How do Thai patients adapt to haemodialysis?

Kantaporn Yodchai
RN, MNS

Submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

Deakin University
March 2014
I am the author of the thesis entitled: **How do Thai patients adapt to haemodialysis?**

submitted for the degree of **Doctor of Philosophy**

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**Date:** 30 March 2014
Abstract

Background
Haemodialysis (HD) is necessary to sustain the lives of people with chronic kidney disease (CKD). However, HD affects people’s quality of life and is associated with physical, psychological and socioeconomic effects in people with CKD receiving HD, and their families. Most studies in Western countries have explored the life experiences of people receiving HD and the effect of CKD and its treatment on their quality of life. However, there are many differences between Asian and Western countries, which could influence the perceptions of people receiving HD and how they cope with CKD and its treatment. Significantly, there is a gap in the literature about how HD affects Thai people with CKD and how Thai people adapt to and cope with its treatment. Thus, these issues warranted further study.

Purpose
The purpose of the current study was to understand the processes Thai people receiving HD used to adapt to CKD and its treatment. The aims were to explore: (1) The effect of HD on Thai people’s self-concept and lifestyle and (2) How Thai people adapt to depending on and learn to live with HD.

Methods
Purposive sampling was used to recruit participants from two Thai outpatient haemodialysis facilities in Songkhla Province, Thailand. Face-to-face, in-depth individual interviews using open-ended questions were conducted at two public hospitals: Songklanagarind Hospital and Hatyai Hospital during January and February 2012. The interviews were audio-recorded and transcribed verbatim. Data from a pilot study and a review of relevant literature relating to people receiving HD and the
methods they used to cope with the resulting pain, informed the content of the interview questions. Data were analysed using Ritchie and Spencer’s Framework method (1994).

Findings
Twenty people receiving HD participated in the study: age range 23-77 years, mean 53.7 (± 16.38 SD), ten were females. Seventeen were Buddhist and three were Muslim. Three main transitional stages of the adaptation process emerged from the interviews and explained people’s experiences as they adapted to life with HD. The three main transitional stages were: being diagnosed with CKD, considering treatment options and accepting, and living with HD. Each transition included one or more turning point or trigger, which are significant events that usually indicated participants needed to adapt to a change. Participants used two main coping styles to manage HD treatment during each transitional stage: health-adjustment and health-behaviour styles. These two coping styles encompassed four specific coping strategies in four areas: religion, spirituality, self-management and social support.

Conclusion
Religion, spirituality, social support and self-management were powerful coping strategies. These coping strategies were strongly influenced by Thai culture and other belief systems. The current study was the first study conducted in Thailand to elicit and understand the experiences of Thai people with CKD receiving HD about how HD affects their lives and how they adapt to HD treatment. The current study contributes important new knowledge regarding cultural beliefs about Thai people with CKD and HD experience and the strategies they used to cope with CKD. The knowledge can help nephrology nurses plan appropriate holistic care.
Acknowledgements

Adaptation is a vital part of learning and understanding to deal with the challenges related to chronic kidney disease. Adaptation was also required in the current study and in my PhD journey. Although undertaking a PhD was challenging, it was enjoyable and I felt it was a valuable experience. It is necessary to acknowledge people who were an important part of my achievement. I would like to deeply thank Professor Trisha Dunning, my principal supervisor for her dedication and for sharing her knowledge with me, her valuable advice, encouragement, time, patience and compassion in supervising me. She was with me anytime I requested help; I always received advice, no matter where she was, even when she was travelling overseas or on holiday. I cannot express how much I appreciate her support and it was an honor to have her not just as my supervisor, but also my role model.

I would like to sincerely thank Dr. Sally Savage and Professor Alison Hutchinson, my associate supervisors, for their excellent feedback about my study, encouragement and spiritual support. They always responded to any request that I had quickly with valuable advice. Assistant Professor Areewan Oumtanee was also a key person who has given me support from when I studied for my Master degree in Thailand, which continued during my big challenge, my PhD at Deakin University, Australia. I would like to give a big thanks to her for her dedication and her willingness to share her knowledge with me.

Part of my data analysis could not have succeeded without Dr. Susan King who showed me how to use NVivo to analyse the data. I would like to thank her for her generous support and the time she spared to teach me some invaluable skills. I would also like to thank Joanne Chadwick, Frontline Services Officer, in the Library, at Geelong Waterfront Campus, Deakin University for her kind support and searching and finding books for my
work, even when I was collecting data overseas. A special thanks to Barbara Green and Zivai Maburuse for reading through the final draft. My thanks also extend to the staff at Deakin University at the Geelong Waterfront Campus for their kind support.

I am grateful to the people receiving HD who openly shared their experiences of living with HD. In addition, I would like to thank the nursing staff of the two participating hospitals, Songkhla, Thailand for their invaluable assistance in recruiting participants. I am very grateful to Deakin University Postgraduate Research Scholarships and the Thai Strength Project (*Thai Kemkang*) 2012 for providing scholarships that enabled me to undertake the study. I would like to dedicate my thesis and my degree to my family in Thailand. My mother, Mayuree, my father Sunan and my older brothers were continually there to provide support. They are looking forward to hearing from me about the progress of my study. My special thanks and acknowledgement goes to my husband, Geoffrey Cox, who always supported me both physically and emotionally throughout my study journey and I am looking forward to welcoming our new baby in June 2014.

Lastly, I would like to thank my colleagues in the Department of Medical Nursing, Faculty of Nursing, Prince of Songkla University for enabling me to take leave to complete my doctoral program at Deakin University. Particularly, Assistant Professor Jaruwan Manasurakarn, Assistant Professor Ploenpit Thaniwattananon, Assistant Professor Kittikorn Nilmanat and Parichat Ratanasimanont, who always contacted me and encouraged me to move forward to achieve my study goals. My special thanks to Assistant Professor Aimon Saejew who always supported me without asking and helped me to look after my family when they were suffering from serious illness.
Definitions and abbreviations

Definition of key terms

The following definitions apply to key terms used in the study.

*Adaptation* refers to ‘the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration’ (Roy & Andrews, 1999, p.30).

*Chronic kidney disease* (CKD) is defined as kidney damage or a glomerular filtration rate (GFR) less than 60 mL/minute/1.73m² body surface area that has been present for more than three months (Agar, 2010).

*Stage five Chronic kidney disease* is defined as the terminal phase of chronic kidney disease. The kidneys no longer filter out toxic compounds, which accumulate in body tissues and fluids and eventually cause death unless treatment is initiated. People with ESRD need renal replacement therapy to survive (Hughson, 2007).

*Glomerular filtration rate* (GFR) refers to the sum of the filtration rates of all functional nephrons in the kidneys. The usual average GFR is around 125 mL/minute/1.73 m² for men and 100 mL/minute/1.73 m² for women (Zheng, 2008).

*Haemodialysis (HD)* is defined literally as “dialysis of the blood” and is distinguished by its location outside the body and by the continuous blood flow across the dialyser membrane, which enables removal of uremic toxins or unwanted fluid and return of
the cleared blood back to the body (Kotanko, Kuhlmann & Levin, 2007; Yeun & Depner, 2005).

**Kidney transplantation** (KT) is one treatment option for end stage renal disease, whereby a donor kidney is transplanted to replace an original non-functioning kidney (Mudge, Carlson & Brennan, 2006).

**Peritoneal dialysis** (PD) refers to the process of artificially removing toxins and excess fluid from the blood by using the lining of the abdomen as a filter when the kidneys are no longer properly functioning (Agar, 2010).
### Meanings of Thai words used in the thesis

<table>
<thead>
<tr>
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<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td><em>Baht</em></td>
<td>Thai currency</td>
</tr>
<tr>
<td><em>Bun</em></td>
<td>Merit</td>
</tr>
<tr>
<td><em>Chang-thao-nar</em></td>
<td>Elephant’s front legs</td>
</tr>
<tr>
<td><em>Chong</em></td>
<td>Bad luck or misfortune</td>
</tr>
<tr>
<td><em>Jao-Mae-Kuan-Yin</em></td>
<td>The Goddess of Mercy</td>
</tr>
<tr>
<td><em>Kam-lang-jai</em></td>
<td>Encouragement</td>
</tr>
<tr>
<td><em>Kao-jai</em></td>
<td>Understand</td>
</tr>
<tr>
<td><em>Khob-khun-mark-ka</em></td>
<td>Thank you very much</td>
</tr>
<tr>
<td><em>Hen-jai</em></td>
<td>Sympathy</td>
</tr>
<tr>
<td><em>Kruat-nam</em></td>
<td>A ceremony of pouring water into a vessel while the monks chant.</td>
</tr>
<tr>
<td><em>Mue-nak</em></td>
<td>Heavy handed</td>
</tr>
<tr>
<td><em>Sawasdee</em></td>
<td>Hello</td>
</tr>
<tr>
<td><em>Taai-wai</em></td>
<td>Early death</td>
</tr>
<tr>
<td><em>Tai-Sui</em></td>
<td>The Chinese God of Destiny</td>
</tr>
<tr>
<td><em>Tai-waai</em></td>
<td>Kidney failure</td>
</tr>
<tr>
<td><em>Tham-bun</em></td>
<td>Merit making</td>
</tr>
<tr>
<td><em>Wai</em></td>
<td>Gesture of greeting, parting and respect made by placing palms of hands together.</td>
</tr>
<tr>
<td><em>Wat</em></td>
<td>Temple</td>
</tr>
<tr>
<td><em>Ya-mor</em></td>
<td>Boiled medicine</td>
</tr>
</tbody>
</table>
# Abbreviations

The following abbreviations were used in the thesis.

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<thead>
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<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>ARF</td>
<td>Acute renal failure</td>
</tr>
<tr>
<td>CG</td>
<td>Cockcroft-Gault formula</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic kidney disease</td>
</tr>
<tr>
<td>CKD-EPI</td>
<td>Chronic Kidney Disease Epidemiology Collaboration</td>
</tr>
<tr>
<td>ED</td>
<td>Erectile dysfunction</td>
</tr>
<tr>
<td>EDTNA/ERCA</td>
<td>European Dialysis and Transplant Nurses Association/European Renal Care Association</td>
</tr>
<tr>
<td>ESRD</td>
<td>End stage renal disease</td>
</tr>
<tr>
<td>eGFR</td>
<td>Estimated glomerular filtration rate</td>
</tr>
<tr>
<td>HD</td>
<td>Haemodialysis</td>
</tr>
<tr>
<td>KT</td>
<td>Kidney transplantation</td>
</tr>
<tr>
<td>MDRD</td>
<td>Modification of Diet in Renal Disease</td>
</tr>
<tr>
<td>MRM</td>
<td>Modeling and Role-Modeling</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal dialysis</td>
</tr>
<tr>
<td>RAM</td>
<td>Roy’s Adaptation Model</td>
</tr>
<tr>
<td>RRT</td>
<td>Renal replacement therapy</td>
</tr>
<tr>
<td>THM</td>
<td>Traditional herbal medicines</td>
</tr>
<tr>
<td>UIT</td>
<td>Uncertainty in Illness Theory</td>
</tr>
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Chapter 1

Background to the study and overview of chronic kidney disease and its treatment


**Chapter introduction**

Chapter one presents the background to the study, a brief overview of the study, the introduction to and statement of the problem, a description of the significance of the study and the purpose of the study. Finally, chapter one presents an overview of the thesis.

**Background to the study**

The researcher has been a staff member in the Faculty of Nursing, Prince of Songkla University, Thailand for four years. In this role the researcher developed a study to determine the effectiveness of using a karaoke DVD as a tool to teach nursing students the key concepts of cardiovascular disease. A quasi-experimental study design (pre/post-test one-group design) was used to determine the effect of using the karaoke DVD on knowledge of nursing care for people with cardiovascular disease in 42 volunteer senior nursing students (4th year) studying at the Faculty of Nursing, Prince of Songkla University (Yodchai, Oumtanee & Sangkharak, 2007). The karaoke study helped nursing students learn about, understand and remember cardiovascular disease concepts. The karaoke cardiovascular DVD is now provided to nursing students in many universities and nurses in various hospitals in Thailand.

Following the success of the cardiovascular DVD and the subsequent positive feedback, many nursing lecturers, students and nurses expressed a desire for a similar karaoke DVD on kidney disease. Consequently, the researcher attended renal conferences in Thailand and the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA) international conference in Slovakia in 2008 to gain up-to-date information to enable her to
summarise the key renal disease concepts and create songs for a karaoke teaching DVD about renal disease.

The following year, 2009, six songs were created that covered concepts such as normal kidney function, acute kidney failure, chronic kidney disease (CKD), haemodialysis, peritoneal dialysis and kidney transplantation. The research required to develop the DVD sparked the researcher’s interest in renal disease; particularly in the way Thai people adapt to having renal disease and its impact on wellbeing and quality of life. Increased interest in adaptation in people with CKD led the researcher to conduct a pilot study that eventually became the basis of the current study (Yodchaisri, Dunning, Hutchinson, Oumtanee & Savage, 2011) see Appendix A. The pilot study was conducted in Thailand to collect preliminary data about how haemodialysis (HD) affects Thai people with CKD in order to inform the need for future research. The pilot study provided important preliminary information that confirmed the need for further research and identified issues that required further study. Thus, a larger study was designed and is the subject of this PhD thesis.

