Very difficult..... If NO (she/he did not have any special equipment):</p> <p>a) Was any equipment needed that she didn't have? </p> <p>b) Would it have helped to have had some of this type of equipment?</p> <p>Very easy..... Quite easy..... Quite difficult..... Very difficult.....</p>	
<p>VOICES version of COPD: Q 5 Did he get help from family and friends (including yourself) with any of the following? (please tick one box for each type of help he got</p> <p style="text-align: center;">Yes...No...Don't know...</p> <p>Personal care (e.g. bathing dressing)..... Household tasks (e.g. shopping, cleaning).... Night time care..... Taking of medicines.....</p>	<p>This question is added. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, who managed without dialysis, in Thailand.</p> <p>The physical impact theme (dependency), showed that the patients depended on their carers for supporting on activities of daily living</p>	<p>Q 13 Did she/he get help from family and friends (including yourself) with any of the following? (please tick one box for each type of help he got</p> <p style="text-align: center;">Yes...No...Don't know...</p> <p>-Personal care (e.g. bathing dressing)..... -Household tasks (e.g. shopping, cleaning) -Night time care..... -Taking of medicines.....</p>	<p>To know about how often patient had to depend on their carer at home and to know how much the burden of the carers.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>If you answer YES in question 5:</p> <p>b) How much time did family and friend (including yourself) spend on these tasks?</p> <p>Less than 5 hours per week.....</p> <p>5-10 hours per week.....</p> <p>11-19 hours per week.....</p> <p>20-39 hours per week.....</p> <p>40 or more hours per week.....</p>	<p>at home. This questionnaire is used to show how often the dependency of the patients on their carers and how much the burden of the carers.</p> <p>The questionnaire's detail remained the same as the VOICES version of COPD</p>	<p>If you answer YES in question 13:</p> <p>a) How much time did family and friend (including yourself) spend on these tasks?</p> <p>Less than 5 hours per week.....</p> <p>5-10 hours per week.....</p> <p>11-19 hours per week.....</p> <p>20-39 hours per week.....</p> <p>40 or more hours per week.....</p>	
<p>VOICES version of COPD: Q 6 Did you get help from health services with any of the following? (please tick one box for each type of help he got)</p> <p>Yes.....No.....Don't know.....</p> <p>- Personal care (e.g. bathing dressing).....</p> <p>- Household tasks (e.g. shopping, cleaning).....</p> <p>- Night time care.....</p> <p>- Taking of medicines.....</p> <p>If you answer YES in question 6:</p> <p>a) How often did he or you get help from the health services?</p> <p>At least one a day.....</p> <p>At least one a week.....</p> <p>At least once a month, but not every week.....</p> <p>Less than once a month.....</p>	<p>This question is added. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand.</p> <p>The health care needs and utilization theme, especially in the aspects of health service provision (support at the end of life) and home visiting (need for regular home visiting), are showed that the carers need support from health care professional at home and their also need regular home visiting.</p> <p>The questionnaire's detail remained the same as the VOICES version of COPD</p>	<p>Q 14. Did you get help from health services with any of the following? (please tick one box for each type of help she/ he got)</p> <p>Yes.....No.....Don't know.....</p> <p>- Personal care (e.g. bathing dressing).....</p> <p>- Household tasks (e.g. shopping, cleaning)...</p> <p>- Night time care.....</p> <p>- Taking of medicines.....</p> <p>If you answer YES in question 14:</p> <p>a) How often did he or you get help from the health services?</p> <p>At least one a day.....</p> <p>At least one a week.....</p> <p>At least once a month, but not every</p>	<p>To know about health services for supporting carers on providing care to their patients.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES -SF: Q 6 Overall, do you feel that you and your family got as much help and support from health and social services as you needed when caring for her/him?</p> <ul style="list-style-type: none"> • Yes, we got as much support as we wanted • Yes, we got some support but not as much as we wanted • No, although we tried to get more help • No, but we did not ask for more help • We did not need help • Please feel free to make comments in the space below:..... 	<p>This question remained the same as the VOICES-SF. Little is changed according to definition of health services in Thailand which means the health care providers who provide care and support for the patients at home. This is different from health and social services in UK.</p> <p>Therefore, the researcher changed from</p> <p><i>Word "health and social services" is changed to "health services"</i></p>	<p>week..... Less than once a month.....</p> <p>Q 15 Overall, do you feel that you and your family got as much help and support from health services as you needed when caring for her/him?</p> <ul style="list-style-type: none"> • Yes, we got as much support as we wanted • Yes, we got some support but not as much as we wanted • No, although we tried to get more help • No, but we did not ask for more help • We did not need help • Please feel free to make comments in the space below:..... 	<p>To evaluate overall health services of ESRD older people management without dialysis at home at the last three months in Thailand.</p>

Section 4: Urgent Care Provided (out of hours and in the week during office hours)

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –SF: Q 7 In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent in the evening or at the weekend? Tick one only</p> <p>Not at all in the last 3 months..... Yes please tick one only Once or twice..... Three or four time..... Five times or more..... Don't know.....</p>	<p>This question is remained as same as the VOICES-SF.</p>	<p>Q10 In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent in the evening or at the weekend? Tick one only</p> <p>Not at all in the last 3 months..... Yes please tick one only Once or twice..... Three or four time..... Five times or more..... Don't know.....</p>	<p>To know the frequency of contacting for receiving the urgent care.</p>
<p>VOICES –SF: Q 8 The last time this happened, who did she/he contact, or who was contacted on her behalf? Tick all that apply</p> <p>Her/his GP or the out-of –hours number NHS Direct District nurses Macmillan nurses She used her 'lifeline' pendent A hospice 999 Something else-please write in the space below:.....</p>	<p>The question remained the same as the question in VOICES-SF. It is designed to delete and add some choices regarding the types of health services which are relevant to health services in Thailand.</p> <p>Choices' are removed; NHS Direct Macmillan nurses She used her 'lifeline' pendent A hospice 999 Choices' are added; Provincial nurses Community nurses Community health volunteer</p>	<p>Q 11 The last time this happened, who did she/he contact, or who was contacted on her behalf? Tick all that apply</p> <p>Her/his GP or the out-of –hours number Provincial nurses District nurses Community nurses Community health volunteer Something else-please write in the space below:.....</p>	<p>To know who was the health care professional that provided the urgent care?</p>
<p>VOICES –SF: Q 9 What happened as a</p>	<p>The question is remained as same as the question in VOICES-SF but it is</p>	<p>Q 18/ 23 What happened as a result? Was</p>	<p>To know what kind of health service</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>result? Was she/he...</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Visited by her GP at home • Visited by another GP at home • Visited by a nurse at home • Visited by a hospice doctor at home • Given medical advice over the telephone • Given another number to ring to get medical advice • Advised to go to an out-of-hours GP surgery • Advised to go to the GP surgery when it opened • Advised to go to an Accident and Emergency department at a hospital • Advised to call 999 • Something else-please write in the space below:..... 	<p>designed to delete and add some choices regarding to the types of health services which relevant with health services in Thailand.</p> <p>Choices' are removed;</p> <ul style="list-style-type: none"> • Visited by a hospice doctor at home • Advised to go to an out-of-hours GP surgery • Advised to go to the GP surgery when it opened • Advised to call 999 <p>Choices' are added;</p> <ul style="list-style-type: none"> • Visited by district nurse at home • Visited by provincial nurse at home • Visited by district doctor or general physician at home • Advised to go to the renal unit at a hospital • Advised to go to the community health services • Advice to go to private clinic 	<p>she/he...</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Visited by district nurse at home • Visited by provincial nurse at home • Visited by district doctor or general physician at home • Given medical advice over the telephone • Given another number to ring to get medical advice • Advised to go to the Emergency department at a hospital • Advised to go to the renal unit at a hospital • Advised to go to the community health services • Advice to go to private clinic • Something else-please write in the space below:..... <p>NB: In VOICES-ESRD, the question 23 will be asked as same as question 18</p>	<p>that the patient received during the urgent care.</p>
<p>Q 10. In your opinion, was this the right thing for them to do, or not? Tick one only</p> <ul style="list-style-type: none"> • Yes • No..... 	<p>The question remained the same as the question in VOICES-SF.</p> <p>In VOICES-ESRD, the question 24 will be asked as same as question 19</p>	<p>Q 19/ 24 In your opinion, was this the right thing for them to do, or not? Tick one only</p> <ul style="list-style-type: none"> • Yes • No..... 	<p>To assess the carer perspective on receiving the urgent care.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Not sure..... <p>Q 11.Overall, do you feel that the care she/he got when she needed care urgently in the evening or weekends in the last three months of life was:</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Excellent • Good • Fair • Poor • Don't know 	<p>The question remained the same as the question in VOICES-SF.</p> <p>In VOICES-ESRD, the question 25 will be asked as same as question 20 but the researcher changed from “the evening or at the weekend” to “during office hours”</p>	<ul style="list-style-type: none"> • Not sure.....; <p>Q 20./ 25 Overall, do you feel that the care she/he got when she needed care urgently in the evening or weekends in the last three months of life was:</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Excellent • Good • Fair • Poor • Don't know 	<p>To evaluate the effectiveness of health services of urgent care.</p>

Section 5: Symptom experiences and treatment

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES version of COPD:</p> <p>Q 7 Was she/he breathless?</p> <p>Yes, all the times</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did he/she receive any treatment for his/her breathlessness? Yes...No...Don't know...</p> <p>b) Did the treatment help her/his breathlessness? Yes.....No.....Don't know.....</p> <p>c) Did she/he have a cough?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know 	<p>This question is changed. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The symptoms experiences, especially physical symptoms, were reported from the qualitative data (phase I) that breathlessness impacted on ESRD older patients who managed without dialysis at home as they had a lot of suffering and received negative impacts. Breathlessness developed physical weakness and sleep disturbance.</p> <p>The VOICES-SF does not have the question related to breathlessness. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage from the qualitative finding in the phase I of the study and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p>	<p>Physical symptoms</p> <p>Breathlessness</p> <p>Q 26. Was she/he breathless?</p> <p style="color: red;">Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for his/her breathlessness? Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help his/her</p>	<p>To evaluate the severity of breathlessness, the effectiveness of the treatment and the impact of breathlessness on daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • d) Did she/he have weakness or fatigue? <ul style="list-style-type: none"> • Yes, all the time • Yes, sometimes • Yes, rarely • Not at all • Don't know e) Did she/he lose his appetite? <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know f) Did she/he find it hard to sleep at night because she was breathlessness? <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know 	<p>The researcher added the duration of symptoms and divided it into 2 categories including in the last 3-12 months and less than 3 months.</p>	<p>breathlessness? Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>c) Did she/he have physical weakness because she/he was breathlessness? Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>d) Did she/he find it hard to sleep at night because she/he was breathlessness? Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p>	

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
		Not at all Don't know....	
<p>7 VOICES version of COPD:</p> <p>Q 7 Was she/he breathless?</p> <p>Yes, all the times</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for his/her breathlessness?</p> <p>Yes.....No.....Don't know.....</p> <p>b) Did the treatment help her/his breathlessness?</p> <p>Yes.....No.....Don't know.....</p> <p>c) Did she/he have a cough?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes 	<p>This question is changed. The reason is based on the literature review and previous research of the symptom experiences of people with ESRD, managed without dialysis, The symptoms experiences, especially of the ESRD patients managed without dialysis were reported from the studies of Murtagh et al (2007, 2009) and Noble et al (2010) that pruritus/itching impacted on ESRD older patients who managed without dialysis at home as they had a lot of suffering and received negative consequences.</p> <p>The VOICES-SF does not have this question. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage between the qualitative finding from the phase I of the study and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p>	<p>Q 27. Did she/he suffer with pruritus/itching?</p> <p>Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she receive any treatment for her/his pruritus/itching?</p> <p>Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help her/his pruritus/itching?</p>	<p>To evaluate the severity of pruritus/itching, the effectiveness of the treatment and the impact of pruritus/itching on daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Yes, rarely • Not at all • Don't know <p>d) Did she/he has weakness or fatigue?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>e) Did she/he lose his appetite?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>f) Did she/he find it hard to sleep at night because she was breathlessness?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know 	<p>The researcher added the duration of symptoms and divided it into 2 categories including in the last 3-12 months and less than 3 months.</p>	<p>Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	
<p>7 VOICES version of COPD:</p> <p>Q 7 Was she/he breathless?</p> <p>Yes, all the times Yes, sometimes Yes, rarely Not at all Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes,</p>	<p>This question is changed. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The symptoms experiences, especially physical symptoms, were reported from the qualitative data (phase I) that</p>	<p>Q 28. Did she/he suffer with pain?</p> <p>Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p>	<p>To evaluate the severity of pain, the effectiveness of the treatment and the impact of pain on daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for her/his breathlessness? Yes.....No.....Don't know.....</p> <p>b) Did the treatment help her/his breathlessness? Yes.....No.....Don't know.....</p> <p>c) Did she/he have a cough?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>d) Did she/he has weakness or fatigue?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>e) Did she/he lose his appetite?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>f) Did she/he find it hard to sleep at night because she was breathlessness?</p>	<p>pain impacted on ESRD older patients who managed without dialysis at home as they had a lot of suffering and received negative consequences.</p> <p>The VOICES-SF does not have this question. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage between the qualitative finding from the phase I of the study and the VOICES-ESRD and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p> <p>The researcher added the duration of symptoms and divided it into 2 categories including in the last 3-12 months and less than 3 months.</p>	<p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/ he receive any treatment for her/his pain? Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help her/his pain? Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know 			
<p>VOICES version of COPD:</p> <p>Q 7 Was she/he breathless?</p> <p>Yes, all the times Yes, sometimes Yes, rarely Not at all Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for his/her breathlessness? Yes.....No.....Don't know.....</p> <p>b) Did the treatment help her/his breathlessness? Yes.....No.....Don't know.....</p> <p>c) Did she/he have a cough?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>d) Did she/he has weakness or fatigue?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes 	<p>This question is changed. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The symptoms experiences theme, especially physical symptoms, were reported from the qualitative data (phase I) that oedema/ swallowing impacted on ESRD older patients who managed without dialysis at home as they had a lot of suffering and received negative consequences.</p> <p>The VOICES-SF does not have this question. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage between the qualitative finding from the phase I of the study and the VOICES-ESRD and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p>	<p>Q 29 Did she/ he have oedema/ swallowing?</p> <p style="text-align: center;">Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for his/her oedema/ swallowing? Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help her/his oedema/</p>	<p>To evaluate the severity of oedema/ swallowing, the effectiveness of the treatment and the impact of oedema/ swallowing on daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Yes, rarely • Not at all • Don't know <p>e) Did she/he lose his appetite?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know <p>f) Did she/he find it hard to sleep at night because she was breathlessness?</p> <ul style="list-style-type: none"> • Yes, all the times • Yes, sometimes • Yes, rarely • Not at all • Don't know 	<p>The researcher added the duration of symptoms and divided it into 2 categories including in the last 3-12 months and less than 3 months.</p>	<p>swallowing? Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	
<p>VOICES version of COPD:</p> <p>Q 12 Did she/he suffer with low mood?</p> <p>Yes, all the times Yes, sometimes Yes, rarely Not at all Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for</p>	<p>This question is changed. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis in Thailand. The symptoms experiences themes, especially psychological symptoms, were reported from the qualitative data (phase I) that anxiety/ worry impacted on ESRD older patients who managed without dialysis at home as they were unable to control their emotions.</p> <p>The VOICES-SF does not have this</p>	<p>Psychological symptoms</p> <p>Q 30 Did she/he have anxiety/ worry? Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes,</p>	<p>To know how much anxiety/worry the patients had, the effectiveness of the treatment and the impact of anxiety/worry on daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>his low mood? Yes.....No.....Don't know.....</p> <p>b) Did the treatment help her/his the low mood? Yes.....No.....Don't know.....</p>	<p>question. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage between the qualitative finding from the phase I of the study and the VOICES-ESRD and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p>	<p>sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for her/his anxiety/worry? Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help her/his anxiety/worry? Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	
<p>VOICES version of COPD:</p> <p>Q 13 Did she/he has anxiety or panic attacks?</p> <p>Yes, all the times Yes, sometimes Yes, rarely Not at all Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes,</p>	<p>This question is changed. The reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The symptoms experiences themes, especially psychological symptoms, were reported from the qualitative data (phase I) that low mood/depression created sense of useless person on older ESRD patients when they managed without dialysis at home. Low</p>	<p>Q 31 Did she/he suffer with low mood/depression related to the health problems?</p> <p>Last 3-12 months...less than 3 months</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p>	<p>To evaluate the low mood/depression of the patients, the effectiveness of the treatment and the impact of low mood/depression on the patients' daily life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for his anxiety or panic attacks?</p> <p>Yes.....No.....Don't know.....</p> <p>b) Did the treatment help the anxiety or panic attacks ?</p> <p>Yes.....No.....Don't know.....</p>	<p>mood/Depression impacted the patients as they lacked concern to taking care themselves.</p> <p>The VOICES-SF does not have this question. Therefore, the researcher tried to find out the questionnaire from other VOICES versions and it was found in The VOICES version of COPD. The questionnaire's detail is changed in order to make the linkage between the qualitative finding from the phase I of the study and the VOICES-ESRD and the studies of Murtagh et al (2007, 2009) and Noble et al (2010) the VOICES-ESRD.</p>	<p>Not at all</p> <p>Don't know....</p> <p>If you ticked 'yes, at all time', 'Yes, sometimes' or 'Yes, rarely'</p> <p>a) Did she/he receive any treatment for her/his low mood/depression? Last 3-12 months...less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p> <p>b) Did the treatment help her/his low mood/depression? Last 3-12 months less than 3 months</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	