**Introduction to and statement of the problem**

**Chronic kidney disease**

CKD is a growing medical and social concern (Stenvinkel, 2010). CKD is a major public health problem in Thailand. In 2014 over 8,000,000 Thai people were diagnosed with CKD, 2,000,000 of whom developed end stage renal disease (ESRD) (Thairathonline, 2014). CKD refers to the progressive and irreversible reduction of renal function where the kidneys are unable to maintain normal metabolic and fluid balance (Menon, Sarnak & Levey, 2008). CKD encompasses a spectrum of different
pathophysiologic processes that occur as kidney function and the glomerular filtration rate (GFR) decline (Bargman & Skorecki, 2010; Herzog, 2011).

GFR is a standard measure of kidney function and refers to creatinine clearance by filtration in the kidneys. GFR is the preferred method of assessing kidney function and is used to diagnose CKD, estimate the degree of kidney damage, guide medicine doses and determine prognosis and management (Stevens et al., 2011; Johnson et al., 2012). The GFR is an accurate and reliable method of evaluating kidney function.

Estimated GFR (eGFR) is an estimated value of the GFR and is calculated using an individualised formula based on age, gender, creatinine level and ethnicity (Hsu, 2005). Several mathematical formulas based on serum creatinine clearance have been developed to estimate GFR such as the Cockcroft-Gault (CG) formula and the Modification of Diet in Renal Disease (MDRD) formula (Gul, Gilbert & Levey, 2007). However, the CG and the MDRD are not as accurate as the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) formula (Gul et al., 2007; Lamb, Webb & O'Riordan, 2007). The CKD-EPI is an accurate predictor of mortality and stage five CKD and it is reliable in various ethnic populations including some non-European populations such as South-East Asian, African, Indian and Chinese people (Johnson et al., 2012; Lowry, 2012).

Many studies suggest the CG and MDRD should be replaced with the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) formula to estimate kidney function (Levey et al., 2009; Stevens et al., 2011; Johnson, 2012; Lowry, 2012). Recently, using the guideline Kidney Disease: Improving Global Outcomes (KDIGO), Kitiyakara et al. (2012) examined the impact of different eGFR formulas developed in
Caucasian and other Asian populations on GFR and the prevalence of CKD in a Thai cohort (n=5526).

The study included 5,526 Thai participants who underwent a physical examination. Serum creatinine (sCr) was used to determine eGFR. The study showed a seven fold difference in the prevalence of stages three to five CKD between Japanese CKD-EPI (J-EPI) and other Asian peoples. In addition, the concordance with the CKD-EPI was more than 90% for the Thai GFR (T-GFR) and the Chinese-MDRD (C-MDRD): both formulas underdiagnosed stages three to five CKD compared to the CKD-EPI (Kitiyakara et al., 2012). The study showed the C-MDRD and the T-GFR tend to underdiagnose CKD, whereas the Japanese CKD-EPI (J-EPI) tends to overdiagnose stages three to five CKD. These findings suggest the CKD-EPI formula is more reliable in Thai people than the other formulas. If healthcare professionals use an unreliable eGFR formula they can misclassify the person’s CKD stage. Misdiagnosing a CKD stage may result in serious physical, psychological and financial harm.

Although the CKD-EPI is used worldwide, the Australasian Proteinuria Consensus Working Group recommended that the CKD-EPI should not be the only method used to estimate kidney function because the CKD-EPI is less accurate in children, pregnant women, and people with different nutritional status and muscle mass (Johnson et al., 2012). Other indices including albuminuria/proteinuria, a marker of kidney damage, and the underlying diagnosis are also important factors to consider when estimating kidney function (Johnson et al., 2012; Kidney Health Australia, 2012). CKD is classified into five stages (see Table 1.1 on page 6).
Table 1.1: Stages of chronic kidney disease and the related eGFR (Kidney Health Australia, 2012).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Estimated glomerular filtration rate (mL/minute/1.73m²)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>&gt; 90</td>
</tr>
<tr>
<td>2</td>
<td>60 - 89</td>
</tr>
<tr>
<td>3</td>
<td>30 - 59</td>
</tr>
<tr>
<td>3a</td>
<td>45 - 59</td>
</tr>
<tr>
<td>3b</td>
<td>30 - 44</td>
</tr>
<tr>
<td>4</td>
<td>15 - 29</td>
</tr>
<tr>
<td>5</td>
<td>&lt; 15</td>
</tr>
</tbody>
</table>

CKD is defined as GFR less than 60 mL/minute/1.73m² continuously for three months or more, irrespective of the underlying cause (Levey et al., 2005; Kidney Health Australia, 2012). CKD can progress to ESRD and is an important risk factor for cardiovascular disease and death (Zoccali, 2008; Ingsathit et al., 2010). It is important to identify factors that increase the risk of CKD using screening programs that accurately identify declining renal function because CKD is often asymptomatic in the early stages and can persist undetected for some time (Stenvinkel, 2010; Kidney Health Australia, 2012).

Imai and Matsuo (2008) stated that screening to identify people at risk of CKD such as people with diabetes, hypertension, aged over 50 years and with a family history of CKD, is the most efficient way to ensure CKD is identified and treated early. Although early screening for CKD is beneficial in at risk populations, and helps promote CKD awareness, it is costly and not available in all countries (Mathew et al., 2010). Therefore, preventing CKD is important in both developing and developed countries and should be supported by governments through targeted prevention programs. CKD risk is ranked differently in various countries in the global public health database depending on the increase in the prevalence and leading causes.
of CKD in each country (Stenvinkel, 2010). Diabetes is the leading cause of CKD in many
countries and is now the single most common cause of CKD in developed and developing
countries (Stenvinkel, 2010). Thus, concomitant screening of at risk populations for diabetes
and kidney disease is essential.

Causes of chronic kidney disease

The most common causes of CKD in Thailand are:

- diabetic nephropathy
- hypertensive nephropathy
- obstructive nephropathy
- presumed glomerulonephritis (no biopsy)
- chronic urate nephropathy
- polycystic kidney disease
- lupus nephritis (Praditpornsilpa, 2010).

The Center for Disease Control and Prevention in the United States reported that 35% of
people aged over 20 years with diabetes had CKD in 2010. In Australia, about 35% of
people with a new diagnosis of CKD have diabetes (Agar, 2010). In Thailand, people
with diabetes accounted for 36.9% of CKD cases in 2008 (Praditpornsilpa, 2008).

Diabetes is usually classified into two main types: type one and type two. Both types are
associated with CKD and have a similar incidence of CKD (Agar, 2010; Atkins &
Zimmet, 2010; Icks et al., 2010). Long-term hyperglycaemia is the leading cause of
microalbuminuria and macroalbuminuria, which are indicators of kidney disease and
nephropathy in individuals with diabetes. People with diabetes need to maintain blood
glucose levels as close as possible to the normal range (3.5-6.5 mmol/L) and HbA1c <7%
(53 mmol/mol) to help reduce the risk of developing and the progression of diabetes-related complications including CKD (Kidney Health Australia, 2012).

The high prevalence of hypertension is a major public health problem in many countries, is a leading cause of cardiovascular disease and CKD, and is often present in people with pre-diabetes and diabetes (Ho, 2009; Lingerfelt & Hodnicki, 2012). In addition, hypertension can be a complication of CKD (Soni, Weisbord & Unruh, 2010). Hypertension contributes to the progression of CKD to stage five; that is, hypertension exacerbates kidney damage (Kidney Health Australia, 2012).

Medicine toxicity is another cause of CKD (Denken & Brenner, 2010). For example, people who frequently take Acetaminophen (paracetamol) or NSAIDs over a long period of time are at risk of kidney damage including increased risk of stage five CKD (Perneger, Whelton & Klag, 1994). In addition, traditional herbal medicines (THM) can cause CKD; this is particularly problematic in some developing countries due to lack of regulatory processes of the THM used (Luyckx & Naicker, 2008; Jha, 2010). In Thailand people use forms of THM such as various herbs including Aristolochia species, Securidaca longipedunculata, Euphorbia matabelensis, Crotalaria laburnifolia and Callilepsis laureola, all of which are nephrotoxic if inappropriately prescribed and/or used (Ingsathit et al., 2010, p.1574).

Thai people commonly use THM to relieve pain and maintain wellbeing (Ingsathit et al., 2010). THM is inexpensive, unregulated, and can be obtained from drug stores, grocery stores and temples in Thailand. Thai people who do not use the correct THM doses, inappropriately self-prescribe and use excessive doses are at greater risk of nephrotoxicity (Ingsathit et al., 2010). Accurate safety data about many THMs is limited and the data that is available to support THM safety and efficacy is often
anecdotal or misleading, which puts people who take nephrotoxic herbal medicines at increased risk of CKD. Healthcare professionals should be aware of the high prevalence of THM use and ask about THM use when consulting with patients. Renal replacement therapy (RRT) is often required to treat THM-induced CKD and other causes of CKD.

**Renal replacement therapy**

The Thai Renal Replacement Registry data shows a dramatic increase in the prevalence of renal replacement therapy from 272.5 per million population (pmp) in 2005 to 749 pmp in 2011 (Praditpornsilpa, 2011). Renal replacement therapy (RRT) includes peritoneal dialysis (PD), haemodialysis (HD) and kidney transplant (KT) and is required for survival when CKD reaches stage five (Yong et al., 2009; Kramer et al., 2009). RRT is also required in some cases prior to reaching stage five CKD; for example, individuals who develop acute renal failure (ARF) (Rabetoy, 2006). Dialysis is essential to remove waste products from the body and avoid the high risk of uraemia, pericarditis, hyperkalaemia and pulmonary oedema. In addition, beginning dialysis early could reduce CKD-related malnutrition, bone disease and improve long-term survival (Schieppati, Pisoni & Remuzzi, 2005).

Mehrotra, Marsh, Vonesh, Peters and Nissenson (2005) undertook a survey to examine the effect of pre-ESRD processes on the selection of RRT among people with stage five CKD in the United States. Data were collected for all people with CKD admitted to 229 dialysis units in the ESRD Network (n=428). Thirty-six percent of participants reported they were unaware of their CKD. Thirty percent of participants reported that treatment options were not presented to them until dialysis was commenced. The majority of participants were not given the option to select PD (66%), HD (88%) or KT (74%). The researchers suggested the low utilisation of home-HD and delayed
access to KT was associated with healthcare professionals spending insufficient time explaining the treatment options to people with stage five CKD. Effective information about the available treatment options could provide equal and timely access for all people with stage five CKD to help them to understand suitable RRT options.

However, only 428 (31%) of eligible participants responded to the survey, therefore, sample size was small. In addition, the authors did not provide details about the relationship between variables such as age and employment status. Consequently, using a small sample size may affect the study results and the results may not be transferable to other people in the sampling population or to other settings.

Deciding whether or not to commence RRT is the first of many decisions people with CKD confront when their kidneys fail (Jablonski, 2008). People with CKD and their families need to be involved in the decision to begin RRT. Those who opt for RRT need to know their survival depends on regular dialysis or a successful KT and controlling comorbid conditions such as diabetes (Jablonski, 2008). When people choose dialysis they need to decide between PD and HD. The choice depends on life-style, preference, treatment availability, medical indications, distance from other people and cost. For example, in Thailand people can make a choice but they may not be able to act on their choice due to financial constraints (Prekbunjun, 2004). Financial issues are discussed in more detail in Chapter six, on page 198.

**Peritoneal dialysis**

People who choose PD usually do so because PD is less expensive than HD, flexible and convenient to perform in their own homes or workplace and because they do not need to make frequent visits to health facilities (Wuerth et al., 2002). PD also enables people to perform dialysis at night, which has less impact on their lifestyle (Icks et al., 2010).
However, PD is not appropriate for all people with CKD; for example, people with concomitant medical conditions such as peritoneal fibrosis and severe malnutrition where PD could further contribute to malnutrition by promoting significant loss of protein and loss of water soluble vitamins and minerals (Kidney Health Australia, 2012).

In addition, PD requires significant self-care skills, thus PD may not be appropriate for older people with CKD who live alone and cannot perform PD independently because they have comorbidities such as eye problems, dementia or poor memory (Fan, Sathick, McKitty & Punzalan, 2008). Many people who commence PD often develop an infection requiring them to change to HD treatment due to peritoneal membrane dysfunction (Wuerth et al., 2002). HD is another treatment option available to people who cannot be treated with PD when KT is also unavailable.

**Haemodialysis**

Haemodialysis (HD) was initially called ‘extracorporeal dialysis’ because it is performed outside the human body (Yeun & Depner, 2005, p. 308). HD is the most common method of treating CKD and it is also used to maintain kidney function while people wait for a KT (Chokephichit, 2003). HD may be required for a considerable period of time because of long waiting lists for KT (Barsoum, 2002). In addition, some people do not meet the transplant criteria or compatible kidneys may not be available (Cornelis et al., 2010) in which case they need to remain on HD to survive. The goals of HD treatment are to:

- correct acidaemia
- restore solute balance
- treat uraemic symptoms
- prevent hyperkalaemia and life-threatening electrolyte disorders
- maintain volume status and nutrition and quality of life
- reduce morbidity and mortality in the long term (Ajuria & Kimmel, 2004).

HD treatment only replaces some of the functions of normal kidneys, particularly removing waste products and excess fluid. However, it is unable to achieve other normal kidney functions such as secreting hormones involved in blood pressure control, producing erythropoietin and maintaining normal bone density (Agar, 2010). Thus, these functions need to be supported by a healthy lifestyle and medicines (Latham, 2006).

HD treatment involves deciding on a HD prescription that suits the individual’s needs. The physician and/or nurse practitioner prescribes HD considering such parameters as the:
- duration of the dialysis session
- blood flow rate and dialysate flow rate
- ultrafiltration rate
- composition of the dialysate
- dialysate temperature
- dialysis frequency
- medicine requirements such as anticoagulants and intradialytic medications (Himmelfarb, Chuang & Schulman, 2008).