Section 6: Provincial, district and community nurses

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
	<p>This question is created by the researcher regarding to the difference between type of nurses and type of home visiting services by nurses (provincial, district or community nurses) in Thailand and in UK.</p>	<p>Q 32 Did any type of nurse visit she/he at home?</p> <ul style="list-style-type: none"> • Provincial N. • District N. • Community N. • Others..... <p>If provincial district or community nurses came to visit she at home</p>	<p>To know the type of nurse, type of service and the frequency of the visiting at home.</p>
<p>VOICES –version of COPD:</p> <p>Q 2 Did she/he receive help at homes for her/his chest trouble from the district nurses?</p> <p>Yes.....</p> <p>No.....</p> <p>Don't know.....</p>	<p>This question remained the same as the VOICES- version of COPD. Little is changed according to the levels of the health services in Thailand which nurses (provincial, district or community nurses) might visit the patient at home This is a little bit different from the levels of nursing care in UK.</p> <p>Also this question was asked related to chest problem of VOICES version of COPD but the researcher changed the question to use with ESRD patients.</p> <p>Therefore, the researcher changed from “for his chest trouble from the district nurses ” <i>is changed to</i> “for his renal trouble from the provincial, district or community nurses”</p>	<p>Q 33, Q 37, Q 38</p> <p>Did she/he receive help at homes for her/his renal trouble from the provincial, district or community nurses?</p> <p>Yes.....</p> <p>No.....</p>	<p>To know did nurses visit the patient at home? and what type of nurse used to visiting at home?</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES -SF: Q .12 How often did the district or community nurses visit (at the most frequent time) Tick one only</p> <p>Provincial N. District N. Community N.</p> <p>More than once a day</p> <p>Every day</p> <p>2-6 times a week</p> <p>Once a week</p> <p>2-3 times a month</p> <p>Less often</p> <p>Don't know</p>	<p>This question remained the same as the VOICES-SF. The little is changed related to the difference of the levels of nursing care between UK and Thailand</p> <p>Therefore, the researcher changed from “ the district and community nurses visit” to “ the provincial, district or community nurses visit”</p>	<p>a) If yes, how often did the provincial, district or community nurses visit (at the most frequent time) Tick one only</p> <p>Provincial N. District N. Community N.</p> <p>More than once a day</p> <p>Every day</p> <p>2-6 times a week</p> <p>Once a week</p> <p>2-3 times a month</p> <p>Less often</p> <p>Don't know</p>	<p>To find out the frequency of the visiting at home by nurse.</p>
<p>VOICES -SF: Q 13 How much of the time was she/he treated with respect and dignity by the district, and community nurse? Tick one only</p> <p>Provincial N. District N. Community N.</p> <p>Always</p> <p>Most of the time</p>	<p>This question remained the same as the VOICES-SF. The little is changed related to the difference of the levels of nursing care between UK and Thailand</p> <p>Therefore, the researcher changed from “ the district and community nurses visit” to “ the provincial, district or community nurses visit”</p>	<p>Q 34, Q 38, Q 42</p> <p>How much of the time was she/he treated with respect and dignity by the provincial, district, or community nurse?</p> <p>Tick one only</p> <p>Provincial N. District N. Community N.</p> <p>Always</p> <p>Most of the time</p>	<p>To know the patient was provided with respect and dignity care by nurse.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>Some of the time</p> <p>Never</p> <p>Don't know</p>		<p>Some of the time</p> <p>Never</p> <p>Don't know</p>	
<p>VOICES -SF: Q 14 Overall, do you feel that the care she got from the district and community nurses in the last three months of life was: Tick one only Provincial N. District N. Community N.</p> <p>Excellent</p> <p>Good</p> <p>Fair</p> <p>Poor</p> <p>No</p> <p>Don't know</p>	<p>This question remained the same as the VOICES-SF. The little is changed related to the difference of the levels of nursing care between UK and Thailand</p> <p>Therefore, the researcher changed from " the district and community nurses visit" to " the provincial, district or community nurses visit"</p>	<p>Q 35, Q 39, Q43 Overall, do you feel that the care she/he got from the provincial, district or community nurses in the last three months of life was: Tick one only Provincial N. District N. Community N.</p> <p>Excellent</p> <p>Good</p> <p>Fair</p> <p>Poor</p> <p>No</p> <p>Don't know</p>	<p>To evaluate the effectiveness of nursing care at the last three months.</p>
	<p>This question is created by the researcher regarding to find out what is the barriers for providing the home visiting services by nurses (provincial, district or community nurses) in Thailand.</p>	<p>Q 36, Q 34, Q44 How far away from the provincial hospital to hia/her home?.....</p> <p>a) How much time it take from the provincial hospital to her home?.....</p>	<p>To know the barriers on providing the home visiting by nurses.</p>

Section 7: General doctors/ physicians

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –version of COPD: Q 27 What services did the GP provide for her/him and you?</p> <p><i>Please tick all the boxes which apply</i></p> <ul style="list-style-type: none"> • Emergency care..... • Repeat prescriptions..... • Changing his medication..... • Emotional support..... • Arranging extra help at home..... • Providing information about his lung l conditions..... • Regular check-ups for his lung condition..... • Referral to outpatients..... 	<p>This question remained the same as the VOICES- version of COPD. The little is changed in the questions’ choices according to the specific disease.</p> <p>In VOICES version of COPD, the question was asked related to lung conditions but the researcher changed the question to use with ESRD patients.</p> <p><i>Therefore, the researcher changed from “lung conditions” is changed to “renal conditions”</i></p> <p><i>The work GPs (General Practitioners) is changed to general doctors or physicians based on the health care system in Thailand.</i></p>	<p>Q 45 What services did the doctor provide for her/him and you?</p> <p><i>Please tick all the boxes which apply</i></p> <ul style="list-style-type: none"> • Emergency care..... • Repeat prescriptions..... • Changing his medication..... • Emotional support..... • Arranging extra help at home..... • Providing information about his/her renal conditions..... • Regular check-ups for his/her renal condition..... • Referral to outpatients..... 	<p>To know what type of services was provided by doctor?</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –version of COPD:</p> <p>Q .25 How much did the GP understand about her/his chest trouble?</p> <ul style="list-style-type: none"> ○ The GP understood her/him very well..... ○ The GP understood her/him quite well..... ○ The GP did not know her/him well at all... ○ Don't know..... 	<p>This question remained the same as the VOICES- version of COPD. The little is changed according to the specific symptoms experiences.</p> <p>In VOICES version of COPD, the question was asked related to lung trouble but the researcher changed the question to use with ESRD patients.</p> <p>Therefore, the researcher changed from “lung trouble” <i>is changed to</i> “renal problems (breathlessness, pain, oedema, worry and depress)”</p>	<p>Q 46 How much did the doctor understand about her/his renal problems (breathlessness, pain, oedema, worry and depress)?</p> <ul style="list-style-type: none"> ○ The doctor understood her/him very well..... ○ The doctor understood her/him quite well..... ○ The doctor did not know her/him well at all... ○ Don't know..... 	<p>To find out if the doctor understand the patients' needs or health problems?</p>
<p>VOICES –version of COPD:</p> <p>Q 28 Do you feel that her/his GP had time to listen and discuss things? <i>Please tick the most suitable box</i></p> <ul style="list-style-type: none"> • Always • Sometimes..... • Rarely..... • Never..... • Not applicable..... 	<p>This question remained the same as the VOICES-version of COPD. In addition, the reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The health care needs and utilization theme, especially in the aspect of health service provision(need for health education),is showed that the patients needed the</p>	<p>Q 47 Do you feel that her/his doctor had time to listen and discuss things? <i>Please tick the most suitable box</i></p> <ul style="list-style-type: none"> • Always • Sometimes..... • Rarely..... • Never..... • Not applicable..... 	<p>To find out if the doctor provide enough time to listen and discuss the patients' needs?</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
	doctors/physicians to provide time and explain how to take care his/her health at home.		
<p>VOICES -SF:</p> <p>Q 15 In the last 3 months, how often did she/he see the GP she preferred to see?</p> <ul style="list-style-type: none"> • Always or almost always..... • A lot of the time..... • Some of the times..... • Never or almost never..... • She/he didn't try to see a particular GP..... • She/he did not need to see GP..... 	<p>This question remained the same as the VOICES-SF. In addition, the reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD who managed without dialysis, in Thailand. The health care needs and utilization theme, especially in the aspect of health service provision (need for specialists and support at the end of life) showed that the patients didn't want to see the doctors/physicians again after they went back home as they thought the doctors/physicians didn't do anything to help them when they were staying in the hospitals.</p>	<p>Q 48 In the last 3 months, how often did she/he see the doctor she/he preferred to see?</p> <ul style="list-style-type: none"> • Always or almost always..... • A lot of the time..... • Some of the times..... • Never or almost never..... • She/he didn't try to see a particular doctor..... • She/he did not need to see doctor 	<p>To find out how often the patient like to see the doctor during the last 3 months?</p>
<p>VOICES -SF:</p> <p>Q 16 How much of the time was she/he treated with respect and dignity by the</p>	<p>This question remained the same as the VOICES-SF. In addition, the reason is based on the framework analysis of the symptom</p>	<p>Q 49 How much of the time was she/he treated with respect and</p>	<p>To know the frequency of the time that the</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>GPs? Tick one only</p> <ul style="list-style-type: none"> • Always..... • Most of the time..... • Some of the time..... • Never..... • Don't know..... 	<p>experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The health care needs and utilization theme, especially in the aspect of health service provision (need providing care with dignity), is showed that the patients were not impressed with the way the doctors/physicians treated them. The patients and carers felt that the doctors/physicians lacked of respect for patient's dignity.</p>	<p>dignity by the doctor? Tick one only</p> <ul style="list-style-type: none"> • Always..... • Most of the time..... • Some of the time..... • Never..... • Don't know..... 	<p>patient s were treated with respect and dignity by the doctor.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES -SF: Q 18 If the GP visited her/him at home in the last three months, how easy or difficult was it to got him/her to visit?</p> <ul style="list-style-type: none"> • Very easy • Fairly easy • Fairly difficult • Very difficult • Don't know • She/he wanted the GPs to visit but they would not visit • Does not apply-the GPs did not need to visit • Don't know <p>Please feel free to make comments in the space below:.....</p>	<p>This question remained the same as the VOICES-SF. In addition, the reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The health care needs and utilization theme, especially in the aspect of home visiting (need for regular home visiting),is showed that the carers thought it is important to the patients and their families as the doctors/physicians can come to assess the patients' health problems at home.</p>	<p>Q 50 If the doctor visited her/him at home in the last three months, how easy or difficult was it to got him/her to visit?</p> <ul style="list-style-type: none"> • Very easy • Fairly easy • Fairly difficult • Very difficult • Don't know • She/he wanted the doctor to visit but they would not visit • Does not apply-the doctor did not need to visit • Don't know <p>Please feel free to make comments in the space below:.....</p>	<p>To assess the possibility of home visiting by the doctor.</p>
<p>VOICES -SF: Q 19 Overall, do you feel that the care she/he got from GP in the last three months of life was</p> <ul style="list-style-type: none"> • Excellent • Good • Fair • Poor • Don't know 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 51 Overall, do you feel that the care she/he got from doctor in the last three months of life was</p> <ul style="list-style-type: none"> • Excellent • Good • Fair • Poor • Don't know <p>Please feel free to make comments in</p>	<p>To evaluate the health services providing by the doctor.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
Please feel free to make comments in the space below:		the space below:	

Section 8: Last Hospital Admission

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –version of COPD:</p> <p>Q 24 Did she/he stay in hospital any time during her/him last three months of life?</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Yes-please write the name of the last hospital she/he stayed in, in the space below:..... • No..... • Don't know..... 	<p>This question remained the same as the VOICES- SF.</p>	<p>Q 52. Did she/he stay in hospital any time during her/him last three months of life?</p> <p>Tick one only</p> <ul style="list-style-type: none"> • Yes-please write the name of the last hospital she/he stayed in, in the space below:..... • No..... • Don't know..... 	<p>To know about patients' hospital admission during the last three months.</p>
<p>VOICES –version of COPD:</p> <p>Q 27 Did the hospital services work well together with her/his GP and other services outside of the hospital?</p> <ul style="list-style-type: none"> • Yes, definitely..... 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 53. Did the hospital services work well together with her/his GP and other services outside of the hospital?</p> <ul style="list-style-type: none"> • Yes, definitely..... • Yes, to some extent..... • No, they did not work well together. 	<p>To evaluate the effective of hospital services and other services outside of the hospital.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Yes, to some extent..... • No, they did not work well together..... • Don't know..... 		<ul style="list-style-type: none"> • Don't know..... 	
<p>VOICES -version of COPD:</p> <p>Q 28 Overall, do you feel that the care she/he got from the staff in the hospital on that admission was:</p> <p style="text-align: center;">Doctors Nurses</p> <p>Excellent Good Fair Poor Don't know</p>	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 54. Overall, do you feel that the care she/he got from the staff in the hospital on that admission was:</p> <p style="text-align: center;">Doctors Nurses</p> <p>Excellent Good Fair Poor Don't know</p>	<p>To evaluate the health services that the patient received from the health care staff in the hospital during the last admission.</p>

Section 9: Experiences in the last 3 days of life

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question						
<p>VOICES –SF: Q 33 During her/his last two days of life was she (Tick one only)</p> <ul style="list-style-type: none"> • At home all the time • In a hospital all the time • Others-please write in the space • 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 55 During her/his last two days of life was she/he (Tick one only)</p> <ul style="list-style-type: none"> • At home all the time • In a hospital all the time • Others-please write in the space 	<p>To know where the patient lived during the last 2 days of life.</p>						
<p>VOICES –SF: Q 34 How much of the time was she/he treated with respect and dignity in the last two days of life?</p> <p>Please answer for both doctors and nurses</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%;"></td> <td style="width: 25%; text-align: center;">Doctors</td> <td style="width: 25%; text-align: center;">Nurses</td> </tr> </table> <p>Always Most of the time Some of the time Never Don't know</p>		Doctors	Nurses	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 56 How much of the time was she/he treated with respect and dignity in the last two days of life?</p> <p>Please answer for both doctors and nurses</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 50%;"></td> <td style="width: 25%; text-align: center;">Doctors</td> <td style="width: 25%; text-align: center;">Nurses</td> </tr> </table> <p>Always Most of the time Some of the time Never Don't know</p>		Doctors	Nurses	<p>To know the frequency of treating with respect and dignity by doctor or nurse to the patients.</p>
	Doctors	Nurses							
	Doctors	Nurses							
<p>VOICES –SF: Q 35 Please look at the following statement and tick the answer box that corresponds most with your opinion about the help she received in the last two days of life</p>	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 57 Please look at the following statement and tick the answer box that corresponds most with your opinion about the help she/he received in the last two days of life</p> <p style="text-align: center;">Tick one box for each question (a-c)</p>	<p>To evaluate the sufficient caring or helping which the patients received during the last 3 days.</p>						

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>Tick one box for each question (a-c)</p> <p>(1) Strongly Agree (2) Agree (3) Neither agree nor disagree..(4) Disagree (5)Strongly disagree (6) Does not apply (7)Don't know</p> <p>(a) There was enough help available to meet her personal care needs (such as toileting needs) (1), (2), (3), (4), (5), (6), (7)</p> <p>(b) There was enough help with nursing care, such as giving medicine and helping her find a comfortable position in bed (1), (2), (3), (4), (5), (6), (7)</p> <p>(c) The bed area and surrounding environment had adequate privacy for her (1), (2), (3), (4), (5), (6), (7)</p>		<p>(1) Strongly Agree (2) Agree (3) Neither agree nor disagree..(4) Disagree (5)Strongly disagree (6) Does not apply (7)Don't know</p> <p>(a) There was enough help available to meet her personal care needs (such as toileting needs) (1), (2), (3), (4), (5), (6), (7)</p> <p>(b) There was enough help with nursing care, such as giving medicine and helping her find a comfortable position in bed (1), (2), (3), (4), (5), (6), (7)</p> <p>(c) The bed area and surrounding environment had adequate privacy for her(1), (2), (3), (4), (5), (6), (7)</p>	
<p>VOICES -SF: Q 36 During the last two days, how do you assess the overall level of support given in the following areas from those caring for her/him?</p> <p>Tick one box for each question (a-e)</p> <p>(1) Strongly Agree (2) Agree (3) Neither agree nor disagree..(4) Disagree (5)Strongly disagree (6) Does not apply (7)Don't know</p>	<p>This question remained the same as the VOICES-SF.</p> <p>Anything to help them when they were staying in the hospitals.</p>	<p>Q 58 During the last two days, how do you assess the overall level of support given in the following areas from those caring for her/him?</p> <p>Tick one box for each question (a-e)</p> <p>(1) Strongly Agree (2) Agree (3) Neither agree nor disagree..(4) Disagree (5)Strongly disagree (6) Does not apply</p>	<p>To assess overall health services that the patients received during the last 3 days.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>(a) Relief of symptoms (1), (2), (3), (4), (5), (6), (7)</p> <p>(b) Spiritual support (1), (2), (3), (4), (5), (6), (7)</p> <p>(c) Emotional support (1), (2), (3), (4), (5), (6), (7)</p> <p>(d) Financial support (1), (2), (3), (4), (5), (6), (7)</p> <p>(e) Support to stay where she/he wanted to be (1), (2), (3), (4), (5), (6), (7)</p>		<p>(7)Don't know</p> <p>(a) Relief of symptoms (1), (2), (3), (4), (5), (6), (7)</p> <p>(b) Spiritual support (1), (2), (3), (4), (5), (6), (7)</p> <p>(c) Emotional support (1), (2), (3), (4), (5), (6), (7)</p> <p>(d) Financial support (1), (2), (3), (4), (5), (6), (7)</p> <p>(e) Support to stay where she/he wanted to be (1), (2), (3), (4), (5), (6), (7)</p>	

Section 10: Circumstances surrounding the death

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –SF: Q 37 Did she/he know she/he likely to die? Tick one only</p> <ul style="list-style-type: none"> • Yes, certainly • Yes, probably • Probably not • No, definitely • Not sure 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 59 Did she/he know she/he likely to die? Tick one only</p> <ul style="list-style-type: none"> • Yes, certainly • Yes, probably • Probably not • No, definitely • Not sure 	<p>To find out if the patients know he/she will die.</p>
<p>VOICES –SF: Q 38 In your opinion, did the person who told her/him she/he was likely to die break the news to her/him in a sensitive and caring way? Tick one only</p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, not at all • Don't know • Does not apply-they did not know she was dying • Does not apply-they did not tell her she was dying 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 60 In your opinion, did the person who told her/him she was likely to die break the news to her/him in a sensitive and caring way? Tick one only</p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, not at all • Don't know • Does not apply-they did not know she was dying • Does not apply-they did not tell her she was dying 	<p>To know if the patient was told they were going to die in a caring and sensitive way.</p>
<p>VOICES –SF: Q 39 Were you contacted soon enough to give you time to be with her/him before she/he died? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • was there already 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 61 Were you contacted soon enough to give you time to be with her/him before she/he died? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • I was there already • It was not clear that she was going 	<p>To know that the patient had enough time with care before death.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> It was not clear that she was going to die soon I couldn't have got there anyway 		<ul style="list-style-type: none"> to die soon I couldn't have got there anyway 	
<p>VOICES -SF: Q 40 Where did she/he die? Tick one only</p> <ul style="list-style-type: none"> In her/his own home In the home of another family member or friend In hospital ward-please write the name of the hospital in the space below:..... In hospital accident and emergency department-please write the name of the hospital in the space below:..... In hospital Intensive Care Unit-please write the name of the hospital in the space below:..... In an ambulance on the way to hospital Somewhere-please write in the space below:..... 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 62 Where did she/he die?</p> <p>Tick one only</p> <ul style="list-style-type: none"> In her/his own home In the home of another family member or friend In hospital ward-please write the name of the hospital in the space below:..... In hospital accident and emergency department-please write the name of the hospital in the space below:..... In hospital Intensive Care Unit-please write the name of the hospital in the space below:..... In an ambulance on the way to hospital Somewhere-please write in the space below:..... 	<p>To know where the patient died.</p>
<p>VOICES -SF: Q 41 Did she/he ever say where she/he was like to die? Tick one only</p> <ul style="list-style-type: none"> Yes No Not sure 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 63 Did she/he ever say where she/he was like to die? Tick one only</p> <ul style="list-style-type: none"> Yes No Not sure 	<p>To know if the patients choose wherever they want to die.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>VOICES –SF: Q 42 Where did she say that she/he would like to die?</p> <ul style="list-style-type: none"> • At home • In a hospital • She said she did not mind where she died • She changed her mind about where she wanted to die • Somewhere else-please write in the space below:..... 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 64 Where did she/he say that she/he would like to die?</p> <ul style="list-style-type: none"> • At home • In a hospital • She said she did not mind where she died • She changed her mind about where she wanted to die • Somewhere else-please write in the space below:..... 	<p>To know where the do patient choose to die.</p>
<p>VOICES –SF: Q 43 Did the health care staff have a record or know of this? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Not sure 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 65 Did the health care staff has a record or know of this? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Not sure 	<p>To find out about the health care professional concerned with the patients’ needs to die.</p>
<p>VOICES –SF: Q 44 Do you think she/he had enough choice about where she/he died? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Not sure • She/he died suddenly 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 66 Do you think she/he had enough choice about where she/he died? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Not sure • She/he died suddenly 	<p>To find out do the patient receive enough choices about where she/he will die.</p>
<p>VOICES –SF: Q 45 On balance, do you think that she/he died in the right place? Tick one only</p>	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 67 On balance, do you think that she/he died in the right place? Tick one only</p> <ul style="list-style-type: none"> • Yes • No 	<p>To explore the carers’ idea about the patient with the right place to die.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> • Yes • No • Not sure 		<ul style="list-style-type: none"> • Not sure 	
<p>VOICES –version of stroke: Q 68 Do you feel that her/his religious and spiritual beliefs were taken into consideration by those caring for him? Tick one only</p> <ul style="list-style-type: none"> • Yes • Yes, partially • No • Don't know <p>Please feel free to make comments below:.....</p>	<p>This question remained the same as the VOICES- version of stroke.</p> <p>In addition, the reason is based on the framework analysis of the symptom experiences and health care needs of older people with ESRD, managed without dialysis, in Thailand. The spiritual distress, spiritual need and spiritual support at the end of life are sub-themes and showed that the patients lacked and needed those support. The carers thought that the spiritual support is the important aspect that it should be provide by health care professional at the end of life in Thailand.</p>	<p>Q 68 Do you feel that her/his religious and spiritual beliefs were taken into consideration by those caring for him? Tick one only</p> <ul style="list-style-type: none"> • Yes • Yes, partially • No • Don't know <p>Please feel free to make comments below:.....</p>	<p>To find out the carer feeling and idea on to order to maintain and support on spiritual belief from health care professional.</p>
<p>VOICES –SF: Q 46 Were you to her/his family given enough help and support by the healthcare team at the actual time of her death? Tick one only</p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, not at all • Don't know 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 69 Were you to her/his family given enough help and support by the healthcare team at the actual time of her death? Tick one only</p> <ul style="list-style-type: none"> • Yes, definitely • Yes, to some extent • No, not at all • Don't know 	<p>To know that the patient get enough help and support from health care professional at the actual time of his/her death.</p>
<p>VOICES –SF:</p>	<p>This question remained the same as</p>	<p>Q 70 After she/he died did staff deal with</p>	<p>To find out if the</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>Q 47 After she/he died did staff deal with you or her/his family in a sensitive manner? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Don't know • Does not apply, I didn't have any contact with the staff <p>Please feel free to make comments in the space below:.....</p>	<p>the VOICES-SF.</p>	<p>you or her/his family in a sensitive manner? Tick one only</p> <ul style="list-style-type: none"> • Yes • No • Don't know • Does not apply, I didn't have any contact with the staff <p>Please feel free to make comments in the space below:.....</p>	<p>health care professional deals with carer in a sensitive manner after the patients' death.</p>
<p>VOICES -SF: Q 48 Looking back over the last three months of her/his life, was she/he involved in decision about her/his care as much as she/he would have wanted? Tick one only</p> <ul style="list-style-type: none"> • She/he was involved as much as she/he wanted to be • She/he would have liked to be more involved • She/he would have liked to be less involved • Don't know 	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 71 Looking back over the last three months of her/his life, was she/he involved in decision about her/his care as much as she/he would have wanted? Tick one only</p> <ul style="list-style-type: none"> • She/he was involved as much as she/he wanted to be • She/he would have liked to be more involved • She/he would have liked to be less involved • Don't know 	<p>To find out do the patient involve on making decision in caring at the last three months of life.</p>
<p>VOICES -SF: Q 49 Looking back over the three months of life, were you involved in decisions about her care as much as you would have wanted? Tick one only</p> <ul style="list-style-type: none"> • I was involved as much as she wanted to be 	<p>This question remained the same as the VOICES-SF</p>	<p>Q 72 Looking back over the three months of life, were you involved in decisions about his/her care as much as you would have wanted? Tick one only</p> <ul style="list-style-type: none"> • I was involved as much as she wanted to be • I would have liked to be more 	<p>To find out if the carer is involved on making decision in caring of the patient at the last three months of the patients' life.</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<ul style="list-style-type: none"> I would have liked to be more involved I would have liked to be less involved Don't know 		<ul style="list-style-type: none"> involved I would have liked to be less involved Don't know 	
<p>VOICES –SF: Q 50 Were any decision made about her/his care that she/he would not have wanted? Tick one only</p> <ul style="list-style-type: none"> Yes No Don't know <p>Please feel free to make comments in the space below:.....</p>	<p>This question remained the same as the VOICES-SF</p>	<p>Q 73 Were any decision made about her/his care that she/he would not have wanted? Tick one only</p> <ul style="list-style-type: none"> Yes No Don't know <p>Please feel free to make comments in the space below:.....</p>	<p>To know if any decisions were made about the patients' care by the carer that they would not have wanted.</p>
<p>VOICES –SF: Q 51 Overall, and taking all service into account, how would you rate her/his care in the last three months of life? Tick one only</p> <ul style="list-style-type: none"> Outstanding Excellent Good Fair Poor Don't know 	<p>This question remained the same as the VOICES-SF</p>	<p>Q 74 Overall, and taking all service into account, how would you rate her/his care in the last three months of life? Tick one only</p> <ul style="list-style-type: none"> Outstanding Excellent Good Fair Poor Don't know 	<p>To know the perspective of carer on the health services patient received during the last three months.</p>
<p>VOICES –SF: Q 52 Since she/he died have you talked to anyone from health and social</p>	<p>This question remained the same as the VOICES-SF.</p>	<p>Q 75 Since she/he died have you talked to anyone from health or social services about your feeling about her illness and</p>	<p>To find out the support or health service that the</p>

VOICES version of COPD, Cancer, Stroke, SF	Reasons to choose, change or move the question	Adapt VOICES version of ESRD in Thailand	Reason to ask the question
<p>services, or from a bereavement service, about your feeling about her illness and death? Tick one only</p> <ul style="list-style-type: none"> • Yes • No, but I would have liked to • No, but I did not want to anyway • Not sure 	<p>Little is changed related to the difference of the health care system between UK and Thailand. In Thailand, we do not have bereavement service of the support system for the carers after the patients' death. Therefore, the researcher changed from "health and social services, or from a bereavement service" to "health or social services"</p>	<p>death? Tick one only</p> <ul style="list-style-type: none"> • Yes • No, but I would have liked to • No, but I did not want to anyway • Not sure 	<p>carer may receive after the patient's death.</p>

**APPENDIX N: Summary of problems with survey questions
whilst conducting cognitive interviewing: 1st cycle**

Summary of problems with survey questions whilst conducting cognitive interviewing: 1st cycle