HD treatment is also indicated for people who develop ARF associated with heart disease, shock, sepsis, anaphylaxis, nephrotoxins, surgery and trauma (Rabetoy, 2006). People with ARF may present various symptoms such as volume overload, electrolyte imbalance, uraemic symptoms and acid-base disturbances due to kidney damage. They need medical treatment including HD to remove metabolic by products and control blood volume, which supports the recovery of renal function and maintains homeostasis (Schiffl, Lang & Fischer, 2002). ARF sometimes progresses to CKD if the primary
disease cannot be cured/treated, in which case HD will be needed for long term treatment (Rabetoy, 2006).

People with CKD generally need to attend a dialysis unit two to three times a week for treatment that lasts approximately four hours per session. Thus, HD represents a considerable time commitment that disrupts normal life. Nurses and technicians carry out the prescribed treatment during which patients are connected to a HD machine and they monitor the person while he or she is on HD (Rubin et al., 2004; Cheng, 2008). Individualised treatment is very important to ensure the individual meets clinical goals and is satisfied with their treatment (Mehrotra et al., 2005). Significantly, long term physical, psychological and social issues and financial problems often occur in people with CKD receiving HD, which often affects their quality of life and their families’ quality of life.

**Haemodialysis complications**

People with CKD receiving HD experience numerous physical symptoms and complications such as pain, fatigue, nausea and vomiting, cold aversion, pruritus, lower torso weakness, difficulty sleeping and sexual dysfunction (Yong et al., 2009; Kastrouni, Sarantopoulou, Aperis & Alivanis, 2010; Horigan, 2012). People receiving HD suffer pain related to CKD and HD such as muscle cramps, bone and joint pain, headache and needle pain, which affects their quality of life (Antoniazzi, Bigal, Bordini, Tepper & Speciali, 2003; Williams & Manias, 2007).

Williams and Manias (2007) conducted a non-comparative cohort study and a prospective clinical audit in Australia to examine pain severity and management in 53 people with CKD. Most of the people with CKD in Williams and Manias’ study experienced one or more causes of pain. Surgical pain and dialysis procedures were
the most common causes of pain. Participants were treated with analgesia, predominantly non-opioid medicines. Significantly, effective pain management for people with CKD should include enhancing wellbeing and quality of life. However, the small sample size may limit the generalisability of the findings. Therefore, further studies with a larger sample would be useful to validate the study findings.

People with CKD also suffer from headaches related to HD. Antoniazzi et al. (2003) conducted a study of headaches in 123 Brazilian people receiving HD in three HD services. Participants with headaches were classified according to the International Headache Society (IHS) criteria. Most participants, 87 (70.7%), reported experiencing headaches. Before starting HD, 48% had a migraine, 19% had tension-type headaches, and eight percent had both. Fifty participants (57.5%) had headaches while receiving HD. The researchers questioned the HIS criteria for headaches on the basis that headaches do not appear to have uniform clinical characteristics. Healthcare professionals need to be aware that headache is common in people receiving HD and develop care strategies to manage their pain and enhance their quality of life.

Thirst is another frequently occurring and distressing symptom experienced by people receiving HD (Welch & Austin, 2001). Food and fluid restrictions are a common part of HD treatment regimens and need to be adhered to, to prevent comorbidities such as heart disease, stroke and hypertension (Cheng, 2008; Brown & Masterson, 2011). People receiving HD are limited to approximately 700-1000 ml of fluid per day and must keep their fluid gains between 500 and 1000 g per day (Fincham, Kagee & Moosa, 2008). Fluid restriction is needed because excess fluid can cause pulmonary oedema, which causes shortness of breath and high blood pressure, which further damages the kidneys (Fincham et al., 2008). In addition, prolonged fluid overload is
associated with congestive heart failure and compromises survival (Wuerth et al., 2002). Significantly, HD also has emotional effects that compromise self-care, wellbeing, quality of life and mental health.

Depression, anxiety, stress, and fear of dying are common mental effects associated with HD (Weisbord et al., 2008). Cukor, Cohen, Peterson and Kimmel (2007) conducted a study involving 70 people receiving HD at a major urban dialysis centre in Brooklyn, United States, and found depression and anxiety were common mental health problems. Importantly, depression was associated with increased morbidity and mortality.

Despite significant progress in the fields of dialysis technology and medical therapy, HD-associated mortality remains high (Raimann, Liu, Ulloa, Kotanko & Levin, 2008). Increased mortality in people receiving HD is mainly attributed to cardiovascular disease, which is responsible for approximately 50% of HD-related deaths (Raimann et al., 2008). Individuals with diabetes and CKD receiving HD have more cardiovascular mortality than their non-diabetic counterparts (Hallan & Orth, 2010; Schernthaner, Ritz & Schernthaner, 2010; Carrero et al., 2011). As indicated previously, type two diabetes is the leading cause of CKD and cardiovascular disease (Atkins & Zimmet, 2010).

Financial issues

People with stage five CKD are major users of health care services. Dialysis is expensive, costing $22.7 billion in America in 2006, accounting for 6.4% of the total Medicare expenditure for approximately 1.2% of all Medicare patients (Li et al., 2011). Kidney Health Australia published a detailed analysis of the economic impact of stage five CKD in Australia, taking into account the cost of equipment, buildings,
maintenance, salaries and wages, consumables, revision of vascular access, medicines, complications and specialist consultations. Dialysis is the most costly hospital treatment in Australia, estimated to cost $82,764 per patient per year. At the end of 2007, 2,286 patients were receiving dialysis in hospital (23.7% of those on dialysis) with an approximate expenditure of $189.2 million per year (Australian Institute of Health and Welfare, 2009).

Praditpornsilpa (2010) indicated the mean HD cost per dialysis session in Thailand increased from 1,888.6 baht in 2009 to 1,931.3 baht in 2010. The financial issues associated with dialysis significantly influence Thai people’s treatment decisions, especially if they have a low income and access the universal coverage (UC) scheme. The UC scheme, currently known as the national healthcare insurance scheme, does not cover HD treatment. However, the scheme does cover PD treatment under a policy known as the ‘PD First’ policy (Praditpornsilpa et al., 2011). Thus, Thai people with CKD who choose HD need to be able to self-fund their HD treatment. For many people, financial constraints affect their treatment choices, cause significant financial problems and represent a considerable family burden. Kidney transplantation (KT) is another treatment option that helps people with CKD to maintain kidney function.

**Kidney transplantation**

KT has become the treatment of choice for most individuals with CKD and people with ESRD who receive a KT have a higher life expectancy than people who remain on dialysis (Carpenter, Milford & Sayegh, 2010). Advances in surgical techniques and immunosuppressive therapy have resulted in increased survival rates for people who receive a KT (Weng, Dai, Wang, Huang & Chiang, 2008). Kidneys for transplanting are acquired from deceased donors (with or without a heartbeat) and living donors, but
KT is a limited treatment option due to the lack of donor organs (Lee et al., 2009). The prevalence of KT in Thailand marginally decreased from 3,618 pmp in 2007 to 3,583 pmp in 2011. Thai people with stage five CKD found it difficult to access a KT (Praditpornsilpa, 2011). These issues are discussed in more detail in Chapter three, on page 76.

Lee et al. (2009) conducted a study in 812 Koreans who had a renal transplant to compare renal allograft outcomes from spousal donors with outcomes of recipients of organs from other living-unrelated donors (LUD). A total of 55 of the 185 recipients received a kidney from their spouses. Compared with LUDs, spousal donors were older and had poorer human leukocyte antigen (HLA). The time from initiation of dialysis to transplantation was shorter in transplantation from spousal donors. The incidence of acute rejection within one year after transplantation was often higher in spousal grafts. However, one year and five year survival rates from spousal (96.3% and 93.7%) and other living-unrelated grafts (99.7% and 89.3%) were not significantly different (p=0.925). Thus, spousal donation, age, health problems and cultural beliefs may affect organ donation and need to be addressed.

Barnieh et al. (2011) studied 196 Canadian KT recipients who declined living donor kidney transplants from a family member or friend. Recipients who refused offers of living donor kidneys did so because they were concerned about the effects on the living donor such as pain, long recovery time, failure of the remaining kidney and possible death of the donor.

Potential recipients indicated the potential donor should be able to decide to donate a kidney without any pressure from family or healthcare professionals, and recipients should not ask family members for a kidney (Gourlay, Stothers & Liu, 2005). Individuals
70 years and over with stage five CKD are rarely considered for a transplant because of the prevalence of co-morbidities, especially cardiovascular disease and intolerance of the side effects of immunosuppressive drugs (Agar, 2010). Renal palliative care or supportive care is another treatment option that is increasingly being incorporated into the treatment plan to help people with CKD enhance their wellbeing.

**Renal palliative care or supportive care**

Renal palliative care or supportive care is an alternative method of managing stage five CKD when conservative treatment (non-dialysis) is indicated or when people decline dialysis therapy (Fassett et al., 2011). Palliative care includes managing pain and other symptoms as well as psychological, social and spiritual care. Palliative care and palliative approaches are offered to people at the terminal stage of life and are often adopted earlier in the course of any chronic and ultimately incurable illness to improve comfort and quality of life (Sepúlveda, Marlin, Yoshida & Ullrich, 2002). Significantly, people with stage five CKD are appropriate palliative care candidates because they face shortened lifespans even when they receive active treatment such as RRT (Jablonski, 2008; Brown & Masterson, 2011). Renal palliative care is an appropriate treatment choice when stage five CKD is diagnosed and dialysis treatment commences and can be maintained until the end of life (Brown & Masterson, 2011).

Renal palliative care involves managing concomitant medical problems, controlling CKD-related symptoms such as fatigue, itching, headache, insomnia, cramps, pain, shortness of breath and nausea and vomiting (Jablonski, 2008). In addition, renal palliative care can promote comfort and help manage psychological and spiritual issues to maximise quality of life for the remaining time the person has, and enables them to finish business such as saying goodbye to loved ones (Holley, 2005; Fassett et al., 2011).
Hence, people with conservatively managed end-stage CKD require symptom management and an effective palliative care program to improve their quality of life and enable them to die in comfort and with dignity.

**Significance of the proposed research**

Many studies have explored the life experiences of people receiving HD and the effect of the disease and its treatment on their wellbeing and quality of life. Some studies used qualitative and some used quantitative methods. Most were conducted in Western countries including:

- Brazil (Ramierz et al., 2012)
- Canada (Ravenscroft, 2005; Logan, Pelletier-Hibbert & Hodgins, 2006)
- Sweden (Hagren, Pettersen, Severinsson, Lützén & Clyne, 2001; Heiwe & Dahlgren, 2004; Hagren, Pettersen, Severinsson, Lützén & Clyne, 2005)
- the UK (Mitchell et al., 2009)
- the United States (Weil, 2000; Welch & Austin, 2001; Curtin, Mapes, Petillo & Oberley, 2002; Tanyi & Werner, 2003; Burns, 2004; Weisbord et al., 2007; Clarkson & Robinson, 2010; Thomas & Washington, 2012).

There are many differences between Asian and Western cultures such as the causes of CKD, financial constraints and different public health policies that could influence the perceptions of people receiving HD and the way they cope with CKD/HD. Significantly, there is a gap in the literature about how HD affects Thai people receiving HD and how Thai people adapt to and cope with HD. Thus, more research is needed to explore how HD affects Thai patients with stage five CKD and understand HD patients’ perspectives about adapting to being dependent on HD. The current study is important to nursing practice, education and research, especially for
nephrology nurses who care for Thai people receiving HD. The findings will help healthcare professionals understand the experiences of Thai people diagnosed with CKD and receiving HD and will help healthcare professionals educate Thai people with renal disease by providing information, counselling and encouragement, as well as helping them find strategies to cope with their life-threatening disease and its treatment. The pilot study that triggered the current research showed Thai people used four main coping processes for improving and maintaining their health:

- planning
- adjusting and avoiding
- believing in religion and superstition
- living with hope.

However, there were limitations associated with the pilot study. First, the sample size was small: only five people participated in the study, consequently it did not represent a broad range of demographic characteristics or points of view. Second, the study participants were all receiving HD at one Thai hospital. These constraints limit the ability to generalise the findings. Despite the limitations, the study provided important preliminary information that confirmed the need for the present study and identified issues that required further study. Therefore, the current study set out to confirm or refute the pilot study findings and address a significant gap in the literature: Thai people’s experiences and perspectives of living with HD.

**Research purpose**

The purpose of the current study was to understand the processes Thai people receiving HD used to adapt to CKD and its treatment. The aims were to explore:

- The effect of HD on Thai people’s self-concept and lifestyle.
- How Thai people adapt to depending on HD and learn to live with HD.
Overview of the thesis

The thesis is organised into six chapters.

Chapter 1: Background to the study and overview of chronic kidney disease and its treatment

Chapter one provides the background to the study and a brief overview of the study, a description of the research significance, the research purpose, and an overview of the thesis.

Chapter 2: Overview of the adaptation process

Chapter two outlines the key nursing adaptation models and nursing theories relevant to the current study, including Roy’s Adaptation Model, the Conservation Model, Uncertainty in Illness Theory and Modeling and Role-Modeling Theory. Chapter two also contains a definition of adaptation and a discussion of key dimensions related to adaptation, the process explored in the current study.

Chapter 3: Literature review

Chapter three describes the search strategy used to identify relevant literature including the aim, the databases searched, the search terms used and the selection criteria. Chapter three also describes the process used to critically review relevant articles. Lastly, the data analysis process and a summary of the key findings are described.