Problems	Recommendations by participants (N=5)	Solutions
1. Difficulties relating to the appearance or formatting of the questionnaire		
Legibility and format	<u>The subject commented that the font size was a bit small and looked difficult to read. (1/5)</u>	The font size was changed from 15pt to 16pt.
2. Difficulties with specific wording (medical terms) or phrasing		
Unfamiliar with specific wording - "the services" (Question No. 9)	<u>Didn't understand the phrase "the services" and needed a definition.(3/5)</u> Subjects looked really confused when the researcher read the words "the services". The subjects asked the researcher what the services were, and who had to provide them. The researcher had to explain that "the services means health services which are provided by health care professionals, such as nurses, doctors or health volunteers, to the patient at home". Then the subjects understood and provided their answer.	This question reworded from "When he/she was at home in the last three months of his/her life, did he/she get any help at home from any of the services listed below?" to <u>"Did the patient receive any health services at home from any of the health care professionals listed below?"</u>

Problems	Recommendations by participants (N=5)	Solutions
<p>“special equipment” (Question No. 11)</p>	<p><u>Didn’t understand “special equipment” and asked for a meaning and an example (5/5)</u> This question clearly didn’t apply to the subjects because they did not know the meaning of the phrase “special equipment”. The researcher had to explain that it means the equipment that the patients needed at home to help them get better, such as oxygen (including types of oxygen support, i.e. a mask or tent).</p>	<p>The researcher provided the explanation of “special equipment” which means the equipment that the patients needed at home to help them get better, such as oxygen (including types of oxygen support, i.e. a mask or tent).</p>
<p>“any equipment” (Question No. 12)</p>	<p><u>Didn’t understand and needed explanation (2/5)</u> This question was also a bit confusing for some subjects because they did not know the meaning of the phrase “any equipment”. The researcher explained the meaning of the phrase “any equipment”, which means any special equipment in addition to the equipment discussed in the previous question that the patients needed at home to help them get better.</p>	<p>The researcher rewords the phrase “any equipment” means any special equipment which was discussed in the previous question that the patients needed at home to help them get better.</p>
<p>“personal care” (Question No. 13)</p>	<p><u>Didn’t understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn’t understand the meaning of the phrase “personal care”. The researcher explained the meaning of the phrase.</p>	<p>The researcher provides more examples for the phrase “personal care”(e.g. bathing, dressing).</p>

Problems	Recommendations by participants (N=5)	Solutions
"household tasks" (Question No. 13)	<p><u>Didn't understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn't understand the meaning of the phrase "household tasks". The researcher explained the meaning of the phrase.</p>	<p>The researcher provides more examples for the phrase "household tasks" (e.g. shopping, cleaning, cooking).</p>
"night time care" (Question No. 13)	<p><u>Didn't understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn't understand the meaning of the phrase "night time care". The researcher explained the meaning of the phrase.</p>	<p>The researcher provide more examples for the phrase "night time care" (e.g. taking to toilet at night, bed time care, providing medicines at night when needed).</p>
"health services" (Question No. 14)	<p><u>Didn't understand and needed a definition (3/5)</u> The subjects looked confused when the researcher read the phrase "health services". The researcher had to explain that "health services means services which are provided by health care professionals such as nurses, doctors or health volunteers to the patient at home". Then the subjects understood and provided their answer.</p>	<p>This question will be <u>reworded from "health services" to "health care professional"</u>.</p>

Problems	Recommendations by participants (N=5)	Solutions
"something urgent" (Question No. 16)	Initially confused by this phrase, but they then did <u>understand and answered appropriately after an explanation (2/5)</u> . The researcher expected that this question might cause difficulty for the subjects, as they might not be familiar with the wording "urgent care" or "out of hours". The confusion happened when the researcher read the phrase "something urgent". This alerted the researcher to the fact that confusion occurred for two subjects, and there could be similar problems for other subjects.	The phrasing "something urgent" is <u>changed the wording to "urgent care"</u> .
"breathlessness" (Question No. 26)	<u>Didn't understand and needed a definition (4/5)</u> Subjects were not clear and asked the researcher to explain the meaning of "breathlessness", and then they were able to answer the question appropriately.	Therefore, the word "breathlessness" is changed the wording to <u>"hard to catch his/her breath"</u> .
"in the last three to twelve months" and "in the last three months" (Question No. 26)	<u>Felt the question was not clear about the phrases "in the last three to twelve months" and "in the last three months" (1/5)</u> One subject felt unclear about the phrases "in the last three to twelve months" and "in the last three months" which were included in the response categories. They suggested that the researcher should add the words "before death" at the end of both response categories, as follows: "in the last three to twelve months before death" and "in the last three months before death".	The researcher will add the words "before death" at the end of both response categories, as follows: <u>"in the last three to twelve months before death" and "in the last three months before death"</u> . The researcher also considers that the phrase "before death" will be applied to questions 27 to 33 as well.

Problems	Recommendations by participants (N=5)	Solutions
"hospital services" and "services outside the hospital" (Question No. 56)	<p><u>Felt a little confused by the phrases "hospital services" and "services outside the hospital" (3/5)</u> Three subjects were a little confused by the phrases "hospital services" and "services outside the hospital". This was because the patients didn't receive health services at home. Therefore, the subjects felt it was difficult to answer. Afterwards the researcher explained the meanings and the subjects understood and felt they could answer the question.</p>	The researcher considered that this question is excluded.
"respect and dignity" (Question No.36)	<p><u>Didn't understand and needed a definition (3/5)</u> The subjects felt unclear and asked the researcher to explain the wording "dignity". After the explanation the subjects answered the question appropriately.</p>	Therefore, the researcher <u>deleted the word "dignity" and by remaining the word "respect". This changing will also apply to question NO. 43 and 50</u>
"religious and spiritual belief" (Question No. 71)	<p><u>Didn't understand and needed a definition (2/5)</u> Two subjects felt unclear and asked the researcher to explain "religious and spiritual belief". After the explanation the subjects answered the question appropriately.</p>	Therefore, the question No. 71 is changed to question No. 62 and the researcher changed the phrasing <u>from "religious and spiritual belief" to "religious, belief or faith in God".</u>

Problems	Recommendations by participants (N=5)	Solutions
"bereavement services" (Question No.78)	<p><u>Didn't understand and needed a definition and example (5/5)</u></p> <p>The one point about which the subjects were a little bit unclear was the phrase "bereavement services". Therefore, the researcher asked the subjects to talk out loud about their understanding of the phrase "bereavement services". The subjects said that this might mean the help or support of a nurse or doctor. The researcher explained this to subjects in more detail, explaining that "bereavement services" means help and support that are provided by health care professionals (nurses, doctors etc.) to the carer after the patient's death, in order to minimise the distress and suffering of the carer after they lose a loved one.</p>	<p>The question No. 78 is changed to question No. 69. This question was changed from "<u>Since she died have you talked to anyone from health services, or from a bereavement services, about your feeling about her illness and death?</u>" to "<u>Since she died have you talked to any health care professionals (nurses, doctors etc.), about your feeling, help and support after the patient's death?</u>"</p>
3. Difficulties with specific questions		
Question No. 7: about the duration of the illness until the patient died	<p><u>Felt the question was difficult to answer because the subjects didn't understand about the period of the time that the question was asking about (2/5)</u></p> <p>This question was a bit confusing to the subjects because subjects thought that they were being asked to identify the period of time before the patients died (i.e. the time between when the patients were allowed to return home and their death). In fact, the object of this question was the duration of the period between when patients were diagnosed with ESRD and refused to receive dialysis until the point at which they died.</p>	<p>Therefore, the researcher will rewrite the question, changing it from "<u>How long had he been ill before he died?</u>" to "<u>How long was it after he was diagnosed with ESRD and managed without dialysis until he died?</u>"</p>

Problems	Recommendations by participants (N=5)	Solutions
Question No. 56: the question asked for an evaluation of health services outside the hospital	<p><u>Could not answer as the patient didn't receive health services at home. Therefore, the subjects felt it was difficult to answer (3/5)</u></p> <p>Three subjects felt a little bit confused by the phrases "hospital services" and "services outside the hospital". This was because the patients didn't receive health services at home. Therefore, the subjects felt it was difficult to answer. Afterwards the researcher explained the meanings of the phrases and the subjects understood and felt they could answer the question.</p>	The researcher considers that if the patients didn't receive health services at home, this question can be skipped.
Question No. 67: the connection between two other questions (Nos. 66 and 67)	This question is connected to question No. 66, "Did he say where he would like to die?". If the answer to that question was "yes", the subject should go on to answer this question.	After discussion with the research supervisor, it was decided that there is no problem with this question.
4. Difficulties regarding the response categories		
<p>Lack of some categories Question Nos. 17 and 22</p>	<p><u>Felt the response categories "nobody" or "couldn't contact" should be added (5/5)</u></p> <p>The subjects recommended that response categories should be added for "nobody" or "couldn't contact", to take account of situations where something happened but patients couldn't contact anybody, or where the patients did contact someone but nobody could come to provide urgent care at home out of hours.</p>	<p>The researcher considered that the response category "Nobody or couldn't contact" should be added for questions 17 and 22.</p> <ul style="list-style-type: none"> o Nobody or couldn't contact

Problems	Recommendations by participants (N=5)	Solutions
Question No. 34	<p><u>Felt the response category of "Didn't have nurse(s) or didn't have nurse visits at home" should be added for this question. (3/5)</u> Three subjects said their relatives didn't receive any home visits from nurses. The subjects could not answer this question because there was no response category relating to their answer.</p>	<p>The response category " o No nurse(s) or nurses didn't visit him at home" is added for this question.</p>
Too many response categories		
Question No. 18	<p><u>Felt there were too many response categories (4/5)</u> Subjects recommended that there were too many response categories, and a few response categories did not make sense. This was because it would be impossible to receive that kind of service.</p>	<p>Therefore, 3 response categories are deleted.</p> <ul style="list-style-type: none"> o Given medical advice over the telephone o Given another number to ring to get medical advice o Advised to go to private clinic
Question No. 23	<p><u>Felt there were too many response categories (3/5)</u> The subjects recommended that there were too many response categories, and a few response categories did not make sense. This was because it would be impossible to receive that kind of service.</p>	<p>Therefore, 3 response categories are deleted them.</p> <ul style="list-style-type: none"> o Given medical advice over the telephone o Given another number to ring to get medical advice o Advised to go to private clinic

Problems	Recommendations by participants (N=5)	Solutions
<p>The response categories were too complicated (Question Nos. 60 and 61)</p>	<p><u>Felt it was too complicated to make a decision and provide an answer. Subjects needed time to think and then they were able to answer (5/5)</u> The researcher considers that the different type of response categories in the questionnaire might hinder the subjects in answering this question. It would be better to have one type of response category, especially when the questionnaire is used with subjects who lack knowledge about the help received. In addition, the researcher will provide time for them to become familiar with types of response category</p>	<p>The question No. 60 is changed to No.51, type of response category is changed to</p> <ul style="list-style-type: none"> o Yes, always o Yes, most of the time o Yes, some of the time o No o Don't know <p>The question No 61 is changed to No. 52, type of response category is changed to</p> <ul style="list-style-type: none"> o Completely, all of the time o Completely, some of the time o Partially o Not at all o Don't know
<p>5. Difficulties with interpreting response categories</p>		
<p>Question Nos. 26 to 33: The level of response categories resulted in an unclear result.</p>	<p><u>This question should separate the response categories into "yes" and "yes rarely". (2/5)</u></p>	<p>The researcher noted that the level of response should be differentiated between "Yes" and "Yes rarely". The resulting different levels of response category will provide for different interpretations. It will be best to revise all the response categories.</p> <p style="text-align: center;">In the last 3-12 months before death In the last 3 months before death</p> <p>Yes, all the time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p>

Problems	Recommendations by participants (N=5)	Solutions
		Don't know
Question No. 64: The response categories were suitable for answers related to patients who had died at the hospital.	<p><u>This question should have an extra response category: "I didn't have contact as he/she died at home". (2/5)</u> The subjects commented that their relatives had died at home, not in the hospital. The response categories are suitable for answers related to patients who died at the hospital.</p>	<p>The question NO. 64 is changed to No. 55. The response category is added: o I didn't have contact as he died at home</p>
6. Comments on the overall length of the questionnaire		
	<p><u>Felt it was not too long or burdensome (3/5)</u> <u>Felt it was long but not too burdensome (2/5)</u></p>	<p>The question No. 56 was excluded. The number of questions in the section 6 Provincial, district and community nurses was considered to reduce in order to avoid the collapsing of the question. Then the overall length of the questionnaire is reduced from 42 pages to 38 pages. The total number of questions were reduced from 78 to 69 questions.</p>

APPENDIX O: Summary of problems with questions whist conducting cognitive interviewing: 2nd cycle

Summary of problems with questions whilst conducting cognitive interviewing: 2nd cycle

Problems from the first cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
1. Difficulties relating to the appearance or formatting of the questionnaire	N/A	N/A	N/A
2. Difficulties with specific wording (medical terms) or phrasing	N/A	N/A	N/A
Unfamiliar with specific wording - "the services" (Question No. 9)	Question No. 9 The question was a bit long and the response categories represented many choices (1/5)	1/5 of subject said "However, the subject said, "This question is OK for me because if the question is made shorter than this it might not be clear for the reader". However, this question should be added: "Please tick one or more" in case respondents want to choose more than one response category.	Adding "Please tick one or more"
"health services" (Question No. 14)	Question No. 14 Problem on the part of Household tasks (e.g. shopping, cleaning). (2/5)	Household tasks (e.g. shopping, cleaning)" needs to be cut or deleted, as this task is not normally the task of a health care professional. So this task would never be provided by them.	The researcher consider to delete the Household tasks.
"respect and dignity" (Question No.36)	Question No. 36 Problem on the question (1/5)	Subject 2: I don't think "tick one only" is necessary to include in the question. " How much of the time was she treated with respect by the nurse?" " <i>Tick one only.</i> "	The researcher might consider to delete "Tick one only".