Chapter 4: Methodology and methods

Chapter four is presented in two parts; part one describes a brief overview of qualitative research, the key elements of qualitative research, the basic characteristics and rigour in qualitative research. Part two describes data collection tools, the data collection process and the interview process.
In addition, part two indicates how bias was managed during data collection and data analysis. Lastly, the ethical considerations are discussed.

Chapter 5: Study findings

Chapter five presents the study findings in two parts: part one encompasses response rate, participants’ demographic data and health information. In addition, part one describes the findings that emerged in interviews undertaken with people receiving HD. Part two presents a synthesis of the findings, which resulted in a model for adaptation that emerged from the interviews and comments on the summary of the findings from participants.

Chapter 6: Discussion and conclusions

Chapter six discusses the significant findings from the study including consequences of haemodialysis and classic coping strategies. Additionally, models and theories related to the current study are discussed. Lastly, Chapter six discusses the strengths and the limitations of the study and outlines recommendations for nursing practice, education and research, as well as stating the conclusions.

Chapter summary

Chapter one described the background to the study, chronic kidney disease, causes of chronic kidney disease, renal replacement therapy including peritoneal dialysis, haemodialysis and kidney transplant, as well as palliative care. Additionally, Chapter one described the significance of the proposed research in order to identify the gap in nursing knowledge about the process of adaptation to having HD from the perspective of Thai people with stage five CKD. Therefore, the current study was designed to bridge this gap. Finally, Chapter one presented an overview of the thesis.
Chapter 2

Overview of the adaptation process
Chapter introduction

Chapter two outlines the main nursing adaptation models and nursing theories relevant to the current study including Roy’s Adaptation Model, the Conservation Model, Uncertainty in Illness Theory and Modeling and Role-Modeling Theory. In addition, chapter two contains a definition of adaptation and a discussion of key dimensions related to adaptation, the process explored in the current study. Adaptation is an essential part of learning and understanding how to live and cope with stressful events.

The basis of the literature review

Chapter two focuses on the review of the main nursing adaptation models and nursing theories as well as the key aspects of adaptation. The concepts and inter-relationships among the concepts in the problem enabled the researcher to select relevant theories and studies to review (Burns & Grove, 2001). The main nursing adaptation models and nursing theories and the key concepts related to adaptation were reviewed to clarify the definitions of adaptation, and to develop and provide the theoretical positions that guided the current study.

The review encompassed two main sections:

- Nursing adaptation models and nursing theories.
- Defining adaptation and key aspects of adaptation.
Nursing adaptation models and nursing theories

Two main adaptation nursing models and two nursing theories describe humans as adaptive systems. These models and theories are:

Models

- Roy’s Adaptation Model (Roy, 1984; Roy & Andrews, 1999).

Theories

- Uncertainty in Illness Theory (Mishel, 1988).
- Modeling and Role-Modeling Theory (Erickson, Tomlin & Swain, 1983).

Roy’s Adaptation Model

Roy’s Adaptation Model (RAM) views humans as adaptive systems that are in constant interaction with and receiving input from internal stimuli originating from within the self and external stimuli originating from the external environment (Roy & Andrews, 1999; Roy, 2009). Roy described three classes of stimuli: focal, contextual and residual.

**Focal stimuli** refers to the most pressing stimuli immediately confronting the individual (Roy & Andrews, 1999). For example, focal stimuli for an individual with CKD could include the diagnosis of CKD, the transition to HD, receiving HD treatment and organising transportation to the dialysis center (Keen et al., 1998; Tanyi & Werner, 2003; Burns, 2004; Mitchell et al., 2009).

**Contextual stimuli** refers to other stimuli that emerge during an event, which in turn strengthen the effect of the focal stimulus (Roy & Andrews, 1999). Contextual stimuli for an individual receiving HD include age, duration of time on dialysis, social support networks and socioeconomic status (Burns, 2004).
Residual stimuli refers to other factors that could influence the situation (Roy & Andrews, 1999) and environmental factors, which although impacting on adaptation, cannot be directly determined (Keen et al., 1998). However, if the factors that make up residual stimuli can be identified, they can be reclassified as focal or contextual stimuli (Samarel et al., 1998).

Adaptive levels

Roy introduced and defined three adaptive levels that occur as a composite effect of the focal, contextual and residual stimuli. These adaptive levels were:

- **Integration**, which refers to the structures and functions of a life process working as a whole to meet the individual’s needs.

- **Compensation**, which refers to the cognator and regulator coping processes, which are activated by the integration processes. Roy and Andrews (1999) described the components of the coping processes associated with the regulator and cognator subsystems. The regulator subsystem changes the internal and external environment through neural, chemical and endocrine pathways. The cognator subsystem changes the environment through cognitive and emotional pathways that involve perception and information processing, learning, judgment and emotion. Cognator and regulator subsystems are inter-related and integrated into life processes.

- **Compromise**, which refers to the integration and compensation processes which, if inadequate, can result in maladaptation. In contrast, if they are adequate, adaptation occurs.

Individuals do not react passively to environmental stimuli; they respond according to their circumstances. Stimuli might come from the internal and/or external...
environment (Phillips, 2010). Hence, internal and environmental stimuli are processed by the regulator and cognator subsystems and result in behavioural responses that consist of four adaptive modes:

1. physiologic-physical
2. self-concept
3. role function
4. interdependence.

**Adaptive modes**

*The physiologic-physical mode* ‘is associated with the physical and chemical processes involved in the function and activities of living organisms’ (Roy & Andrews, 1999, p. 102). Five needs are involved in the physiologic-physical mode:

1. oxygenation
2. nutrition
3. elimination
4. activity and rest
5. protection.

In addition, four complex processes are involved in the physiologic-physical mode to maintain homeostasis:

1. senses
2. fluid, electrolyte and acid-base balance
3. neurologic function
4. endocrine (hormone) function.

The physiologic-physical mode is compromised in people with CKD because CKD is associated with a range of complications including shortness of breath, fluid overload,
reduced activity tolerance, anaemia, bone and joint pain, insomnia and infections (Tanyi & Werner, 2003). Consequently, people with CKD need to adapt to physical imbalance or dysfunction associated with HD to sustain their lives.

**The self-concept mode** encompasses psychological and spiritual integrity. The basic need underlying the self-concept mode is ‘the need to know who one is so that one can be or exist with a sense of unity, meaning and purpose in the universe’ (Roy & Andrews, 1999, p.107). The self-concept mode has two components: the physical self, encompassing body sensation and body image (Roy, 2009), and the personal self, which encompasses self-efficacy, self-ideal related to what individuals wish to be or do, and the moral-ethical-spiritual self (Roy, 1984; Roy & Andrews, 1999). People living with CKD and HD experience multiple self-concept mode issues such as lowered self-esteem and distorted body image due to vascular access scarring, weight loss, hair loss and skin pigmentation (Tanyi, 2002; Yodchai, Dunning et al., 2011).

**The role function mode** refers to the way people respond to stimuli relative to their roles in society. Role function is classified into primary, secondary and tertiary roles (Roy & Andrews, 1999):

- **The primary role** refers to the main function an individual performs at a particular period of their life. The primary role is determined by society, culture, age, gender and developmental stage.

- **The secondary role** refers to activities an individual is expected to complete as part of their developmental stage and primary role. For example, the role of husband, wife, father, mother or teacher.
• *The tertiary role* relates primarily to secondary roles and depicts the ways ‘in which people meet their role-associated obligations’ (Roy & Andrews, 1999, p. 434). Tertiary roles are generally temporary in nature and chosen by the individual and can include activities such as club membership and hobbies.

The role function mode can be disrupted in individuals living with CKD and HD if individuals cannot sustain their usual life roles. They can feel socially isolated, and social functioning can be compromised. Yodchai, Oumtanee, Matchim and Niyomthai (2011) found people with CKD receiving HD experienced difficulty maintaining roles such as the employee role because they tired easily and worried about becoming unemployed.

Sexual dysfunction, a common complication of CKD, affects the spousal role. People on HD often report diminished interest in sexual activity (Rosas et al., 2003). Males with CKD frequently suffer from reduced libido, difficulty reaching orgasm and erectile dysfunction (Finkelstein, Finkelstein, Wuerth, Shirani & Troidle, 2007). Erectile dysfunction (ED) is reported to be the most common cause of sexual dysfunction amongst men generally, as well as men with renal disease.

Women with CKD report low libido, difficulty becoming sexually aroused, vaginal dryness, pain during intercourse and difficulty achieving orgasm (Finkelstein & Finkelstein, 2002). Consequently, people with CKD may not be able to maintain a key aspect of their usual role as husband or wife, and may divorce, separate or live in disharmony.

*The interdependence mode* refers to the relationships between people that involve their willingness and ability to love, respect and value others, and to accept and respond to love and respect from other people (Roy & Andrews, 1999, p. 306). Interdependence is a provide-and-acquire status, which is an individual’s capability to
give and accept from other people such as love, respect, value, food, knowledge and skills that could include a partner, supportive family, friends and society (Maxwell, Givant & Kowalski, 2001). People with chronic illness receiving life-prolonging treatment often obtain support from family members, friends, community and professional support in various forms such as information or education, physical and spiritual support (Patel, Peterson & Kimmel, 2005). Thus, social support is vital for people with CKD and enables them to deal with the demands of having CKD and its treatment (Weil, 2000; Thong, Kaptein, Krediet, Boeschoten & Dekker, 2007).

It is interesting to note that support systems are a source of hope for people with stage five CKD. For example, Weil (2000) used semi-structured interviews to explore the definition of hope as well as sources of hope of 14 people with CKD in the United States. Family members, friends, spirituality and technology were sources of hope. Based on these findings, Weil (2000) suggested individuals with CKD who have been on dialysis for a long period of time may be better adapted to dialysis treatment than those who are new to dialysis because they develop coping techniques to deal with CKD/HD. However, the sample size was small (n=14); therefore, the study findings cannot be transferred to other settings.

Thong et al. (2007) examined the association between social support and survival of people receiving dialysis (PD/HD) in the Netherlands. Participants (n=528) completed the Social Support List (SSL) three months after receiving dialysis. The findings suggest social support was not associated with survival of people on dialysis. In addition, the effect of social support on survival was similar to people on either HD or PD. Only daily emotional support remained significant for people on HD after adjusting to manage their HD. Adjustment is a significant coping technique that helps people on HD
cope with its treatment and enable them to survive their life crisis. However, a study at one point in time might not capture all aspects of social support relevant to people receiving dialysis. Longitudinal designs could help capture more aspects of social support in future research.

**Criticisms of Roy’s Adaptation Model**

RAM has been used for approximately four decades in nursing practice, education and research. In Thailand, researchers have employed RAM as the conceptual framework in studies addressing chronic illnesses such as cancer (Holaday, Phuphaibul & Muensa, 1999), diabetes (Siripitayakunkit et al., 2008), traumatic brain injury (Petchprapai, 2007) and HIV (Khumasen, Aoup-por & Thammachak, 2012). These quantitative studies used questionnaires based on the key elements of RAM, which could limit the relevance of the information provided by Thai people with chronic illnesses. RAM is a model rather than a questionnaire. Differences in cultural beliefs, customs, healthcare systems and healthcare policies can influence Thai people with CKD’s perspectives, responses to chronic illness and its treatment and their coping strategies. These factors influence everybody’s perspectives and responses. Thus, the RAM triggered the researcher’s concern about the processes Thai people receiving HD used to adapt to CKD and its treatment.

RAM seems relevant to people with CKD receiving HD especially in Western countries, as discussed previously. However, RAM is grounded in Western culture, therefore it might not capture the multidimensional picture of Thai people with CKD receiving HD. Differences in cultural beliefs, customs, healthcare systems and healthcare policies may influence Thai people with CKD’s perspectives, responses to illness and its treatment, as well as their coping strategies. Therefore, RAM prompted the
researcher to think about the adaptation process adopted by Thai people with CKD receiving HD. Another nursing model that highlights adaptation is Levine’s (1973) Conservation Model.

**The Conservation Model**

Levine (1973) defined adaptation as a process of change in which individuals adjust and interact with internal and external environments to maintain wholeness within their existing environment. *Internal environment* refers to organs and cells inside the human body, which are part of homeostasis. *External environment* refers to everything outside the human body. Levine described three environmental components of her model:

- **Perceptual**, which refers to the way an individual acts in their environment, using sensory organs such as sight, hearing, touch, taste and smell.
- **Operational**, which refers to the environmental factors individuals cannot identify by colour or smell, such as radiation, micro-organisms and toxins that affect health and wellbeing.
- **Conceptual**, which refers to culture, language, thinking, individual styles and spirituality, which affect how individuals adjust to change in their external environment.

Various diseases are the consequence of disturbed homeostasis, which is influenced by both the internal and external environments. For example, the underlying causes of CKD such as diabetes, cardiovascular disease, hypertension, overweight/obesity, systemic kidney inflammation and lupus are part of the internal environment or biomedical risk factors (Australian Institute of Health & Welfare, 2009). The development of disease is also influenced by lifestyle behaviours such as tobacco smoking, physical inactivity and poor nutrition, and environmental factors such as
occupational exposures and water and air pollution (Australian Institute of Health & Welfare, 2011).

Interestingly, the effects of risk factors can vary due to the disease it is linked to and may increase the risk of developing other comorbidities. For example, people with hypertension have a greater risk of developing CKD, heart disease and stroke. CKD itself increases the risk of heart disease, stroke and high blood pressure (Australian Institute of Health & Welfare, 2010).