Problems from the first cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
Question No. 17 and 22 Unfamiliar with the phrase	"Out of hours hospital number" and "Something else".	- "Out of hours hospital number" should be changed to "The hospital's operator" and - "Something else" should be changed to "Someone". This is because the question asked about "Who did the patient contact or who was contacted on their behalf?" So the response categories should refer to persons or someone, somebody, rather than something.	The researcher considered the changing as subjects might not understand or felt confuse with phrases "Out of hours hospital number" and "Something else".
3. Difficulties with specific questions			
Question No. 7: about the duration of the illness until the patient died		Question No. 7: One subject thought the current response categories provided were good and felt they were clearer than numbers, especially for elderly caregivers. This was because elderly caregivers might be confused when they read the response categories which contained numbers.	
4. Difficulties regarding the response categories			
Too many response categories			

Problems from the first cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
Question No 56.	(3/5)	Three response categories should be reduced and rearranged. These three response categories: <ul style="list-style-type: none"> o In hospital ward-please write the name of the hospital in the space below:..... o In hospital accident and emergency department-please write the name of the hospital in the space below:..... o In hospital Intensive Care Unit-please write the name of the hospital in the space below:..... 	Three response categories were changed to 1 response category ; <ul style="list-style-type: none"> o In hospital's name and please write the name of the ward, unit or department in the space below:.....
Question No. 44	4/5 subjects don't mind if it will be reduced or not.	There are too many response categories. If it is possible, the response categories should be arranged from <ul style="list-style-type: none"> o Very easy o Fairly easy o Very Difficult o Fairly Difficult Reduce to <ul style="list-style-type: none"> o Easy o Difficult 	Will have discussion with supervisors
The response categories were too complicated			

Problems from the first cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	Question No. 49 (1/5)	Don't think the phrase "all the time" is necessary in the response categories. o At home <u>all the time</u> o In a hospital <u>all the time</u>	Changing to o At home o In a hospital
	Question No 13. Problem with the response categories.(2/5) o Less than 5 hours per week o 5-10 hours per week o 11-19 hours per week o 20-39 hours per week o 40 or more hours per week	The response categories should be changed from hours to days. This is because the patient depended on the subject all the time. The amount of hours may make elderly caregivers feel it is difficult to count and they might be unable to remember how many hours they spent caring for their patients.	The response categories should be changed from hours to days. o Less than 1 day o 1-3 days a week o 3-5 days a week o 5-7 days a week o 7 days a week
5. Difficulties with interpreting response categories	N/A	N/A	N/A
6. Comments on the overall length of the questionnaire	N/A	N/A	N/A
7. The way to do the questionnaire (post, interviewing or e-mail)	Which way you like to answer this questionnaire?		
		<u>Felt it should be an administered questionnaire (5/5)</u>	
8. Anything else to be improved			

Problems from the first cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	- Anything else that you think this questionnaire should be improved?	<u>Felt it was not needed to add or improved (5/5)</u> <u>Felt it is ready to use (5/5)</u>	
9. Time spent during interviewings			
	Do you think is it take time for answering this questionnaire (35-45 mins)?	<u>Felt it was not take time to answer the questionnaire (5/5)</u>	

APPENDIX P: Comparing of problems from the 1st and 2nd cycles of cognitive interviews

Comparing of problems from the 1st and 2nd cycles of cognitive interviews

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
1. Difficulties relating to the appearance or formatting of the questionnaire						
Legibility and format	<u>The subject commented that the font size was a bit small and looked difficult to read.</u> (1/5)	The font size was changed from 15pt to 16pt.	No problem (5/5)			
2. Difficulties with specific wording (medical terms) or phrasing						
Unfamiliar with specific wording - "the services" (Question No. 9)	<u>Didn't understand the phrase "the services" and needed a definition.</u> (3/5) Subjects looked really confused when the researcher read the words "the services". The subjects asked the researcher what the services were, and who had to provide them. The researcher had to explain that "the services means health services which	This question reworded from "When he/she was at home in the last three months of his/her life, did he/she get any help at home from any of the services listed below?" to <u>"Did the patient receive any health</u>	No problem (4/5)	Question No. 9 The question was a bit long and the response categories represented many choices (1/5)	1/5 of subject said "However, the subject said, "This question is OK for me because if the question is made shorter than this it might not be clear for the reader". However, this question should be added: "Please tick one or more" in case respondents want to choose more than one	Adding "Please tick one or more"

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	are provided by health care professionals, such as nurses, doctors or health volunteers, to the patient at home". Then the subjects understood and provided their answer.	<u>services at home from any of the health care professionals listed below?"</u>			response category.	
"special equipment" (Question No. 11)	<u>Didn't understand "special equipment" and asked for a meaning and an example (5/5)</u> This question clearly didn't apply to the subjects because they did not know the meaning of the phrase "special equipment". The researcher had to explain that it means the equipment that the patients needed at home to help them get better, such as oxygen (including types of oxygen support, i.e. a mask or tent).	The researcher provided an explanation of "special equipment" which means the equipment patients needed at home to help them get better, such as oxygen (including types of oxygen support, i.e. a mask or tent).	No problem (5/5)			
"any equipment" (Question No. 12)	<u>Didn't understand and needed explanation (2/5)</u> This question was also a bit confusing for some subjects because they did not know the meaning of the phrase "any equipment". The researcher explained the meaning of the phrase "any equipment", which means any	The researcher reworded the phrase "any equipment" to mean any special equipment discussed in the previous question that patients needed at home to	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	special equipment in addition to the equipment discussed in the previous question that the patients needed at home to help them get better.	help them get better.				
"personal care" (Question No. 13)	<u>Didn't understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn't understand the meaning of the phrase "personal care". The researcher explained the meaning of the phrase.	The researcher provides more examples for the phrase "personal care"(e.g. bathing, dressing).	No problem (5/5)			
"household tasks" (Question No. 13)	<u>Didn't understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn't understand the meaning of the phrase "household tasks". The researcher explained the meaning of the phrase.	The researcher provided more examples for the phrase "household tasks" (e.g. shopping, cleaning, cooking).	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
"night time care" (Question No. 13)	<u>Didn't understand and needed a definition and example (3/5)</u> In this question, a problem occurred with the response categories. The subjects seemed unable to answer this question because they didn't understand the meaning of the phrase "night time care". The researcher explained the meaning of the phrase.	The researcher provided more examples for the phrase "night time care" (e.g. taking to toilet at night, bed time care, providing medicines at night when needed).	No problem (5/5)			
"health services" (Question No. 14)	<u>Didn't understand and needed a definition (3/5)</u> The subjects looked confused when the researcher read the phrase "health services". The researcher had to explain that "health services means services which are provided by health care professionals such as nurses, doctors or health volunteers to the patient at home". Then the subjects understood and provided their answer.	This question will be <i>reworded from "health services" to "health care professional"</i> .	No problem (5/5)	Question No. 14 Problem with the term Household tasks (e.g. shopping, cleaning). (2/5)	Household tasks (e.g. shopping, cleaning) needs to be cut or deleted, as this task is not normally the task of a health care professional. So this task would never be provided by them.	To delete the response option household tasks

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
“something urgent” (Question No. 16)	Initially <u>confused by this phrase, but did then understand and answered appropriately after an explanation (2/5)</u> The researcher expected this question might cause difficulty for subjects, as they might not be familiar with the wording “urgent care” or “out of hours”. The confusion happened when the researcher read the phrase “something urgent”. This alerted the researcher to the fact that confusion occurred for two subjects, and there could be similar problems for other subjects.	The phrase “something urgent” was changed to <u>“urgent care”</u> .	No problem (5/5)			
“breathlessness” (Question No. 26)	<u>Didn’t understand and needed a definition (4/5)</u> Subjects were not clear and asked the researcher to explain the meaning of “breathlessness”, and then they were able to answer the question appropriately.	Therefore, the word “breathlessness” was changed to <u>“hard to catch his/her breath”</u> .	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
<p>"in the last three to twelve months" and "in the last three months" (Question No. 26)</p>	<p><u>Felt the question was not clear about the phrases "in the last three to twelve months" and "in the last three months" (1/5)</u> One subject felt unclear about the phrases "in the last three to twelve months" and "in the last three months" which were included in the response categories. They suggested that the researcher should add the words "before death" at the end of both response categories, as follows: "in the last three to twelve months before death" and "in the last three months before death".</p>	<p>Add the words "before death" at the end of both response categories, as follows: <i>"in the last three to twelve months before death" and "in the last three months before death".</i> The adding of "before death" will be applied to questions 27 to 33 as well.</p>	<p>No problem (5/5)</p>			
<p>"hospital services" and "services outside the hospital" (Question No. 56)</p>	<p><u>Felt a little confused by the phrases "hospital services" and "services outside the hospital" (3/5)</u> Three subjects were a little confused by the phrases "hospital services" and "services outside the hospital". This was because the patients didn't receive health services at home. Therefore, the subjects felt it was difficult to answer.</p>	<p>Remained the same</p>				

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	Afterwards the researcher explained the meanings and the subjects understood and felt they could answer the question.					
"respect and dignity" (Question No.36)	<u>Didn't understand and needed a definition (3/5)</u> The subjects felt unclear and asked the researcher to explain the wording "dignity". After the explanation the subjects answered the question appropriately.	<u>Deleted the word "dignity" so just referred to as "respect". This change will also apply to question NO. 43 and 50</u>	No problem (5/5)	Question No. 36 Problem on the question (1/5)	Subject 2: I don't think "tick one only" is necessary to include in this question. "How much of the time was she treated with respect by the nurse?" <u>"Tick one only."</u>	Remained the same
"religious and spiritual belief" (Question No. 71)	<u>Didn't understand and needed a definition (2/5)</u> Two subjects felt unclear and asked the researcher to explain "religious and spiritual belief". After the explanation the subjects answered the question appropriately.	Therefore, question No. 71 was changed to question No. 62 and the researcher changed the phrasing <u>from "religious and spiritual belief" to "religious belief or faith in God"</u> .	No problem (5/5)			
				Question No. 17 and 22 Unfamiliar with the phrases "Out of hours hospital number" and "Something	- <u>"Out of hours hospital number"</u> should be changed to "The hospital's operator" and - <u>"Something else" should be changed to "Someone"</u> . This is because the question	The researcher considered the changing as subjects might not understand or felt confuse with phrases <u>"Out of hours hospital</u>

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
				else".	asked about "Who did the patient contact or who was contacted on their behalf?" So the response categories should refer to persons or someone, somebody, rather than something.	<i>number</i> " and <i>"Something else"</i> .
"bereavement services" (Question No.78)	<u>Didn't understand and needed a definition and example (5/5)</u> The one point about which the subjects were a little bit unclear was the phrase "bereavement services". Therefore, the researcher asked the subjects to talk out loud about their understanding of the phrase "bereavement services". The subjects said this might mean the help or support of a nurse or doctor. The researcher explained this to subjects in more detail, explaining that "bereavement services" means help and support that are provided by health care professionals (nurses, doctors etc.) to the carer after the patient's death, in order to minimise the suffering.	The question No. 78 was changed to question No 69 from <u>"Since she died have you talked to anyone from health services, or from a bereavement services, about your feelings about her illness and death?"</u> to <u>"Since she died have you talked to any health care professionals (nurses, doctors etc.), about your feeling, help and support after the patient's death?"</u>	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
3. Difficulties with specific questions						
Question No. 7: about the duration of the illness until the patient died	<u>Felt the question was difficult to answer because subjects didn't understand about the period of the time that the question was asking about (2/5)</u> This question was a bit confusing to the subjects because subjects thought that they were being asked to identify the period of time before the patients died (i.e. the time between when the patients were allowed to return home and their death). In fact, the object of this question was the duration of the period between when patients were diagnosed with ESRD and refused to receive dialysis until the point at which they died.	Question No 7 to be rewritten, changing it from " <i>How long had he been ill before he died?</i> " to " <i>How long was it after he was diagnosed with ESRD and managed without dialysis until he died?</i> "	No problem (5/5)		Question No. 7: One subject thought the current response categories provided were good and felt they were clearer than numbers, especially for elderly caregivers. This was because elderly caregivers might be confused when they read the response categories which contained numbers.	
Question No. 56: the question asked for an evaluation of health services outside the	<u>Could not answer as the patient didn't receive health services at home. Therefore, the subjects felt it was difficult to answer (3/5)</u> Three subjects felt a little bit confused by the phrases	The researcher considered that if the patients didn't receive health services at home, this question could be skipped.	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
hospital	“hospital services” and “services outside the hospital”. This was because the patients didn’t receive health services at home. Therefore, the subjects felt it was difficult to answer. Afterwards the researcher explained the meanings of the phrases and the subjects understood and felt they could answer the question.					
Question No. 67: the connection between two other questions (Nos. 66 and 67)	This question is connected to question No. 66, “Did he say where he would like to die?”. If the answer to that question was “yes”, the subject should go on to answer this question.	After discussion with research supervisors, it was decided there was no problem with this question.	No problem (5/5)			
4. Difficulties regarding the response categories						
Lack of some categories Question No. 17 and 22	<u>Felt the response categories “nobody” or “couldn’t contact” should be added (5/5)</u> Subjects recommended that response categories should be added for “nobody” or “couldn’t contact”, to take account of situations where	The response category “Nobody or couldn’t contact” to be added to questions 17 and 22. o Nobody or couldn’t contact	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	something happened but patients couldn't contact anybody, or where the patients did contact someone but nobody could come to provide urgent care at home out of hours.					
Question No. 34	<u>Felt the response category of "Didn't have nurse(s) or didn't have nurse visits at home" should be added for this question. (3/5)</u> Three subjects said their relatives didn't receive any home visits from nurses. The subjects could not answer this question because there was no response category relating to their answer.	The response category "o No nurse(s) or nurses didn't visit him at home" is added for this question.	No problem (5/5)			
Too many response categories						
Question No. 18	<u>Felt there were too many response categories (4/5)</u> Subjects felt there were too many response categories, and a few response categories did not make sense. This was because it would be impossible to receive that kind of service.	Therefore, 3 response categories are deleted. o Given medical advice over the telephone o Given another number to ring to get medical advice o Advised to go	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
		to private clinic				
Question No. 23	<u>Felt there were too many response categories (3/5)</u> Subjects recommended there were too many response categories, and a few response categories did not make sense. This was because it would not be possible to receive that kind of service.	Therefore, 3 response categories will be deleted. <ul style="list-style-type: none"> o Given medical advice over the telephone o Given another number to ring to get medical advice o Advised to go to private clinic 	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
				Question No 56. (3/5)	Three response categories should be reduced and rearranged. These three response categories: o In hospital ward-please write the name of the hospital in the space below:..... o In hospital accident and emergency department-please write the name of the hospital in the space below:..... o In hospital Intensive Care Unit-please write the name of the hospital in the space below:.....	Remained the same

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
<p>The response categories were too complicated (Question Nos. 60 and 61)</p>	<p><u>Felt it was too complicated to make a decision and provide an answer. Subjects needed time to think and then they were able to answer (5/5)</u> The researcher considers that the different type of response categories in the questionnaire might hinder the subjects in answering this question. It would be better to have one type of response category, especially when the questionnaire is used with subjects who lack knowledge about the help received. In addition, the researcher will provide time for them to become familiar with types of response category</p>	<p>Question No. 60 is changed to No.51, and type of response category is changed to</p> <ul style="list-style-type: none"> o Yes, always o Yes, most of the time o Yes, some of the time o No o Don't know <p>Question No 61 is changed to No. 52 and type of response category is changed to</p> <ul style="list-style-type: none"> o Completely, all of the time o Completely, some of the time o Partially o Not at all o Don't know 	<p>No problem (5/5)</p>			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
				Question No. 49 (1/5)	Don't think the phrase "all the time" is necessary in the response categories. <ul style="list-style-type: none"> o At home <u>all the time</u> o In a hospital <u>all the time</u> 	Remained the same
				Question No 13. Problem with the response categories.(2/5) <ul style="list-style-type: none"> o Less than 5 hours per week o 5-10 hours per week o 11-19 hours per week o 20-39 hours per week o 40 or more hours per week 	The response categories should be changed from hours to days. This is because the patient depended on the subject all the time. The amount of hours may make elderly caregivers feel it is difficult to count and they might be unable to remember how many hours they spent caring for their patients.	Remained the same
5. Difficulties with interpreting response						

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
categories						
Question No. 26 to 33: The level of response categories resulted in an unclear result.	<u>This question should separate the response categories into "yes" and "yes rarely". (2/5)</u>	<p>The researcher noted response categories needed to be revised. This is because the level of response should be differentiated between "Yes" and "Yes rarely". The resulting different levels of response category will provide for different interpretations. Decision made to revise all the relevant response categories.</p> <p>In the last 3-12 months before death In the last 3 months before death Yes, all the time Yes, sometimes Yes, rarely</p>	No problem (5/5)			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
		Not at all Don't know				
Question No. 64: The response categories were suitable for answers related to patients who had died at the hospital.	<u>This question should have an extra response category: "I didn't have contact as he/she died at home". (2/5)</u> The subjects commented that their relatives had died at home, not in the hospital. The response categories are suitable for answers related to patients who died at the hospital.	The question NO. 64 is changed to No. 55. The response category is added: o I didn't have contact as he died at home	No problem (5/5)			
6. Comments on the overall length of the questionnaire	<u>Felt it was not too long or burdensome (3/5)</u> <u>Felt it was long but not too burdensome (2/5)</u>	The number of questions in section 6 Provincial, district and community nurses was considered to reduce in order to avoid the collapsing of the question. Then the overall length of the questionnaire is reduced from 42 pages to 38 pages. The total number of questions were reduced from 78 to 69 questions.	<u>Felt it was not too long or burdensome (5/5)</u> <u>Felt it was long but not too burdensome (5/5)</u>			

Problems from the first cycle	Recommendations by participants from the first cycle (N=5)	Solutions for the first cycle	Problem from the second cycle	New problems from the second cycle	Recommendations by participants from the second cycle (N=5)	Solutions
	-		-	7. The way to complete the questionnaire (post, interview or e-mail) - Which way you like to answer this questionnaire?	<u>Felt it should be an interview administered questionnaire (5/5)</u>	
	-		-	8. Anything else to be improved - Anything else that you think this questionnaire should be improved?	<u>Felt there was nothing to add or improve (5/5)</u> <u>Felt it is ready to use (5/5)</u>	
	-		-	9. Time spent during interviewings - Do you think is it take time for answering this questionnaire (35-45 mins)?	<u>Felt it was not take time to answer the questionnaire (5/5)</u>	

APPENDIX Q: Statistic report for the pilot survey (Phase III)

Statistic report for the pilot survey (Phase III)

1. Demographic characteristics of the informants and the deceased

The majority of informants were either the patients' daughters or sons (50%) (Table 1). Around 15% of informants were husbands, wives or partners. The proportion of neighbours was equal to the number of sons-in-law or daughters-in-law but was higher (10%) than the proportion of other relatives (5%) who regarded themselves as carers. Most informants were aged between 50 and 59 years (60 %), and there were fewest informants ages between 70 and 79 years (5%). The ratio of genders was equal between males and females at 50%. Informants were Buddhists (100%).