Individuals usually need to modify their lifestyles in order to slow the progression of CKD (Kidney Health Australia, 2012). External environmental factors such as culture, values, religious and spiritual beliefs and practices have a major impact on the way individuals adjust to life with CKD and its treatment. For example, Chinese Buddhists in Malaysia believe bad karma caused their health issues. They relieved their suffering by performing meritorious behaviors such as meditating and asking for blessings from monks and nuns (Ting & Ng, 2012). Thus, religious beliefs and practices give Chinese Buddhists the inner strength to manage their thoughts, feelings and suffering.

**Characteristics of adaptation**

Levine (1973) described three characteristics of adaptation:

- historicity
- septicity
- redundancy.

*Historicity* refers to individuals’ genetic makeup and individual life experiences (Levine, 1973). Historicity for people with CKD includes genetic predisposition to kidney disease. For example, multifactorial disorders are caused by gene-environment interactions that
lead to diseases such as diabetes, hypertension and lupus, which are associated with CKD (Cashion & Driscoll, 2006). People with CKD who had several years’ experience of the illness and its treatment were able to adapt to the challenges associated with CKD better than people newly diagnosed with CKD because CKD was a new, unknown experience (Tanyi & Werner, 2003). Thus, both genetic history and individual life experience have a significant effect on the way people live with CKD and are vital predictors of an individual’s ability to manage CKD and its treatment.

**Septicity** refers to the innate inflammatory response; however individual characteristics affect the way people respond to triggers or significant events. Stress is a natural response to danger and helps individuals survive (Lupien, Maheu, Tu, Fiocco & Schramek, 2007). Stress is a significant adaptive mechanism; however, prolonged stress results in burnout which is represented as maladaptation. Individuals with high levels of stress release high levels of norepinephrine and cortisol hormones (the stress hormones). In turn, the stress response inhibits the immune system and increases the risk of infection, hypertension, cardiovascular disease and stroke, as well as impairing the healing response (Levine, 1973; Seybold & Hill, 2001). Thus, individuals with CKD need to manage stress to reduce the risk of stress-related physical and psychological complications.

**Redundancy** refers to a continuum of fluctuating responses during adaptation experienced by individuals when external stimuli emerge (Fawcett, 1991, p. 20). Redundancy is an important part of the adaptation process and enables individuals to continue to adapt (Levine, 1973). However, redundancy can be reduced or lost, which compromises people’s ability to adapt when they become old, develop disease or find it difficult to manage life situations. For example, if individuals with diabetes are unable to control their blood glucose levels, they can develop complications including
CKD (Morsy & Shamaa, 2009). Thus, maintaining redundancy is essential to enable individuals to deal with change.

**Conservation principles**

Levine (1973) described four conservation principles:

- energy
- structural integrity
- personal integrity
- social integrity.

**Energy**: individuals depend on energy balance and continuous renewal of energy levels to maintain life processes and enable the individual to perform their daily activities (Douglas, 2010). However, when people become ill, their demand for energy increases (Levine, 1973). People with CKD receiving HD often lack energy and become fatigued easily (Noble, 2008). Fatigue presents in different ways, but common symptoms are tiredness, lack of energy, weakness, exhaustion, feeling heavy and slow (Noble, 2008; Mollaoglu, 2009; Bossola, Di Stasio, Antocicco & Tazza, 2013).

People on HD become fatigued for various reasons including treatment-related factors such as rapid osmotic changes during HD, carnitine deficiency, hypotension and interactions between blood and the dialysis membrane (Cohen, Moss, Weisbord & Germain, 2006). In addition, depression, sleep disturbances, malnutrition, anaemia and side effects of medications are common causes of fatigue (Liu, 2006). Thus, individuals need to develop strategies to conserve energy and avoid fatigue to successfully adapt to CKD/HD and be able to continue to perform usual physical activities.
**Structural integrity** involves balancing, maintaining and restoring physical structure, preventing physical dysfunction and promoting healing (Levine, 1973). However, individuals with permanent disease need long-term treatment to maintain structural integrity. For example, individuals with CKD require dialysis to survive. HD is the most common way of treating CKD to maintain kidney function while people wait for a kidney transplant, and in most cases, becomes life-long treatment (Chokephichit, 2003).

**Personal integrity** refers to self-identity and self-worth, which are vital aspects of personal integrity (Levine, 1973). Individuals with CKD find the demands of CKD and HD unpleasant and often overwhelming, which affects their personal sense of self. Coping strategies such as religious and spiritual beliefs and practices often enable people to find meaning and purpose in life with CKD (Bayhakki & Hatthakit, 2012). Curtin et al. (2002) reported individuals with CKD indicated they wanted to live (self-preservation); therefore, they realised they needed to accept HD to preserve their lives. In addition, Curtin et al. (2002) found people with CKD who reported an unchanged sense of self or self-identity could possess appropriate coping strategies that enabled them to adapt and accept CKD.

**Social integrity**: people are inherently social beings and develop relationships with other people (Levine, 1973). People with CKD may find it difficult to maintain their social lives, activities and relationships with other people for various reasons. For example, people with CKD often feel frustrated by the time they spend on dialysis and the frequency of HD appointments, which affects their life styles (Hagren et al., 2005; Lin, Lee & Hicks, 2005; Ravenscroft, 2005; Clarkson & Robinson, 2010; Herlin & Wann-Hansson, 2010; Griva et al., 2012).
Criticisms of the Conservation Model

A major strength of the conservation model is that it describes a conceptual environment that includes an individual’s culture, language, thinking, personal style and spirituality, which are vital aspects of the adaptation to life crisis. In addition, Levine’s Model emphasises nurses’ responsibility to help individuals maintain and balance their lives and find strategies that enable them to adapt to changed health status. Thus, nurses can use techniques such as education, acknowledging problems and supporting people through life challenges (Schaefer & Potylycki, 1993).

Levine’s Model encompasses adaptation, which describes individual interaction with both internal and external environments and the three characteristics of adaptation including historicity, septicity and redundancy. These key elements seem relevant to people with CKD receiving HD, but with regard to the Thai context, Levine’s Model does not account for cultural aspects. Mishel’s Uncertainty in Illness Theory is another nursing theory that highlights uncertainty and the adaptation process.

Uncertainty in Illness Theory

The Uncertainty in Illness Theory (UIT) developed by Mishel (1988) defines uncertainty as an individual’s inability to understand the meaning of illness. Uncertainty in acute and chronic illnesses are different. Individuals with acute illness experience uncertainty during diagnosis, treatment and recovery (Mishel, 1997). However, individuals with chronic illnesses experience uncertainty, not only concerning diagnosis and treatment, but for several other reasons. For example, doubt about the effectiveness of treatment, fear of long-term treatment side effects as well as uncertainty about their future and survival (Mishel, 1997).
Uncertainty for individuals living with CKD presents a life-long challenge because of the chronic nature of CKD. The diagnosis of CKD usually creates uncertainty initially, because the prognosis and course of CKD and its treatment are unpredictable (Moulton, 2008). In addition, uncertainty is very evident when individuals are waiting for a renal transplant. People can be on the waiting list for a long time and often become discouraged, stressed and depressed because there is no guarantee they will ever receive a kidney (Pelletier-Hibbert & Sohi, 2001; Herlin & Wann-Hansson, 2010). Moreover, women with CKD are often uncertain about having a child and may be advised to terminate a pregnancy because of the risk of hypertension and other complications (Tong et al., 2009). Uncertainty is a major cause of psychological stress in individuals with CKD on HD.

Cognitive schema is another central concept in Mishel’s Uncertainty in Illness Theory. Cognitive schema refers to an individual’s perception and understanding of their illness, treatment and the healthcare system (Mishel & Clayton, 2003). If individuals are capable of developing an integrated cognitive schema, they are able to interpret the disease and its treatment in a way that enables them to accept the illness (Mishel, 1988). Cognitive schema occurs as a result of stimuli frame.

**Stimuli frame**

Stimuli frame refers to an individual’s ability to understand and have ideas about forms, components and patterns of the stimuli related to the illness experience (Mishel, 1988). The stimuli frame encompasses three components:

- **Symptom pattern** refers to the individual’s ability to understand the symptoms of their illness (Mishel, 1988). The symptoms can be evaluated by noting number, intensity, frequency, periods of time and location of the illness (Mishel, 1988).
CKD stages, including stages one and two, are usually ‘silent’ and undetected until the advanced stages (four/five) in which the symptoms of kidney failure become evident (Ingsathit et al., 2010). Consequently, people often develop uncertainty about the diagnosis because they do not experience symptoms. If people with CKD are capable of identifying and acknowledging CKD symptoms they may experience less uncertainty. Therefore, education about risk factors for CKD can help people detect or predict CKD and delay the progression of the disease (early diagnosis).

- *Event familiarity* refers to the individual’s ability to identify and become familiar with the disease, treatment and healthcare environment (Mishel, 1988). Familiar events constantly occur through repeated individual experiences. People with CKD who commence HD often initially face uncertainty because they are not familiar with HD or the treatment environment but they become more familiar with the environment and treatment and less uncertain over time (Polaschek, 2000).

Similarly, Moulton (2008) indicated that people receiving HD struggle to understand the technical environment associated with HD treatment and need time to adapt to the routines, procedures and the sights and sounds of the HD machines and their alarms. When individuals with CKD adapt to the HD environment and begin to understand ‘CKD language’ and procedures and develop relationships with healthcare professionals, their uncertainty diminishes. Time is needed for people to become familiar with and develop trust in healthcare professionals.
• *Event congruence* occurs when an individual’s expectations and experiences of their illness are the same as the actual outcomes (Mishel, 1988). HD does not cure CKD; it replaces kidney function to preserve life (Lin et al., 2005). In addition, most individuals with CKD hope for a KT, they expect it to improve their quality of life and help them live as normally as possible. However, the consistency between the individual’s expectation of receiving KT and actually having a KT are different, because most people with CKD will not receive a KT, or if they do, they may reject the kidney, which causes great uncertainty.

According to the Uncertainty in Illness Theory, structure providers are required when an individual lacks knowledge associated with the disease, treatment and healthcare environment.

**Structure providers**

Structure providers refer to resources that help people interpret internal and external stimuli (Mishel, 1988). Some structure providers are:

• *Education*, which has an indirect and direct relationship with uncertainty through past experience and education level. In the indirect relationship, individuals who have illness-related experience have less uncertainty. For example, Langnak (2008) reported that people with high educational levels and long experience with dialysis felt less uncertainty than people with low educational levels. Thus, patients with low education levels are likely to have high levels of uncertainty.

In contrast, individuals who have no experience of illness or lack information about illness and its treatment can be less uncertain than people with more experience and knowledge about illness and treatment. For example, people
with diabetes reported illness-related information physicians provide created uncertainty and various sources of information resulted in increased new sources of uncertainty (Middleton, LaVoie & Brown, 2012). Thus, having more information does not necessarily reduce uncertainty: various sources of information may increase uncertainty or reduce it.

- **Social support** helps people understand the meaning of events and reduces uncertainty. Social support is commonly provided by family members, friends, acquaintances in the workplace and healthcare professionals (Patel et al., 2005; Cukor et al., 2007). Social support is provided in various forms such as physical, spiritual as well as information that enables individuals to cope with life difficulties such as CKD and HD (Welch & Austin, 2001). In fact, individuals with social support are able to manage life better than people without support (Patel et al., 2005; Rambod & Rafii, 2010). If an individual perceives social support as unnecessary or feels over supported, they may become stressed and depressed, which inhibits the adaptation process (Moulton, 2008). Thus, enough and necessary support has a significant effect on the way individuals manage life with CKD and its treatment.

- **Credible authority** refers to the degree of trust an individual has in healthcare professionals (Mishel, 1988). When individuals receive HD, they often feel insecure about the care they receive from inexperienced staff (Herlin & Wann-Hansson, 2010). Individuals receiving HD need to learn to trust their healthcare professionals, whereas healthcare professionals need to be knowledgeable and competent to deliver high quality care that meets peoples’ safety needs and reduces uncertainty.
Mishel (1988) stated that an individual’s experience of uncertainty is a neutral zone where the experience can be either an opportunity (desirable) or harmful (avoid) until they appraise how they will cope with uncertainty. Two appraisal processes are used to investigate the level of uncertainty in Mishel’s theory.

- **Inference** refers to evaluating uncertainty using past experience and knowledge to relate to new situations (Mishel, 1990). Some individuals view new situations as an opportunity, others view them as threats. However, individuals do not always respond the same way (opportunity/threat) to new situations. Previous illness experience often causes people to view uncertainty as a crisis or danger; therefore, coping strategies are required to deal with the change.

- **Illusion** refers to the pattern of beliefs about the self, other people and the real world. Illusion enables people to view uncertainty as positive and is commonly used in negative situations. For example, people often find the diagnosis of a serious disease a threat initially, and have difficulty accepting the disease and its treatment. Illusion is a significant source of hope when coping with prolonged serious illness (Miller, 1985). Illusion can be viewed as a form of denial of the reality or maladaptive behaviours, but positive illusion may help individuals cope with stress or threatening situations such as the diagnosis of incurable disease (Telford, Kralik & Koch, 2006). Thus, illusion helps people with chronic illness to maintain hope and reduce uncertainty during stressful events. Coping strategies are usually activated or created to reduce uncertainty.
Coping strategies

Coping strategies enable individuals who evaluate uncertainty as a danger to come to terms with illness and its treatment. Various coping strategies are used such as avoidance, optimism and fatalism (Mishel & Clayton, 2003). For example, individuals with chronic illness seek information from their partners, family members, healthcare professionals and the media to deal with life’s uncertainty (Checton, Greene, Magsamen-Conrad & Venetis, 2012). Similarly, Wonghongkul, Dechaprom, Phumivichuvate and Losawatkul (2006) reported that Thai women living with breast cancer commonly sought social support to help them cope with uncertainty and stress.