Table 1 Demographic characteristics of the informants and the deceased – frequencies (%)

	Informants		Deceased	
	(N=20)	(%)	(N=20)	(%)
Relationship with deceased				
Husband/Wife/Partner	3	15		
Son/Daughter	11	55		
Brother/Sister	1	5		
Son-in-law/Daughter-in-law	2	10		
Other relative	1	5		
Neighbour	2	10		
Friend	0	0		
Someone else	0	0		
Age				
20-29	2	10		
30-39	3	15		
40-49	2	10		
50-59	12	60	2	10
60-69	0	0	8	40

Appendix Q

	Informants		Deceased	
	(N=20)	(%)	(N=20)	(%)
70-79	1	5	8	40
80-89	0	0	2	10
Gender				
Male	10	50	10	50
Female	10	50	10	50
Religion				
Buddhist	20	100	20	100
Duration of illness from diagnosis until death				
Sudden death				
< 24 hours			1	5
1 day but < 1 week				
1 week but < 1 month			2	10
1 month but < 3 months			6	30
3 months but < 6 months			4	20
6 months but < 1 year			5	25
1 year or more			2	10
Time spend at home during the last three months				
Yes			20	100
No			0	0

There was an equal distribution of patients in terms of gender. Most patients were aged between 60 and 79 years. The majority (30%) were ill for a period of over 1 month, but less than 3 months. A small number (5%) died within twenty-four hours of receiving their diagnosis of ESRD. 25% of patients died between 6 months but 1 year from diagnosis, 10% died between 1 week but 1 month and another 10% lived for longer than a year. All the patients (100%) spent time at home during the last three months of their life.

1.1 Experiences and care needs

Data on individual items from the VOICES questionnaire (ESRD-VOICES/Thai version) will be reported according to the different sections of the questionnaire. And presented for the whole sample and displayed as frequencies and percentages. The qualitative data from open ended questions at the end of each section were analysed and coded by section. Before reporting responses to individual questions the next section addresses the findings about overall care quality and views on care provided by different services.

1.2 Overall care of quality according to care setting

The quality of care in the last three months of life was evaluated using a general question about overall satisfaction with different services (including help at home, urgent care out of hours services, urgent care in office hours, district and community nurses, doctors, hospital nurses, hospital doctors) and satisfaction with overall care (questions 15, 20, 25, 37, 45, 48, 68).

Table 1.2 Overall care quality according to care setting - frequencies (%)

Overall care in the last three months of life	Excellent		Good		Fair		Poor		Don't know	
	N	%	N	%	N	%	N	%	N	%
Help at home	1	5	4	20	8	40	7	35	0	0
Urgent care out of hours	4	20	3	15	5	25	1	5	7	35
Urgent care in office hours	1	25	6	30	3	15	1	5	9	45
District and community nurse	1	5	2	10	1	5	1	5	15	75
District doctors	0	0	6	30	11	55	2	10	1	5
Hospital nurses	1	5	10	50	7	35	2	10	0	0
Hospital doctors	1	5	11	55	7	35	1	5	0	0
Overall care	2	10	8	40	10	50	0	0	0	0

The data from the Table 1.2 compares the quality of care from different settings by nearly half of the respondents (N = 8, 40%) thought that the quality of care at home should be rated as “fair”. Only one respondent (5%) thought the quality of care at home was as “excellent”. The quality of urgent care in office hours was rated as “fair” (30%), but the quality of urgent care out of hours was also reported at “fair” (25%) and 35% did not know. The quality of care provided by hospital doctors was rated as “good” (55%), but district doctors were rated as “fair” (55%). 75% of the respondents were unable to rate the overall quality of care provided by district and community nurses. However, half or respondents rated the quality care of hospital nurse at “good” (50%). Finally, the overall quality of care received by older ESRD patients who managed without dialysis during the last three months was rated as “fair” (50%).

Qualitative comments:

Help at home

During the interviews, three thought that the help at home was terrible. This was because no nurse or doctor came to visit their patients at home between the time when the patient left the hospital until their death. Two respondents said they were visited by community health volunteers at home, but they did not provide any necessary health support for their patients.

It is a terrible	nothing
3/20	2/20
<p><i>“It is a terrible</i> thing. I think my husband really wanted a nurse to come to see him at least once at home. It was bad that I had to take him to the hospital often. The last time, he died on the way to the hospital.”</p>	<p>The community health volunteer came to see my mother once or twice, but you know, <i>it was nothing more than social communication.</i>”</p>

Urgent care out of office hours

Four respondents considered the quality of urgent care out of office hours as “good”. The respondents said that when their patients had the emergency health problems, the patients received immediate care from doctors and nurses at the emergency units in hospitals.

quite good

4/20

<p>“I do think the care provided by the doctors and nurses at emergency unit at night is quite good as my father often had breathlessness at night time, and when we went to the hospital all the nurses and doctors tried to help him as much as they could.”</p>

Urgent care within office hours

The overall comments on the quality of urgent care in office hours indicate that it was viewed by respondents as unproblematic. This was because this kind of service was not normally required. However, three respondents provided negative comments, stating that they had to wait for many hours for a meeting at the hospital before their patients could see the doctors. Moreover, it seemed to them that the time allocated by the doctors for examining their patients was very short (only two to five minutes) compared with the time they have to wait, which was around five to six hours. This made respondents wonder about the quality of the health check-up.

bored and annoyed	insufficient for health check up
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3/20	3/20
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<p>“For me, taking my Mom to the hospital was not the problem. I was just bored and annoyed about the waiting time at the hospital, as it took too long before my Mom could meet with the doctor.”</p>	<p>“You know, on the day of the appointment we have to wake up early in the morning at around four am as it take two to three hours to travel from our home (in Mae Eye district) to the provincial hospital. We have to arrive at the hospital before seven am otherwise there will be a long queue, but the doctor spent just two to five minutes checking up on my father’s health. I don’t think this is sufficient time to check all of his health problems.”</p>
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Provincial nurses

Half of the respondents felt satisfied with the quality of care provided by the hospital nurses. Seven respondents provided positive comments that the nurses at the hospital were effective in providing care for older ESRD patients. Particularly, renal nurses at the renal unit did not only provide care, but also taught patients and carers how to live without dialysis at home.

smart and effective	felt confident/ worked quite well
7/20	10/20
<p>"I like the nurse at the renal unit. Everyone is smart and effective in providing specific care for the patients. I can compare them with the nurses at the district hospital –they provide good communication, basic care or basic health monitoring for patients and carers, but they do not provide complex specific care for ESRD patients like my father." with the doctor."</p>	<p>"I felt confident when my father was treated at the renal unit because the nurses worked quite well by trying to help him and many medical treatments were immediately provided – for example, they did laboratory testing, X-rays, blood transfusions etc. The nurse also told me regularly about my father's condition and informed me step by step what they would do and what would happen with my father."</p>

District and community nurses

One respondent said that his mother received excellent care from the district nurse every time he took the patient to the hospital. Sometime the nurse came to see the patient and provided physical health monitoring at home. This is similar to another two respondents who felt satisfied (good) with the support from district nurses and their understanding of patients' needs during the last three days of their lives.

understood	I was satisfied
1/20	2/20
<p>“The district nurse <i>understood</i> about my mother’s health problems quite well. The nurse came to see my mother once a month at home and more often during the last months.”</p>	<p>“I always asked the district nurse about complications and medicines for ESRD patient when they managed without dialysis, how to support my father’s emotions. Even though the nurse could not come to see my father at home, <i>I was satisfied</i> with the way the nurse tried to help and provided suggestions every time when I went to the hospital or called the nurse.”</p>

General doctors and physicians

More than half the respondents (N=11) provided comments regarding the overall care that their patients received from general doctors and physicians. Respondents pointed out that general doctors at district hospitals provided good communication to the patients. However, the doctors were quite busy and did not have enough time to listen and discuss health problems in detail with patients and carers.

quite a nice	couldn’t imagine
11/20	2/20
<p>“The doctor at Mae Tang hospital was <i>quite a nice</i> doctor. He was also polite and was never angry or annoyed when I tried to ask him questions regarding my father’s health problems. However, the doctor was quite busy and did not have time to see my father at home.”</p>	<p>“Sorry, I couldn’t imagine how easy or difficult for the doctor to see my mother at home.”</p>

1.3 Dignity and respect

How much of the time was she/he treated with dignity and respect by <i>the district and community nurses, doctors or health care professionals?</i>
All the time
Most of the time
Some of the time
Never

The question above related to questions 36, 43 and 50, asked within each care setting including help at home, urgent out of hours care services, urgent care in office hours, district and community nurses, doctors, hospital nurses, hospital doctors and overall care.

Table 1.3.1 Dignity and respect from doctors and nurses – frequencies in the last three months (%)

(Question Nos. 36 & 43)	Doctor	Nurse
How much of the time was she/he treated with respect by	N (%)	N (%)
Always	8 (40)	1 (5)
Most of the time	8 (40)	1 (5)
Some of the time	1 (5)	2 (10)
Never	2 (10)	1 (5)
Don't know	1 (5)	15 (75)

Eight (40%) of the respondents related that their relative was “always” treated with dignity and respect from the doctors and nurses at the district hospital. Another eight (40%) reported rated dignity and respect was shown towards their relative “most of the time”. Only 10% rated this answer as “never”.

Table 1.3.2 Dignity and respect during the last three days - frequencies (%)

(Question No. 50) How much of the time was she treated with respect in the last three days of life?	Always		Most		Sometime		Never		Don't know	
	N	%	N	%	N	%	N	%	N	%
At home all the time	9	90	1	10	0	0	0	0	0	0
At the hospital all the time	0	0	6	60	2	20	2	20	0	0

For care received at home, most of respondents rated the level of dignity and respect during the last three days of their patients' lives as "always" (90%). 10% was rated it at "most of the time". In contrast, the level of dignity and respect during the last three days of patients' lives at hospital was rated "most of the time" (60%), "sometimes" (20%) and "never" (20%).

1.4 Co-ordination of Care

(Q 10 and Q 47) When she was at home in the last three months of life, did all the services work well together?

Yes definitely

Yes to some extent

No they did not work well together

Don't know

The question above was applied to items No 10 and 47 in the questionnaire in order to ask about the co-ordination of care between the health services at home in the last three months and the health services provided during the last hospital admission.

Table 1.4 Co-ordination of Care – frequencies (%)

In the last three months of life, did all the services work well together? (Question no. 10 & 47)	Yes definitely		Yes to some extent		No		Don't know	
	N	%	N	%	N	%	N	%
At home	3	15	9	45	7	35	1	5
During the last hospital admission	2	10	11	55	5	25	2	10

Regarding the co-ordination of care during the time that the patients were at home in the last three months of life, 45% answered “yes to some extent”, 15% said “yes definitely”, while 35% responded “no”. This is a little different from the answers regarding the co-ordination of care during the last hospital admission as 55% answered “yes to some extent”, 10% said “yes definitely” but 25% responded “no”.

Qualitative comments:

Nine out of twenty respondents suggested that when the patients were at the hospital the health services showed more effective co-ordination and worked better than when the patients were at home.

“If I compare the health services which my mother received at the hospital during her last admission, they were better than when she lived at home.”

“It was difficult to receive a good co-ordination of health services when my father was at home. I had to contact the doctor or nurse at the district hospital and also had to take my father to the provincial hospital myself. No nurse or doctor would come to do this for us. They wanted the patients come to the hospital themselves.”

1.5 Section 3: Help at home

Question No 9. Did the patient receive any health services at home from any of the health care professionals listed below?

This question aims to find out health services or types of helping at home that the patient received during the last three months.

Table 1.5.1 Proportion receiving health services at home – frequencies (%)

Question 9	Number	Percentage
Health services received at home by	(N=20)	(%)
A district, community or provincial nurse	5	25
Doctor	2	10
Community health volunteer	4	20
Renal nurse specialist	0	0
Social worker/support worker	0	0
Occupational therapist (OT)	0	0
Counsellor	0	0
Did not receive any care	9	45
Religious leader (did not provide health services)	0	0
Don't know	0	0

The majority (45%) of the patients did not receive any care when they were managed without dialysis at home. However, 25% received health services from a district, community or provincial nurse, 20% received health services from community health volunteers and 10% received health services from doctors at home.

The question No 11 aims to evaluate the patients' needs about special medical equipment support at home.

Table 1.5.2 The patients' needs about special medical equipment support at home

Question 11. Did she have any special equipment, the equipment that the patient need at home to help her get better, (including types of oxygen support, i.e. a mask or tent), wheelchair etc.?	
<input type="checkbox"/>	Yes
<input type="checkbox"/>	No
<input type="checkbox"/>	Don't know

Question 11. Did she have any special equipment, the equipment that the patient need at home to help her get better? including types of oxygen support, i.e. a mask or tent wheelchair etc.	Yes		No		Don't know	
	N	%	N	%	N	%
	3	15	17	85	0	0

15% of respondents reported that their relatives were received special equipment support at home but other 85 % did not.

Qualitative comments:

The three respondents who reported that their relatives were received special equipment support at home such as oxygen and it equipment.