Some people use avoidance to protect themselves from unpleasant knowledge and feelings. For example, individuals living with CKD use avoidance to overcome physical and mental fatigue (Takaki et al., 2003; Heiwe & Dahlgren, 2004; Lee, Lin, Chaboyer, Chiang & Hung, 2007; Ibrahim, Taboonpoong & Nilmanat, 2009). Therefore, individuals with chronic illness often use denial to deal with uncertainty when they learn they have a serious disease. Denial may relieve emotional distress but could lead to worsening health status.

Criticisms of the Uncertainty in Illness Theory

Mishel indicated adaptation occurs when an individual adjusts to and manages uncertainty. Mishel’s theory triggered the researcher’s interest in the concept of uncertainty and its relevance to the current study because people with chronic diseases such as CKD often encounter uncertainty. However, people with CKD face uncertainty as well as physical and socioeconomic issues; therefore, Mishel’s theory may not comprehensively cover all aspects of adaptation experienced by Thai people.
with CKD requiring HD. Another nursing theory that encompasses adaptation is the Modeling and Role-Modeling Theory.

**Modeling and Role-Modeling Theory**

Erickson, Tomlin and Swain (1983) developed the Modeling and Role-Modeling (MRM) theory. The MRM theory focuses on nurses’ role in helping individuals cope with illness. It concerns adaptation and encompasses the ways in which individuals differ.

**Ways in which individuals differ**

Although people have many similarities because they belong to the same species, they also have many differences, which makes them individuals. Erickson (2010) asserted individuals differ in various ways:

*Inherent endowment:* each individual is born with a particular genetic makeup that predetermines their appearance, growth, development process and the way they respond to life events. Genetic makeup and inherited characteristics influence growth and development and may influence an individual’s self-perception and the way they respond to triggers or significant events. There are three types of genetic disorders: single gene disorders, chromosome disorders and multifactorial diseases (Cashion & Driscoll, 2006). Diabetes, hypertension and lupus are examples of multifactorial diseases that are caused by gene-environment interactions (Dunning, 2013).

*Adaptation* refers to a process in which individuals respond to both external and internal stressors. The way people respond affects the way the individual adapts. Adaptation is health-directed and growth-directed (Erickson et al., 1983, p. 47). People living with CKD and HD may struggle to manage intensely stressful and life-threatening situations (Hagren et al., 2005). They find it difficult to fulfill their basic needs and they may not
be able to adapt to CKD and HD, unless or until they develop appropriate coping strategies.

**Mind-Body relationships**: Erickson (2010) regards individuals as biophysical and psychological beings who develop their potential to the best of their ability. People with CKD want to live, which means making a choice between living and dying (Molzahn, Bruce & Shields, 2008; Moulton, 2008). The will to live is powerful and enables individuals to enhance their strengths and accept they need HD. Although HD enables individuals with CKD to maintain life, it significantly affects their lifestyle. People with CKD use various coping strategies to manage life with CKD and HD (Lin et al., 2005). People have many differences; however, they share similarities such as holism, basic needs, development and connectedness.

**Ways in which individuals are similar**

Erickson (2010) indicated that individuals are alike in four significant components:

**Holism**: Erickson et al. (1983) viewed individual beings as having multiple interacting components: genetic makeup, spiritual drive, body, mind and emotions, which are parts of a unified whole that affect and control each other. When an individual develops CKD the inter-relatedness can become unbalanced, which affects holism and wellbeing. Individuals need to adapt to various changes in the environment, treatment regimen, vascular access and HD complications when they develop CKD (Moulton, 2008). These changes mean the individual tries to maintain holism by accepting the changes, modifying their lifestyle and developing effective relationships with healthcare professionals (Moulton, 2008).

**Basic needs**: each individual has basic needs. The MRM theory incorporates Maslow’s hierarchy of needs theory (Maslow, 1998) and helps explain personal needs. Maslow,
who is considered to be the father of humanistic psychology, proposed a hierarchy of needs to explain people’s motives for behaving in various ways and proposed five levels of needs:

- **Physiological needs** are the lowest level of Maslow’s hierarchy of needs: food, air, water, sleep, sex, shelter and other needs required to maintain life.
- **Safety needs**: if physiological needs are met, safety or security needs are required.
- **Love and belonging needs**: the fulfillment of physiological and safety and security needs drives the individual to fulfill social needs such as belonging, companionship and social acceptability. People want to share and socialise with their family and other people to assure themselves they are loved and accepted.
- **Esteem needs**: after people begin to satisfy their need to belong and be loved, they develop a desire for status, self-respect, self-esteem and the respect or esteem of others. When esteem needs are fulfilled people feel self-confident and have a sense of power, worth, adequacy and usefulness.
- **Self-actualisation needs**: once the lower order needs are satisfied, individuals are motivated to fulfill their potential.

Although Maslow described the hierarchy of needs in a linear fashion; basic needs may not necessarily follow higher order needs in people with illnesses. Illness occurs if basic physiological needs are not met and disrupt or unbalance the individual’s physical and psychological status. In the current context people with CKD require HD to restore basic physical needs. However, HD can threaten and disrupt other needs such as safety, love and belonging needs, esteem needs and self-actualisation. Thus,
meeting individual’s needs is required during threatening events such as CKD/HD to enable them to reach fulfillment.

**Lifetime growth and development** are dynamic psychological and cognitive processes.

- **Psychological processes**: individuals need to decide between basic issues; trust or distrust and life or death (Erickson, 2010). Such decisions represent significant turning points. For example, people with CKD often make decisions such as choosing life or death, a balance between independence or dependence, restriction or freedom, feeling normal or feeling abnormal and feeling alone or connected (Molzahn et al., 2008). Therefore, individuals are likely to fulfill their needs and grow and develop with a life-threatening disease like CKD, if they are able to balance competing choices.

- **Cognitive process**: refers to the way people think about how to deal with problems (Erickson, 2010). People with CKD use various cognitive styles, including positive reappraisal, optimism, realistic expectations, acceptance and social comparisons, which help them manage CKD and its treatment (Mitchell et al., 2009).

**Affiliated-individuation** refers to an individual’s need to depend on other people or support systems. People with CKD struggle to manage life with CKD/HD and often need to depend on their family and healthcare professionals (Axelsson, Randers, Lundh, Jacobson & Klang, 2012). Although strong support from family helps individuals manage life better than usual, individuals in Axelsson et al.’s (2012) study felt they were a burden to their families, and consequently felt vulnerable because they could receive unnecessary and irrelevant support. Therefore, relevant support is vital to help people with CKD manage their illness and its treatment.
Criticisms of the Modeling and Role-Modeling Theory

Although the MRM theory concerns adaptation and encompasses the ways in which individuals differ and are similar; the MRM theory appears less relevant to the current study than other models and theories because MRM theory focuses on the nurses’ role in helping individuals cope with illness, while the current study focused on the way patients with CKD adapt to HD. Therefore, the MRM was not relevant to the current study. The following section describes the defining adaptation and key dimensions of adaptation.

Defining adaptation

The biological and psychological disciplines view adaptation as the historical end product of the process of evolution, in which successful adaptation is demonstrated when individuals are able to respond to stressors and as a result, survive and reproduce (Schmitt & Pilcher, 2004). In the current study, adaptation refers to an individual’s capability of responding to physical, psychological and socioeconomic changes associated with CKD and HD. When individuals with CKD are able to manage and cope with changes and integrate them into their lives; development and spiritual growth occur, which are at the heart of a successful adaptation process. The following section describes the main nursing models and nursing theories concerning the process of ‘adaptation.’
The key dimensions of adaptation

Adaptation consists of various key dimensions that relate to how individuals manage positive and negative life events:

- spirituality
- religion
- social support
- turning points and transitions
- stress.

Spirituality

The term spirituality is from the Latin *spiritus*, which means breath. Breath in Greek refers to spirit or soul, which is vital and motivates individuals (O’Neill & Kenny, 1998). Definitions of spirituality encompass a search for meaning, purpose in being, and enable an individual to find direction, hope, inner peace and harmony in their lives (Miller, 1995; Burkhardt & Nagai-Jacobson, 2002). Spirituality is central to adaptation and holism. It helps people find balance and a sense of control over their life, even when their life is threatened.

Many authors view spirituality and religion as overlapping concepts, but they are separate issues because spiritual people may or may not be religious and some spiritual people do not believe in any God (Miller, 1995; Dyson, et al., 1997; McSherry, 2000; Baldacchino & Draper, 2001; Parsian & Dunning, 2009). However, religious practices may be encompassed in spirituality for some people who regard spirituality as concerned with self, other people, the environment, God and the earth. Consequently, spiritual expression can take various forms such as appreciation of music, literature and humour that help individuals develop and grow spiritually.
Many authors have explored the key components of spirituality that enable individuals to achieve self-actualisation (Martsolf & Mickley, 1998; Kelly, 2004). The key components of spirituality are:

- meaning
- connectedness
- transcendence
- hope
- becoming.

*Meaning* is an important aspect of spirituality and enables individuals to understand life events and find purpose in their existing life (Puchalski & Romer, 2000; Burkhardt & Nagai-Jacobson, 2002). Individuals with chronic diseases such as cancer, diabetes, cardiovascular disease, HIV/AIDS and kidney disease may experience imbalance or disharmony of body, mind and spirit and emotional distress (Narayanasamy, 2007). Consequently, spirituality can help people cope with chronic health conditions and accept the reality of living with an incurable disease, which is the positive thinking aspect of spirituality.

The concept of meaning is vital to the current study because individuals may find CKD an overwhelming experience that results in disconnection and loss of meaning and purpose in their lives. Individuals who try to find meaning and purpose in CKD/HD could regard CKD as a turning point that enables them to learn new skills and have a connected life with self and others (Baldacchino & Draper, 2001).

*Connectedness* generally refers to a relationship with oneself, other people (spouse, friends), the environment, life events (support, occupation, sports), God/higher power, nature and the world (Dyson, et al., 1997; Martsolf & Mickley, 1998; Finocchiaro,
Love, harmony, and integrated wholeness are the most important of these relationships (Dyson, et al., 1997; Chiu, Emblen, Van Hofwegen, Sawatzky, & Meyerhoff, 2004). Connectedness is significantly related to the current study because during life crisis an individual with chronic illness often develops spiritual distress, which impairs their wellbeing and quality of life.

However, individuals who lack connection or relationships with self and other people can become estranged, lonely and experience spiritual distress (Tanyi, 2002). Individuals with CKD who develop trust and are confident about health professionals, have a feeling of security and a sense of love and belonging, which enables them to transcend the diagnosis and move on. Transcendence is a significant component of spirituality.

Transcendence refers to an individual’s capacity to overcome difficulty and move on (Reed, 1987; Martsolf & Mickley, 1998; Tanyi, 2002). They discover new perspectives and experiences when life is threatened (Kaye & Raghavan, 2002; Kelly, 2004). Thus, spirituality is a key coping resource for individuals with chronic illnesses. Hope is another central aspect of spirituality.

Hope refers to an individual’s expectation about life fulfillment becoming reality (Burkhardt & Nagai-Jacobson, 2002; Chiu, et al., 2004). Hope emerges from various sources such as an individual’s faith/beliefs, expectation and experiences (Baldacchino & Draper, 2001). Hope also arises from relationships with other people, feeling needed and having goals. In fact, spirituality gives people hope that helps them cope with life crises (Baldacchino & Draper, 2001). For example, the beginning of Spring with the growth of green leaves, flowers blooming and the birth of newly
born birds provides individuals living with CKD with a sense of hope and renewal (Weil, 2000).

Hope can be impaired if people’s beliefs and expectations are not fulfilled or are not consistent with reality. For example, Weil (2000) found individuals with CKD felt hopeless due to CKD and dialysis complications and because they knew other people with CKD who were dying. Hope can diminish when individuals face uncertainty and feel unbalanced, which impairs their wellbeing and quality of life. If individuals can maintain hope, they are more likely to find meaning and purpose in their life and fulfill their potential.

**Becoming** refers to self-transformation; physical or psychological that contributes to self-knowledge and leads to personal development and empowerment (Miller, 1995). Becoming involves reflection and enables an individual’s life to ‘unfold’ (Taylor, 2001, p. 198). For example, Walton and Sullivan (2004) reported males with prostate cancer reflected on life and death, which enabled them to connect with their inner-self and understand their suffering. In addition, the men believed facing death was a natural part of life. The belief enhanced the men’s self-awareness and helped them realise they can be fulfilled, even though they have cancer (Walton & Sullivan, 2004). Thus, reflection can help people find peace, love, joy and harmony. Religion also can be a source calmness and peace for some people.

**Religion**

The term religion stems from the Latin *re-ligare*, which means to reconnect (O’Neil & Kenny, 1998). Many authors view religion as an organised system of beliefs about the cause, purpose, and nature of the world that is shared by a group of people and
encompasses practices such as worship and ritual related to the particular religious system (Taylor, 2001; Burkhardt & Nagai-Jacobson, 2002).