“During the time my father was at home, he had problem with the breathlessness and it made him unable to breath properly. So, I took him to the district hospital, when he was discharged from the hospital, the doctor allowed me to bring the oxygen mask and it' equipment including the portable oxygen tang back home.”

Question 12. Was any equipment, the equipment apart from special equipments that the patient needed at home to help her get better from her symptoms, needed that she didn't have?

- Yes
 No
 Don't know

If Yes:

a) Please state what equipment was needed.....

The question No 12 is to evaluate about any special equipment that the patients were needed but did not receive when they were managed without dialysis at home.

Table 1.5.3 Special equipment - frequencies (%)

(Question no. 11 & 12) Any special equipment was needed but did not receive at home	Yes		No	
	N	%	N	%
Toilet chair	2	10	18	90
Walker	3	15	17	85

Five respondents (25%) reported that their relative needed other special equipments during the time they were at home (Table 9.6.4.3). Two respondents (10%) suggested the toilet chair and 15% recommended that the walker were required.

Qualitative comments:

Five respondents explained that their relatives needed to receive any special equipment such as the toilet chair was required at home. Two of them used to say that their relatives were unable to help themselves when wanted to go to toilet and some respondents felt difficult to help their relatives.

“You know what. It got the difficulty times when I had to carry my father who couldn’t ether stand by himself to the toilet and I had to do 3-5 times a day including at night. If it is possible, It will be good if the hospital will provide the toilet chair for the patients’ home.”

Three complaining were related to the complication of oedema that impacted on their relatives were unable to walk properly and the walker was the useful equipment to support them when walked.

“Oedema was the cause that made my mother couldn’t stand or walk without helping by someone. I had to buy the walker for her. This equipment should not be paid by patients who got severe oedema and were not unable to walk without supporting.”

(Question No. 13) Did she get help from family and friends (including yourself) with any of the following? (please tick one box for each type of help he got)			
	Yes	No	Don't know
Personal care			
Household task			
Night time care			
Taking of medicine			

This question is described in order to know about how often patient had to depend on their carer at home and to know how much the burden of the carers were.

Table 1.5.4 Help from family and friends at home- frequencies (%)

(Question No. 13) Did s/he get help from family and friends with any of the following?	Yes		No		Don't know	
	N	%	N	%	N	%
Personal care	15	75	5	25	0	0
Household tasks	17	85	3	15	0	0
Night time care	16	80	4	20	0	0
Taking of medicine	15	75	5	25	0	0

There was shows that the most of respondents helped their relatives on four main tasks including personal care (75%), the night time care (80%) and taking of medicine (75%) and the household task was the task that was rated at the highest score at 85%.

Question No. 14 Did you get help from health care professional with any of the following? (please tick one box for each type of help she got)			
	Yes	No	Don't know
Personal care			
Household task			
Night time care			
Taking of medicine			

Table 1.5.5 Help from health care professional at home- frequencies (%)

(Question No. 14) Did you get help from health care professional with any of the following?	Yes		No		Don't know	
	N	%	N	%	N	%
Personal care	10	50	10	50	0	0
Night time care	0	0	20	100	0	0
Taking of medicine	0	0	20	100	0	0

50% of respondents received help on the person care from health care professionals but 100% of respondents did not get help on night time care and taking of medicine from health care professional at home.

<p>Question No. 14 a How often did she or you get help from the “health care professional”? (personal care, night time care and taking of medicine?) At least once a day At least once a week At least once a month Less than once a month</p>
--

The question No 14 (a) was likely to ask how much time was spend by carer for caring their patients in each tasks?

Table 1.5.6 Frequency of health care professional for help at home

Hours/ week	Personal care N (%)	Night time care N (%)	Taking of medicine N (%)
At least once a day	0 (0)	0 (0)	0 (0)
At least once a week	0 (0)	0 (0)	0 (0)
At least once a month	2 (20)	0 (0)	0 (0)
Less than once a month	8 (80)	0 (0)	0 (0)

The majority of respondents (80%) reported they were supported by help care professionals on personal care less than once a month. 20% was received the help on personal care at least once a month.

1.6 Section 4: Urgent Care (out of hours and in the week during office hours.)

(Question No. 16 & 21) In the last three months of life, while she was at home, did she ever need to contact a health professional for “urgent care/ during office hours” in the evening or at the weekend?

Tick one only

Not at all in the last 3 months

If yes please tick one only

Once or twice

Three or four time

Five times or more

Don't know

The above question was asked to know the frequency of contacting for receiving the urgent care during out of hours and in the week during offices hours.

Table 1.6.1 In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent?

(Question No. 16 & 21)	Yes		No	
	N	%	N	%
In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent?				
Q 16: Out of hours	15	75	5	25
Q 21: During office hours	9	45	11	55

Table 1.6.1 shows the difference between needs to contact health professional for something urgent during the out of hours and in the offices hours. 75% of respondents reported that they needed to contact health professional for something urgent during out of hours. In contrast, the needs to contact health professional in office hours was rated as 45%.

Table 1.6.2 The frequency s/he need to contact a health professional for something urgent

(Question No. 16 & 21 cont.)	Q 16		Q 21	
In the last three months of life, while she was at home, did she ever need to contact a health professional for something urgent	Out of hours		During office hours	
	N	%	N	%
Once or more	8	54.	7	78
Three or four times	5	33.	2	22
Five times or more	2	13	0	0
Don't know	0	0	0	0

54% of respondents who their relative needed urgent care during out of hours provided the score at “once or more” and 33% was at “three or four times.

Whist, 78% of respondents reported that their relatives needed to contact health professional in office hours at “once or more” and 22% was at “three or four times”.

(Question No. 17 & 22) The last time this happened, who did she/he contact, or who was contacted on her behalf?

Tick all that apply

- General doctor/physician
- The special out-of hours number.....
- Provincial nurses
- District nurses
- Community nurses
- Community health volunteer
- Something else-please write in the space

below:.....

This type of question was developed to ask the informants about who was the health care professional that provided the urgent care to the deceased during out of hours and in the week during offices hours.

Table 1.6.3 The last time this happened, who did she contact, or who was contacted on his/her behalf?

(Question No. 17 & 22)	Q 17		Q 22	
The last time this happened, who did she contact, or who was contacted on his/her behalf?	Out of hours		During office hours	
	N	%	N	%
Out of hours hospital number	1	6.67	1	11
General doctor or physician	0	0	0	0
Provincial, District or community nurses	10	66.67	8	89
Nobody or can't contact	3	20	0	0
Someone else (village health volunteer)	1	6.67	0	0

Urgent care during out of hours, provincial, district or community nurses were contacted by respondents (66.67%) while 20% of the respondents couldn't contact to health professional. In comparison, 89% of respondents reported that they could be contacted to provincial, district or community nurses during office hours and 11% was able to call the out of hours hospital number.

(Question No. 18 & 23) What happened as a result? Was she/he...

Tick one only

- Visited by district nurse at home
- Visited by provincial nurse at home
- Visited by district doctor or general physician at home
- Given medical advice over the telephone
- Given another number to ring to get medical advice
- Advised to go to the Emergency department at a hospital
- Advised to go to the renal unit at a hospital
- Advised to go to the community health services
- Advice to go to private clinic
- Something else-please write in the space

below:.....

This question was asked the informants about what kind of health service that the patients received for the urgent care during out of hours and in the week during offices hours.

Table 1.6.4 Health services for the urgent care during out of hours and in the week during offices hours

(Question No. 18 & 23)	Q 18		Q 20	
	Out of hours		During office hours	
	N	%	N	%
Visited by a district nurse at home	0	0	1	11
Visited by a provincial nurse at home	0	0	0	0
Visited by district doctor or general physician at home	1	6.67	1	11
Visited by a provincial doctor at home	0	0	0	0
Advised to go to the Emergency department at a hospital	13	86.67	4	45
Advised to go to the renal unit at a hospital	0	0	2	22
Advised to go to the community health services	1	6.67	1	11
Something else (Can't contact)	0	0	0	0

During out of hours (Table 1.6.4), 86.67% of respondents were advised to go to the emergency department .While 45% were advised to go to the emergency department and 22% was advised to go to the renal unit at a hospital in the office hours.

1.7 Section 5: Symptom experiences and treatment

<p>Question No 26-33</p> <p>Did she/he suffer with (Breathlessness, Itching, Pain, Oedema, Nausea/vomiting and Poor appetite?</p> <p>Yes, all time</p> <p>Yes, sometimes</p> <p>Yes, rarely</p> <p>Not at all</p> <p>Don't know</p>
--

This question was applied to question No 26-33 for symptoms experiences and treatments of ESRD patients who managed without dialysis during the last year of life.

Table 1.7.1 Symptoms experiences

Question No 26-33	3-12 months before death-N (%)					The last 3 months-N (%)				
	All time	Sometime	Rarely	No	Don't know	All time	Sometime	Rarely	No	Don't know
Breathlessness	1(5)	4(20)	3(15)	12(60)	0(0)	5(25)	13(65)	0(0)	1(5)	1(5)
Itching	1(5)	1(5)	4(20)	11(55)	3(15)	4(20)	7(35)	1(5)	7(35)	1(5)
Pain	2(10)	7(35)	2(10)	7(35)	2(10)	9(45)	9(45)	0(0)	1(5)	1(5)
Oedema	0(0)	7(35)	3(15)	6(30)	4(20)	9(45)	7(35)	2(10)	2(10)	0(0)
Nausea/vomiting	1(5)	5(25)	6(30)	6(30)	2(10)	5(25)	6(30)	2(10)	6(30)	1(5)
Poor appetite	0(0)	3(15)	7(35)	8(40)	2(10)	4(20)	13(65)	1(5)	1(5)	1(5)
Worry	0(0)	6(30)	1(5)	8(40)	5(25)	3(15)	9(45)	1(5)	3(15)	4(20)
Low mood	0(0)	6(30)	1(5)	8(40)	5(25)	3(15)	10(50)	1(5)	4(20)	2(10)

During the last twelve months, 40% of respondent rated pain and oedema was the main suffering symptoms that were happened “sometime”, whilst 30% provided as low mood and worry. In addition, 35% of respondent provided the score at “rarely” for poor appetite and 30% was nausea/vomiting. In contrast, 60% of respondents said their relative didn’t suffer with breathlessness, 55% didn’t suffer with itching. 10-25% of respondents didn’t know their relative suffered with symptoms (including itching, pain, oedema, nausea/ vomiting, poor appetite, worry and low mood) (Table 1.7.1)

In the last three months, 45% of respondents recommended that pain and oedema made the most suffering to their relatives at “all time”. 65% reported that breathlessness and poor appetite were “sometimes” happened to their relatives. 50% of respondents reported low mood was “sometime” developed and 35-45% reported their relatives “sometime” got pain, oedema, itching,

nausea/vomiting and worry. 5-20% of respondents “did not know” their relatives faced with symptom’s’ experiences (Table 1.7.1).

Question No 26-33		
a)	3-12 months before death...	The last3 months
Yes.....		
No.....		
Don't know.....		

Table 1.7.2 (a) Did the patient receive any treatment for his/her symptoms?

Question No 26-33 (a)	3-12 months before death -N (%)			The last 3 months-N (%)		
	Yes	No	Don't know	Yes	No	Don't know
Breathlessness	8(100)	0(0)	0(0)	12(66)	6(33)	2(11)
Itching	5(83)	1(17)	0(0)	10(83)	2(17)	0(0)
Pain	11(100)	0(0)	0(0)	15(83)	3(17)	0(0)
Oedema	10(100)	0(0)	0(0)	15(83)	3(17)	0(0)
Nausea/vomiting	9(75)	3(25)	0(0)	12(92)	1(8)	0(0)
Poor appetite	8 (80)	2(20)	0(0)	14(78)	4(22)	0(0)
Worry	6(86)	1(14)	0(0)	12(92)	1(8)	0(0)
Low mood	7(100)	0(0)	0(0)	12 (86)	2(14)	0(0)

According to the last year of the patients’ life, the symptoms management related to breathlessness, pain ,oedema and low mood was considered by respondents as well provided (100%).The majority of respondents also reported their relatives was provided with treatments to control symptoms including itching (83%) poor appetite (80%), worry (86) and nausea/vomiting (75%) (Table 1.7.2).

Comparing with in the last three months, the treatments for controlling patients' symptoms (breathlessness (66%), pain (83%), itching (83%), oedema (83%), poor appetite (78%) and low mood (86%) were less likely provided to the patients than the treatments provided in the last year of patients' life. However, the increasing of score for receiving treatments to control symptoms was focused on nausea/vomiting and worry at 92%.

Question No 26-33		
b) Did the treatment help his/her breathlessness?		
	3-12 months before death...	The last3 months
Yes.....		
No.....		
Don't know		

Table 1.7.3 (b) Did the treatment help the patients release from his/her symptoms?

Question No 26-33 (b)	3-12 months before death N (%)			The last 3 months-N (%)		
	Yes	No	Don't know	Yes	No	Don't know
Breathlessness	8(100)	0(0)	0(0)	12(66)	5(28)	1(6)
Itching	4(66)	1(17)	1(17)	7(58.3)	4(33.3)	1(8.3)
Pain	11(100)	0(0)	0(0)	12(66)	6(34)	0(0)
Oedema	10(100)	0(0)	0(0)	14(78)	3(16)	1(6)
Nausea/vomiting	10(83)	2(17)	0(0)	11(79)	3(21)	0(0)
Poor appetite	8(80)	2(20)	0(0)	10(56)	8(44)	0(0)
Worry	6(86)	1(14)	0(0)	10(77)	3(23)	0(0)
Low mood	6(86)	1(14)	0(0)	10(83)	2(17)	0(0)

Table 1.7.3 shows the contradiction between the effectiveness of symptom managements for releasing patients' suffering during the last year and the last three months. During the 3-12 months before death, all respondedents (100%)

reported the treatments helped their patients released from the symptoms' experiences such as breathlessness, pain, and oedema. In addition, more than half of the respondents reported the treatments helped their relatives released suffering from symptom including worry and low mood (86%), nausea/vomiting (83%), poor appetite (80%) and itching (66%).

In contrast within the last three months, the scores of the treatments to release the patients' sufferings from symptoms were dropped in all symptoms including breathlessness (66%), pain (66%), oedema (78%), worry (77%), low mood (83%), nausea/vomiting (79%), poor appetite (56%) and itching (58.3%).

1.8 Section 6: Provincial, district and community nurse

<p>Question 34 Did nurse(s) visit she/he at home?</p> <p>a) If yes, which type of nurse visited he/she?</p> <p>Provincial N.</p> <ul style="list-style-type: none"> <input type="radio"/> District N. <input type="radio"/> Community N. <input type="radio"/> Others..... <p>b) Did she/he receive help at homes for his/her renal trouble from the provincial, district or community nurses?</p> <p>Yes.....</p> <p>No.....</p>

The question above aims to know about nurses visiting the patient at home and who is the nurse that used to visit at home.

Table 1.8.1 Provincial, district or community nurse

Question No. 34 Did a nurse(s) visit his/her at home?	N	%
Yes	5	25
No	15	75
a) Which type of nurse(s) visited he/she at home?	N	%
Provincial nurse	1	20
District nurse	3	60
Community nurse	1	20
b) Did he/she receive help at home for his/her renal trouble from the nurses?	N	%
Yes	2	40
No	3	60

The vast majority of respondents (75%) reported nurse(s) did not visit the patients at home, but 25% of respondents said their relatives were visited by nurse(s) at home. The variety of nurse(s) who visited at home was reported including district nurse (60%), community nurse (20%) and provincial nurse (20%) (Table 1.8.1). 60% of respondent said their relatives did not receive any help related renal problems at home by nurses.

Question No. 35: How often did the nurses visit (at the most frequent time)?

More than once a day

Every day

2-6 times a week

Once a week

2-3 times a month

Less often

Don't know

Table 1.8.2 Visiting by nurse (at the most frequent time)

(Question No. 35) How often did the nurses visit (at the most frequent time?)	N	%
More than once a day	0	0
Every day	0	0
2-6 times a week	0	0
Once a week	2	50
2-3 times a month	3	50
Less often	0	0
Don't know	0	0

50% of respondents reported the frequency of the nurses visiting at home as “once a week” and another 50% was at “2-3 times a month” (Table 1.8.2).

1.9 Section 7: General doctors & physicians

<p>Question 39 What services did the doctor provide for him/her and you?</p> <p>Please tick all the boxes which apply</p> <p><input type="radio"/> Emergency care.....</p> <p><input type="radio"/> Repeat prescriptions.....</p> <p><input type="radio"/> Changing his medication.....</p> <p><input type="radio"/> Emotional support.....</p> <p><input type="radio"/> Arranging extra help at home.....</p> <p><input type="radio"/> Providing information about his/her renal conditions.....</p> <p><input type="radio"/> Regular check-ups for his/her renal condition.....</p> <p><input type="radio"/> Referral to outpatients.....</p>
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Table 1.9.1 Services provided by doctors/ physicians

(Question No. 39) What services did the doctor provide for her and you?	N	%
Emergency care	17	85.0
Repeat prescriptions	18	90.0
Changing his/her medication	9	45.0
Emotional support	9	45.0
Arranging extra help at home	4	20.0
Providing information about his/her health conditions	9	45.0
Regular check-ups for his/her health condition	16	80.0
Referral to outpatients unit	16	80.0

Table 1.9.1 presents the services provided by doctors during the last three months. Four main services were provided by doctors including repeat prescriptions (90%), emergency care (85%), regular health check-ups for the patients' conditions (80%) and the referral to outpatients (80%). Only 20% was an arranged extra help at home.

<p>Question 40 How much did the doctor understand about his/her renal problems (breathlessness, pain, oedema, worry and depress)?</p> <p><input type="radio"/> The doctor understood him very well.....</p> <p><input type="radio"/> The doctor understood him quite well.....</p> <p><input type="radio"/> The doctor did not know him well at all.....</p> <p><input type="radio"/> Don't know.....</p>
--

Figure 1.9.2 Understanding of the doctor to his/her renal problems

(Question No.40)	Very well		Quite well		Not well		Don't know	
	N	%	N	%	N	%	N	%
The doctor understand about her renal problems	13	65	6	30	1	5	0	0

During the last three months, 65% of respondents thought the doctor understood their relatives’ renal problems “very well” but 5% reported the doctor “did not understand” the patients’ renal problem (Table 1.9.2).

Question 41 Do you feel that his/her doctor had time to listen and discuss things?
Please tick the most suitable box

- Always
- Sometimes.....
- Rarely.....
- Never.....
- Not applicable.....

Table 1.9.3 Having time to listening and discussing

(Question No. 41)	Always		Sometime		Rarely		Never		Not applicable	
	N	%	N	%	N	%	N	%	N	%
The doctor had time to listen and discuss things	7	35	5	25	4	20	3	15	1	5

Table 1.9.3 shows that 35% of respondents felt the doctors “always” provided time to listen and discuss things to the patients. While 15% of respondents reported the doctors never had time to listen or discuss with their relatives.

Question 44 If the doctor visited him/her at home in the last three months, how easy or difficult was it to get him/her to visit?

- Very easy
- Fairly easy
- Fairly difficult
- Very difficult
- Don’t know
- She/he wanted the doctor to visit but they would not visit
- Does not apply-the doctor did not need to visit
- Don’t know

Please feel free to make comments in the space below:.....

Table 1.9.4 The opportunity of visiting by the doctor at home in the last three months

(Question No. 44)	Very easy		Fair difficult		Very difficult		Don't know	
	N	%	N	%	N	%	N	%
The doctor visit her/him at home ?	2	10	5	25	11	55	2	10

55% of respondents considered as “very difficult” for the doctor visiting the patients at home but only 10% said it was “very easy” (Table 1.9.4).

Qualitative comments:

Eleven respondents expressed their thought on the possibility of the doctor for visiting at home as “very difficult”. They provided the reasons that the doctor always busy even in the hospital. So, it was very difficult for the doctors to have time for visiting the patients at home

“The doctor was always busy during the time he work at the hospital so it was very difficult for the doctor to see my father at home.”

1.10 Section 8: Last hospital admission

<p>Question 46 Did he/she stay in hospital any time during her/him last three months of life?</p> <p>Tick one only</p> <p><input type="radio"/> Yes-please write the name of the last hospital she/he stayed in, in the space below:.....</p> <p><input type="radio"/> No.....</p> <p><input type="radio"/> Don't know.....</p>

Table 1.10 Last Hospital Admission

(Question No. 46) Did she stay in hospital any time during her last 3 months?	N	%
Yes	8	40
No	12	60

The majority of respondents (60%) reported their relative did not stay in the hospital but 40% said their relative used to stay in the hospital during the last three months.

1.11 Section 9: The last 3 days

<p>Question 49 During her/his last two days of life was she/he</p> <p>Tick one only</p> <p><input type="radio"/> At home all the time</p> <p><input type="radio"/> In a hospital all the time</p> <p><input type="radio"/> Others-please write in the space</p>

Table 1.11.1 Support in the Last 3 days of life

(Question No. 49) During her last three days of life was he	N	%
At home all the time	10	50
At the hospital at the time	10	50

During the last three days of life was reported that 50% of respondents their relative lived at home all the time while another 50% was at the hospital all the time.

Question 51		Yes, always	Yes, most of the time	Yes, some of the time	No	Don't know
51	Your opinion about the help she received in the last three days of life					
(a)	Was there was enough help available to meet his personal care needs (such as toileting needs)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b)	Was there was enough help with nursing care, such as giving medicine and helping him find a comfortable position in bed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c)	Did the bed area and surrounding environment have adequate privacy for him?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Table 1.11.2 Opinion about the help received in the last 3days

(Question No 51)	Always		Most		Sometime		Never		Don't know	
	N	%	N	%	N	%	N	%	N	%
Opinion about the help received in the last 3days										
Enough help for the personal care needs	7	35	7	35	5	25	1	5	0	0
Enough help with nursing care	8	40	7	35	3	15	2	10	0	0
Adequate privacy of surrounding environment	6	30	10	50	1	5	3	15	1	5

Table 1.11.2 shows the enough help on the personal care was mostly rated at always” (35%) and “almost” (35%). 40% of respondents rated the nursing care was “always” provided to their relative in the last 3 days. According to adequate privacy of surrounding environment was rated as “mostly” (50%).

Question 52	Yes, always	Yes, most of the time	Yes, some of the time	No	Don't know
(a) How well were her symptoms relieved?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(b) Did she receive spiritual support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(c) Did she receive emotional support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(d) Did she receive financial support?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
(e) Did she receive any support to stay where she/he wanted to be?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Table 1.11.3 Supports during the last three days

(Question No.52)	Always		Most		Sometime		Never		Don't know	
	N	%	N	%	N	%	N	%	N	%
During the last three days										
How well were her symptoms relieved?	4	20	9	45	4	20	3	15	0	0
Did she received spiritual support?	3	15	6	30	5	25	3	15	3	15
Did she received emotional support?	4	20	7	35	6	30	3	15	0	0
Did she received financial support?	2	10	7	35	6	30	5	25	0	0
Did she allow to stay where she/he wanted ?	2	10	10	50	5	25	2	10	1	5

During the last three days, the symptoms relived was rated at “most” (45%). Spiritual support was also rated as “most” (30%). Respondents reported that their relative received the emotional support was at “most” (35%) as same as receiving financial support (35 %). The half of respondents (50%) said the patients were allowed to stay where they wanted as “most”.

1.12 Section 10: Circumstances surrounding the death

Question 53 Did he/she know she was likely to die?

Tick one only

Yes, certainly

Yes, probably

Probably not

No, definitely

Not sure

Table 1.12.1 Circumstances surrounding the death

(Question No. 53) Did he/she know she was likely to die?	N	%
Yes, certainly	3	15
Yes, probably	8	40
Probably not	4	20
No, definitely	5	25
Not sure	0	0

There was variety of findings on rated by respondents about “Will the patients know he/she die?”. 40% of respondents said “yes probably” their relatives knew where they want to die and 15% was “certainly know”. However, 25% was rated at “probably not” and 25% was said “no definitely”.

Question 56 Where did she die?

Tick one only

In her own home

In the home of another family member or friend

In hospital ward-please write the name of the hospital in the space below:.....

In hospital accident and emergency department-please write the name of the hospital in the space below:.....

In hospital Intensive Care Unit-please write the name of the hospital in the space below:.....

In an ambulance on the way to hospital

Somewhere-please write in the space below:.....

Table 1.12.2 Where did she die?

(Question No. 56) Where did she die?	N	%
In her/him own home	10	50
In the home of another family member or friend	0	0
In hospital ward-(medical ward)	7	35
In hospital accident and emergency department	1	5
In an ambulance on the way to hospital	2	10

Half of respondents reported their relative died “in his/her own home. While another half was provided the data that their relative 35% died in the hospital ward, 10% died in an ambulance care on the way to the hospital and 5% died in hospital accident or emergency department.

Question 58 Where did she say that she would like to die?

At home

In a hospital

She said she did not mind where she died

She changed her mind about where she wanted to die

Table 1.12.3 Where did she say that she would like to die?

(Question No. 58) Where did she say that she would like to die?	N	%
At home	7	87.5
In a hospital	0	0
She said she did not mind where she died	1	12.5
She changed her mind about where she wanted to die	0	0
Somewhere else	0	0

The vast majority of respondents (87.5%) reported their relative would like to die at home. Only 12.5% of respondents their relative did not mind where they will die.

<p>Question 59 Did the health care staff have a record or know of this?</p> <p>Tick one only</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Not sure</p>

Table 1.12.4 Did the health care staff have a record or know of this?

(Question 59)	Yes		No		Not sure	
	N	%	N	%	N	%
During the last three days						
Did the health care staff have a record of this?	7	35	10	50	3	15

Half of respondents thought staff did not record or know where the patients would like to die.

Question 62 Do you feel that her religious, beliefs or faith in God were taken into consideration by those caring for her? Tick one only

- Yes
- Yes, partially
- No
- Don't sure

Please feel free to make comments below:.....

Table 1.12.5 Religious, beliefs or faith in God were taken into consideration

(Question 62)	Yes		Yes, partially		No		Not sure	
	N	%	N	%	N	%	N	%
During the last three days								
Do you feel that her religious, beliefs or faith in God were taken into consideration by those caring for her?	7	35	2	10	11	55	0	0

More than half of respondents reported that the patients' religious, beliefs or faith in god were not taken into consider. However 35% of the respondents reported their relative religious, belief or faith in God was fully considered by health care professional.

Question 63 Were you or her family given enough help and support by the healthcare team at the actual time of her death?

Tick one only

- Yes, definitely
- Yes, to some extent
- No, not at all
- Don't know

Table 1.12.6 Was family given enough help by the healthcare team at the time of her death?

(Question 63)	Yes		Yes, partially		No		Not sure	
	N	%	N	%	N	%	N	%
During the last three days								
Was Family given enough help by the healthcare team at the time of her death?	4	20	4	20	10	50	2	10

50% of respondents were not given enough help and support at the time of their relative death.

<p>Question 65 Looking back over the last three months of her life, was she involved in decision about her care as much as she would have wanted?</p> <p>Tick one only</p> <p><input type="checkbox"/> She was involved as much as she wanted to be</p> <p><input type="checkbox"/> She would have liked to be more involved</p> <p><input type="checkbox"/> She would have liked to be less involved</p> <p><input type="checkbox"/> Don't know</p>

Table 1.12.7 Was s/he involved in decision about her/his care as much as s/he wanted?

(Question 65)	Yes		Yes, partially		No		Not sure	
	N	%	N	%	N	%	N	%
During the last three days								
Was s/he involved in decision about her/his care as much as s/he wanted?	10	50	7	35	3	15	0	0

Half of respondents reported that their relative involved in decision about the care as much as they wanted.

Question 66 Looking back over the three months of her life, were you involved in decisions about her care as much as you would have wanted?

Tick one only

- I was involved as much as I wanted to be
- I would have liked to be more involved
- I would have liked to be less involved
- Don't know

Table 1.12.8 Were you involved in decisions about her care as much as you wanted?

(Question 66)	Yes		Yes, partially		No		Not sure	
	N	%	N	%	N	%	N	%
During the last three days								
Were you involved in decisions about her care as much as you wanted?	9	45	10	50	1	5	0	0

The half of respondents (50%) “partially” involved in the decisions about caring of their relatives and 45% “fully” involved in the decision on caring of their relative.

Question 69 Since she died have you talked to any health care professionals (nurses, doctors etc.) about your feeling, help and support after the patients’ death?

Tick one only

- Yes
- No, but I would have liked to
- No, but I did not want to anyway
- Not sure

Table 1.12.9 After-death support

(Question No. 69) Since she died have you talked to any health care professionals about your feeling, help and support after the patients' death?	N	%
Yes	2	10
No, but I would have liked to	5	25
No, but I did not want to anyway	13	65
Not sure	0	0

The majority of respondents (65%) reported that they did not want to discuss with any health care professional about their feelings, needed of help and support after the patients' death. Only 10% of respondents used to talk to any health care professional in order to support them after the patients' death.

**APPENDIX R: The refined VOICES-ESRD/Thai questionnaire
(English version) (please see separated document)**

**APPENDIX S: The refined VOICES-ESRD/Thai questionnaire
(Thai version) (please see separated document)**

APPENDIX T: Experts contributing to the study

Subject areas	The name of expertise
Developing VOICES questionnaires	<p>1. Prof. Julia Addington-Hall (Professor of End of Life Care, Faculty of Health Sciences, University of Southampton, UK)</p> <p>2. Dr. Katherine Hunt (Senior Research Fellow, Faculty of Health Sciences, University of Southampton, UK)</p>
Thai experts on ESRD	<p>1. Associate Prof. Dr. Linchong Pothiban (Director of Centre of Excellence in Nursing, Faculty of Nursing, Chiang Mai University, Thailand)</p> <p>2. Ms. Kesorn Kumdee (Master of nursing, Advanced renal nurse specialist, Thailand)</p> <p>3. Ms. Kithiya Sathaya (Master of nursing, Advanced renal nurse specialist, Thailand)</p>
Thai experts in the English and Thai languages	<p>1. Assistant Prof Dr. Sirirat Panuthai (Head of Centre for Research and Innovation in Elderly Care, Faculty of Nursing, Chiang Mai University, Thailand)</p> <p>2. Dr. Nitthaya Gale (ATDBio Ltd, School of Chemistry, University of Southampton, UK)</p>
English proof readers	<p>1. Dr. David Boorer (Proof reading on the interim assessment report)</p> <p>2. Dr. Louise Maskill (Proof reading on the DClInP thesis)</p>

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