The term religion is a composite term that refers to several religious practices such as Christianity, Judaism, Buddhism, Hinduism, Islam and other religions (Koenig, Larson & Larson, 2001, p. 353). Christians make up the largest religious population in the world (33%), followed by Muslims (22.43%), Hindus (13.78%), Buddhists (7.13%) and other assorted religions (11.7%). Buddhism is the main religion in Thailand (93.6%), followed by Islam (4.9%), Christianity (1.2%) and other religions (0.2%) (Central Intelligence Agency (Thailand), 2014). Each religion can be a source of strength that enables growth or development when people face life crises (Burkhardt & Nagai-Jacobson, 2002).

In Western cultures, religion is a private and personal choice (Ting & Ng, 2012). Religion in Asian countries is based either on heritage or personal choice (Knodel, Gray, Sriwatcharin, & Peracca, 1999). In both Western and Asian cultures, religion is grounded in traditional practices such as festivals, story-telling, moral guidance, grieving rituals and developmental transitions (Burkhardt & Nagai-Jacobson, 2002; Padela, Killawi, Forman, DeMonner, & Heisler, 2012; Ting & Ng, 2012).

Religion is an important part of Thai culture (Pargament, 1994). Buddhism plays a fundamental and significant role in mediating Thai people’s values and beliefs, perceptions and knowledge and provides guidance about how to live in the world. Buddhism influences behaviour and affects how people make sense of and find meaning throughout their lives (Mulder, 2000). Many previous studies suggest religion is important to how Thai people adapt to the burden of illness (Phillips et al., 2009; Naewbood, Sorajjakool, & Triamchaisri, 2012; Ting & Ng, 2012) because it provides a cognitive framework that can minimise suffering, increase one’s purpose and help them
find meaning in illness (Koenig et al., 2001). Religious beliefs and practices people use to cope with stressful events include prayer, trust and faith in God, reading religious scriptures and depend on the support of other church members (Koenig, et al., 2001).

Religious beliefs and practices help Thai people with hypertension in the USA manage stress and modify/improve their health through food and exercise (Naewbood et al., 2012). For example, Christian Thai people believed their body was ‘God’s temple,’ which they needed to look after to the best of their ability in order to improve their health (Naewbood, et al., 2012). Buddhist people believe in the law of karma, following the Middle Path and mindfulness practice, which helps them manage stress and anxiety (Naewbood, et al., 2012). Thus, religious beliefs and practices play a vital role in helping individuals with hypertension control their blood pressure, which slows the progression of disease and reduces the risk of kidney disease.

In addition, religion helps Malaysian people with CKD adapt to life with HD treatment (Ibrahim, Desa & Chiew-Tong, 2012). Ibrahim et al. (2012) explored the influence of illness perception and religious coping strategies on health-related quality of life (HRQoL) (n= 274) in people with stage five CKD receiving dialysis. Illness perception and religious coping strategies were significantly correlated with HRQoL. The authors concluded that religion helps people with chronic illness such as diabetes, hypertension and CKD maintain a sense of control when their life is threatened and achieve a sense of inner peace and wellbeing. Social support is another key element of adaptation that helps people with chronic illnesses manage in times of crisis.
Social support

Social support refers to physical and emotional resources other people provide in a variety of social networks and relationships that strengthen individuals’ ability to cope with their daily lives (McClellan, Stanwyck, & Anson, 1993; Kara, Caglar, & Kilic, 2007; Janicki-Deverts & Cohen, 2011). Social support plays an important part in people’s wellbeing and the way people with chronic illness cope with the physical and psychological consequences of their chronic illness (Halter & Varcarolis, 2010). People with CKD receive support from family members (spouses, siblings), friends, doctors, nephrology nurses and other people with CKD on dialysis (McClellan, et al., 1993; Patel, et al., 2005; Cukor, et al., 2007).

Many authors describe several types of support that help individuals cope with change (DiMatteo, 2004; Kara, et al., 2007; Schaffer, 2009; Janicki-Deverts & Cohen, 2011). The main types of support are:

*Emotional support* refers to feeling liked, pleased, admired, respected and loved (Schaffer, 2009). Emotional support involves empathy, caring, encouragement and trust and giving individuals the opportunity to express their emotional distress (Kara, et al., 2007; Janicki-Deverts & Cohen, 2011). Many studies suggest people with CKD commonly receive emotional support from family members, friends, neighbours, health professionals and other people with CKD (Lin, et al., 2005; Mitchell, et al., 2009). Significantly, encouragement from family enables individuals with CKD to accept and manage HD treatment (Lin, et al., 2005). Previous studies of people with chronic illness such as arthritis (Revenson, Schiaffino, Deborah & Gibofsky, 1991), diabetes (Abdoli, Ashktorab, Ahmadi, Parvizy & Dunning, 2011), and cardiovascular
disease (Lett et al., 2005) suggest emotional support from families helped individuals to cope with serious and life-threatening events.

**Information support** refers to knowledge (people turn information into knowledge) individuals receive during times of stress that helps them solve problems (Kara, et al., 2007; Schaffer, 2009). Many studies show people with CKD on HD need education/information to enable them to understand the issues surrounding stage five CKD and its treatment (Mitchell, et al., 2009; Clarkson & Robinson, 2010; Lai, Loh, Mooppil, Krishnan & Griva, 2012). However, if people with CKD do not believe what health professionals such as physicians, nurses, and other nephrology staff tell them, they may experience emotional distress and find it difficult adapt to HD.

**Tangible instrumental support** involves providing material assistance such as tangible aids, goods, financial support and services (Kara, et al., 2007). Tangible support might include families reminding people with CKD to take their medicines and accompanying them to HD treatment (Lai, et al., 2012). Many studies show people on HD who perceived high levels of family support were more compliant/adherent to treatment and had lower potential risk of dying (Christensen et al., 1992; Cohen et al., 2007). Kara et al. (2007) found most people on HD had high levels of social support from family and friends, which helped them comply with food and fluid restrictions and adhere to other treatments. However, Kara et al. (2007) also found young/married people on HD reported a low level of social support and were less adherent to diet and fluid limitations. Being non-adherent to treatment for a long-time can affect an individual’s health and increase the risk of adverse events and death.
Turning points and transitions

Turning points and transitions are different aspects of the adaptation process (Rutter, 1996; King, Willoughby, Specht, & Brown, 2006). Turning points are defined as a major change, experience, or realisation that can be gradual or sudden (Lowenthal, 1972; Rutter, 1996; King, et al., 2006). Transitions have been defined as a continuous or discontinuous process involving moving from one life stage, status, event or condition to another; development and growth occur if an individual is able to adapt to their life crisis (Adams, Hayes, & Hopson, 1976; Brammer, 1992; Wilson, 1997; Petch, 2009).

Each person experiences positive and negative transitions during their life time. A transition is usually triggered by a significant turning point such as becoming ill, being diagnosed with incurable disease, recovery and death. Some transitions are triggered by positive turning points such as job promotion and getting married, which represent opportunities rather than losses (Schumacher, Jones & Meleis, 1999). A classic description of transitional phases is presented by Bridges (2009). Transitions consist of three phases:

**Ending** is the first phase of a transition. ‘Ending’ refers to disengagement from current relationships’ situations or from ways of behaving and usually encompass a change in the individual’s sense of self. In the ending phase, individuals let go of their old ways and old beliefs. The ending phase, in which people have to find new coping strategies to deal with their losses or gains, may be positive or negative (Bridges, 2009; Petch, 2009).

**Neutral zone** is the second phase of a transition (Bridges, 2009). The neutral zone is an in-between period when the pre-existing situation disappears but the existing situations has not yet emerged. In the neutral zone, individuals may feel disorientated
or uncertain as a result of losses they experience in the first ending phase. Bridges (2009) considered the neutral zone to be the key to the transition process and indicated the neutral zone has both danger and opportunity. In the neutral zone, maladaptive habits are changed to adaptive ones if sufferers are able to overcome their life crisis. For example, Curtin et al. (2002) suggested individuals come to terms with CKD and HD by restructuring the self and their illness experience. If individuals are able to adapt to life with CKD and HD treatment, positive change occurs.

**New beginning** is the third phase of a transition (Bridges, 2009). If people are able to adapt to their life crisis, they can find new meaning/purpose in the changed situation and a sense of control. The new beginning is considered to complete the transition process. For example, people with CKD who are able to adapt to the disease and find meaning and purpose in their changed health status and are able to accept and live with CKD, and can grow and develop in the next life phase. Each transition and turning point often creates tension or stress.

**Stress**

Stress is the disturbing or distressing physical, emotional, psychological, social or spiritual outcome for an individual produced by significant event or crisis (Hungerford & Harrison, 2012). As indicated previously, any turning point or life transitions can result in some degree of stress; the degree of stress depends on the demands the stress makes on the person’s ability to cope and their resilience (Adams, et al., 1976). People diagnosed with stage five CKD usually change in various dimensions: physical, psychological, spiritual and socioeconomic (Burns, 2004; Castner, 2011; Zalai, Szeifert, & Novak, 2012). People with CKD usually experience multiple transitions and various turning points as the disease progresses.
Stress is a natural response to danger or adversity and helps people survive and maintain wellbeing if they are able to manage their stressors (Lupien et al., 2007). Stress due to physical response involves a series of biochemical changes involving the sympathetic nervous system (SNS) and homeostasis. Stress stimulates the hypothalamic-pituitary-adrenal axis (HPA) whereby neurons in the hypothalamus release corticotrophin-releasing hormone (CRH) (Miller & O'Callaghan, 2002). CRH triggers the pituitary gland to secret adrenocorticotropicin (ACTH).

ACTH acts on the adrenal cortex of the adrenal gland situated above the kidneys resulting in the release of two stress hormones: the glucocorticoids and adrenaline and noradrenaline (Lupien et al., 2005). The glucocorticoids prepare the body for fight or flight by releasing glucose from energy stores in the liver and muscles to enable the individual to respond to danger and cope and/or survive (Ashfield, 2010).

Stress is an essential adaptive mechanism, but prolonged unrelieved stress results in burnout or maladaptation. Unrelieved stress can trigger hyperglycemia, cardiovascular disease and hypertension, which are key underlying causes of chronic kidney disease (Ashfield, 2010; Pryor, 2008). Thus, prolonged high stress levels have an adverse effect on individual’s lives; therefore, coping strategies are necessary for people to manage stressful events.

**Suggestions for the current study**

In conclusion, the two nursing models (Roy’s Adaptation Model and the Conservation Model) and the two nursing theories (Uncertainty in Illness Theory and Modeling and Role-Modeling) are grounded in Western culture and are all related to CKD/HD, especially in Western countries. In Thailand less is known about how people adapt to CKD and its treatment; therefore, these nursing models and theories may not capture
the multidimensional Thai context including influences of the healthcare system, social structures and cultural norms that affect the way individuals respond to stressful situations, in this case CKD/HD. However, these nursing models and nursing theories triggered the researcher’s interest in the concepts related to adaptation and informed the researcher’s approach to framing the research aim and research questions, developing the interview guide, and undertaking data analysis. Thus, in-depth individual interviews were employed to understand the processes Thai people receiving HD used to adapt to CKD and its treatment.

**Chapter summary**

Chapter two outlined the main nursing models, Roy’s Adaptation Model and the Conservation Model, and nursing theories, Uncertainty in Illness Theory and Modeling and Role-Modeling Theory, which highlighted adaptation as a key concept in adapting to CKD and HD. Chapter two also defined adaptation and the key dimensions of adaptation including: spirituality, religion, social support, turning points and transitions, and stress. This review of nursing models and theories as well as the key aspects of adaptation enabled the current researcher to frame the research purpose and develop an interview guide for use in the study during data collection and analysis.
Chapter 3

Literature review
Chapter introduction

Chapter three describes the basis of the literature review, the search strategy used to identify relevant literature, the search aim, the databases searched, the search terms used and the selection criteria. In addition, Chapter three describes the critical appraisal process used to assess the quality of each study. Data analysis and synthesis and a summary of the key findings are also described and discussed.

Search aim

The aim of the literature review was to identify and synthesise literature describing how HD affects people with CKD and how people adapt to HD.

The basis of the literature review

The literature review aimed to show the topic is crucial, unresolved and that further study is required. The literature review involved systematically identifying, locating and analysing material related to the research questions (Bloomberg & Volpe, 2008). In the current study the literature review was conducted by:

- identifying and retrieving literature
- reviewing the literature
- analysing and synthesising the studies
- summarising and discussing the key findings.
Search strategy

Electronic databases searched were all on EBSCOhost and were relevant to medicine and nursing. The EBSCOhost database includes the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature On-Line (MEDLINE), PsychINFO, E-Journal and Global Health. Scopus, the Australian Articles (APA-FT), Science Direct and Google Scholar were also searched. A librarian at Deakin University provided expert advice about the search technique, databases, keywords and search terms.

Keywords used to search the literature were chronic kidney disease, haemodialysis, adaptation and coping strategies. Keywords were also combined using Boolean operators, AND/OR. The Boolean operator, AND, was used to connect “haemodialysis” AND “Adaptation” AND “chronic kidney disease.” A question mark was used to capture alternative word spelling by placing it to replace one character such as h?emodialysis.

Some identified articles using these terms were not relevant to the research topic and the aim of review. Therefore, the search was narrowed by adding the terms adjustment, spirituality, religion and social support because they are related to adaptation. Hence, references were retrieved that contained the search terms listed below:

1. H?emodialysis OR dialysis OR renal replacement therapy AND adaptation OR adjustment. AND
2. Chronic kidney disease OR renal failure OR kidney disease OR end stage renal disease. AND
3. Coping strategy OR coping AND adjustment OR spirituality OR religion OR social support.
The initial search yielded 209 potentially relevant articles. The following inclusion and exclusion criteria were used to identify articles relevant to the aim of the literature review.

**Selection criteria**

Articles included in the review had to meet the following inclusion criteria:

- Written in Thai or English.
- Concerned adults aged 18 and above.
- Concerned patients with CKD receiving haemodialysis.
- Published in a peer-reviewed journal.
- Included both qualitative and quantitative studies.
- Published between 2000 and 2012 to retrieve the most up-to-date information.
- Addressed adaptation and coping strategies patients use to manage chronic kidney disease and haemodialysis.

Exclusion criteria were:

- Not in Thai or English.
- Included patients younger than 18 years.
- Not published in a peer-reviewed journal.
- Not about adaptation or coping strategies.
- People receiving peritoneal dialysis or kidney transplant.
- Not published between 2000 and 2012.

On initial examination, seventy-two articles appeared to meet the inclusion criteria. The titles and abstracts were further examined and decisions made about their suitability for full review according to the inclusion and exclusion criteria.
Forty-seven articles did not meet the inclusion criteria and were excluded:

- Twenty-seven articles were not concerned with coping strategies and focused on PD.
- Thirteen articles were duplicated in databases and were removed.
- Six articles focused on caregivers but not people receiving HD.
- One article was published twice in two different journals.

The reference lists of the included articles were also searched for any further relevant articles and five were added. In total 30 articles met the inclusion criteria. Grey literature/unpublished studies also were sought such as nursing theses because they concerned people with CKD coping with HD. Nursing theses were read to ascertain their applicability to the aim of study and four Thai nursing theses (Chokephichit, 2003; Prekbunjun, 2004; Sa-ngakul, 2006; Langnak, 2008) and three nursing theses from Western countries (Hay, 2005; Scaife, 2006; Dip, 2008) were included. In total, 30 published articles and seven nursing master and PhD theses met the inclusion criteria and were reviewed (see Figure 3.1).
Figure 3.1: The figure illustrates the search strategy that encompassed three steps: using the search terms, examining full text articles and reviewing reference lists related to the research topic and the aims of review.

The critical appraisal process

The critical appraisal tools for reviewing quantitative (Law et al., 1998) and qualitative (Letts et al., 2007) studies created by the McMaster University Occupational Therapy Evidence-Based Practice Research Group were used to assess the quality of each included study. The critical appraisal form for quantitative studies encompasses eight main sections, including study purpose, literature, design,
sample, outcomes, intervention, results, conclusions and clinical implications (see Appendix B). Each section includes one or more questions to enable the reviewer to rate the quality of the study out of a total score of eight for intervention studies and out of a total score of seven for non-intervention studies. A comments column is provided to record further relevant information.

The critical review form for qualitative studies encompasses eight main sections, including study purpose, literature, study design, sampling, data collection, data analysis, overall rigour, conclusions and implications (see Appendix B). Each section includes one or more questions to enable the reviewer to rate the quality of the study out of a total score of eight. The researcher critiqued and scored all publications and nursing master and PhD theses and the principal supervisor who has experience in both quantitative and qualitative research independently reviewed and scored 10% of these articles to test inter-rater reliability of the review.

The researcher developed score categories based on the critical appraisal questions created by the McMaster University Occupational Therapy Evidence-Based Practice Research Group for qualitative and intervention studies. The eight scores from the qualitative and intervention studies were divided into four categories. These score categories were as follows:

- 0.00 - 2.00 poor quality
- 2.10 - 4.00 fair quality
- 4.10 - 6.00 good quality
- 6.10 - 8.00 excellent quality.

The researcher also developed score categories based on the critical appraisal questions created by the McMaster University Occupational Therapy Evidence-Based Practice
Research Group for non-intervention studies. The seven scores from the non-intervention studies were divided into four categories. The score categories were as follows:

- 0.00 - 1.75    poor quality
- 1.76 - 3.50    fair quality
- 3.51 - 5.25    good quality
- 5.26 - 7.00    excellent quality.

The score for quantitative studies ranged between 5.5 and 7 and the average score was 6.1 whereas the score for the qualitative studies ranged between 5.5 and 7.0 and the average score was 6.31. Therefore, overall both quantitative and qualitative studies represent excellent quality.

**Data analysis**

Content analysis was used to analyse primary research and to synthesise the studies by creating categories and counting themes related to the study question/hypothesis (Dixon-Woods, Agarwal, Jones, Young & Sutton, 2005; Bernard & Ryan, 2010). There are no fixed rules for content analysis; but it commonly involves establishing categories and counting the number of instances that fall into each category (Silverman, 2006). The data were synthesised based on the design, methods, sample, limitations and any similarities and differences or inconsistencies in the results/findings.

Content analysis involved three stages including: preparation, organising and reporting (Eto & Kyngäs, 2008).

1. **Preparation stage**: the researcher read and reread the articles to understand the contexts that emerged in each study. The researcher then selected the unit of analysis such as a word from the text depending on the study question.
2. *Organising stage:* inductive content analysis was used to organise and analyse the studies including three main steps: open coding, creating categories and abstraction. The open coding step involved reading and rereading the articles to understand the issues that emerged in the studies. The NVivo 9 (© QSR International) computer program was used to manage the information and classify words or themes into categories in the second step. The researcher also wrote memos using the computer software to describe all issues that emerged in the studies.

Once each category was generated, the list of each category was grouped under a higher heading. In the abstraction step, the researcher gave each category names and grouped similar subcategories into the categories. Categories were also grouped into core categories. The core categories and sub-categories are listed in Table 3.1.

3. *Reporting stage:* the findings were reported in the final stage. The summary and discussion of the key findings that emerged included articles described in the following section.

<table>
<thead>
<tr>
<th>Categories</th>
<th>Sub-categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>HD-related concerns</td>
<td>- Physical symptoms</td>
</tr>
<tr>
<td></td>
<td>- Disruption of normal life</td>
</tr>
<tr>
<td></td>
<td>- Emotional distress</td>
</tr>
<tr>
<td>Managing HD-related concerns</td>
<td>- Seeking useful support</td>
</tr>
<tr>
<td></td>
<td>- Avoiding ill health</td>
</tr>
</tbody>
</table>
Summary and discussion of the key findings

Thirty-seven studies met the inclusion criteria, of which 20 were quantitative studies and 17 were qualitative studies and mainly conducted in the United States. Year ranged between 2000 and 2012. Most of the quantitative studies used descriptive-correlational design whereas two were randomised controlled trial (RCT) (Devins, Mendelssohn, Barré, Taub & Binik, 2005; Tsay, Lee & Lee 2005). Most qualitative studies used phenomenological design (Scaife, 2006; Lee et al., 2007; Dip, 2008; Yu & Petrini, 2010). The majority of qualitative studies used semi-structured interviews while questionnaires were utilised in quantitative studies.

The literature review examined how HD affects people with CKD and how people adapt to HD. The qualitative and quantitative studies reviewed identified several challenges people receiving HD experienced and the main coping techniques they used to manage their challenges. Two main categories emerged from the 37 studies:

- HD-related concerns including physical symptoms, disruption of normal life and emotional distress.
- Managing HD-related concerns including seeking useful support and avoiding ill health.

These categories and sub-categories are inter-related in and among the included studies. HD-related concerns are described in the following section.

Haemodialysis-related concerns

HD-related concerns are considered to be negative effects; the literature reported HD-related concerns in three sub-categories: physical symptoms, disruption to normal life and emotional distress.
Physical symptoms

Physical symptoms including fatigue, pain, vertigo, thirst and muscle cramps were common physical symptoms people receiving HD reported (Lee et al., 2007; Lai et al., 2012). Fatigue was frequently reported in quantitative studies (Mok & Tam, 2001; Tanyi & Werner, 2003; Burns, 2004; Logan et al., 2006; Weisbord et al., 2007) and qualitative studies (Chokephichit, 2003; Heiwe & Dahlgren, 2004; Ravenscroft, 2005; Lee et al., 2007; Yu & Petrini, 2010; Lai et al., 2012).

Fatigue is one of the most significant physical problems people receiving HD report. The fatigue was induced by the HD itself and uraemic symptoms (Chokephichit, 2003; Lee et al., 2007; Lai et al., 2012). For example, people with volume overload experienced fatigue during and after receiving HD treatment (Chokephichit, 2003). Interestingly, fatigue was a significant predictor of symptom burden in people receiving HD because fatigue commonly impaired their wellbeing and quality of life. Prolonged maladaptation to fatigue results in people receiving HD developing emotional distress, feeling bored, frustrated and becoming depressed (Burns, 2004; Hagren et al., 2005; Lee et al., 2007; Weisbord et al., 2007; Lai et al., 2012).

In addition, fatigue increased people with CKDs’ dependence on their families and caregivers (Hagren et al., 2001; Clarkson & Robinson, 2010). Fatigue also compromised people’s capacity to participate in social activities and affected their relationships with other people and their ability to obtain and maintain employment (Logan et al., 2006; Horigan, 2012; Lai et al., 2012). Being unemployed can cause financial difficulties for people with CKD, which makes it hard for them to accept and adapt to CKD and HD. Fatigue is a complex issue and can hinder adaptation to CKD and its treatment. Therefore, successful adaptation to HD related-fatigue not only
helps people with CKD survive but also enhances their quality of life. People with CKD felt HD disturbed their normal life.

**Disruption of normal life**

Many qualitative researchers (Chokephichit, 2003; Ravenscroft, 2005; Clarkson & Robinson, 2010; Lai et al., 2012) and quantitative researchers (Mok & Tam, 2001; Burns, 2004; Tsay et al., 2005; Kara et al., 2007; Yeh & Chou, 2007) found HD disturbed individuals’ daily life in various ways especially in relation to food and fluid restrictions.

**Food and fluid restrictions**

Cultural background exerts a strong influence on the way people manage chronic illnesses (Fisher et al., 2004; Davidson et al., 2007; Shaw, Huebner, Armin, Orzech & Vivian, 2009). Davidson et al. (2007) indicated culture provides a significant framework in which to interpret attitudes, values, and beliefs and manage health and illness. Cultural beliefs related to health and illnesses contribute to an individual’s ability to understand and adhere to their treatment. For example, lifestyle, food and stress are shaped by culture and play an important role in the management of chronic illnesses such as diabetes, high blood pressure and heart disease, all of which are related to CKD (Shaw et al., 2009).

HD related-food and fluid concerns affected people receiving HD’s quality of life. The literature suggests people with CKD find food and fluid restrictions difficult to change due to their established eating habits or lifestyles (Chokephichit, 2003; Ravenscroft, 2005; Kara et al., 2007; Yeh & Chou, 2007; Clarkson & Robinson, 2010; Lai et al., 2012). It is interesting to note that culture affects whether people adhere to food and
fluid restrictions such as traditional eating and drinking and can be a barrier to adapting to HD (Mok & Tam, 2001; Curtin et al., 2002; Chokephichit, 2003; Burns, 2004).

Belief systems and culture play an important role and help and/or hinder influences on quality of life for people receiving HD in Asian and Western countries (Mok & Tam, 2001; Curtin et al., 2002; Chokephichit, 2003; Burns, 2004; Ravenscroft, 2005; Kara et al., 2007; Yeh & Chou, 2007; Clarkson & Robinson, 2010; Lai et al., 2012). Food and drink are symbols of enjoyment and are a central part of social function in Chinese families such as habits of drinking tea and soup with meals (Mok & Tam, 2001; Curtin et al., 2002; Chokephichit, 2003; Burns, 2004; Ravenscroft, 2005; Kara et al., 2007; Yeh & Chou, 2007; Clarkson & Robinson, 2010; Lai et al., 2012). Turkish people generally drink a lot of black tea and many Western people drink a lot of alcoholic beverages (Kara et al., 2007). Habits such as drinking tea and alcoholic beverages might be difficult to change because some substances are addictive. People receiving HD who cannot adapt to the change in their food and fluid consumption to comply with restrictions might potentially suffer severe health complications such as pulmonary oedema and cardiovascular disease.

Considering other peoples’ feelings is also an essential part of Thai culture; for example, giving and receiving gifts, including food and drink (Klausner, 2000). Giving food and drink is considered to be a form of caring for other people in Thai culture. Therefore, Thai people receiving HD may find it difficult to avoid/deny food and drink provided by their loved ones. Cultural influences related to food and fluid restrictions could be barriers to or facilitators of adaptation to HD if people with CKD fail to reconcile their culture, customs and belief systems. When individuals do not adapt to
their life-threatening condition and are unable to cope with the changes and integrate them into their lives, maladaptation takes place.

People with CKD need to find alternative techniques to help them cope with food and fluid restrictions otherwise they will face serious health conditions. Some people receiving HD tried to manage their food and fluid restrictions by avoiding social activities, which can compromise relationships with other people and society (Mok & Tam, 2001; Kara et al., 2007).

**Impact on family, work capacity and social activities**

HD affects individuals’ relationships with their family and their roles in the family (Hagren et al., 2001; Hagren et al., 2005; Lin et al., 2005; Ravenscroft, 2005; Yeh & Chou, 2007; Clarkson & Robinson, 2010). As the change in health status and the demands of HD treatment on individuals with CKD can create negative impact on family relationships, CKD and HD can result in changes in people’s roles (Coyne, 2013). In Thai culture, Buddhist teaching indicates six social relationships help individuals enhance harmony and peaceful and spiritual growth. In fact, Buddhist teaching has become the foundation of Thai culture, and gives Thai people guidance about how to interact with each other. These include the relationships between:

- parents and children
- teacher and student
- husband and wife
- individual and neighbours
- employer and employee
- monks and lay people (Kaewpimon & Hieu, 2008).
Each individual may take several roles such as parents, husband/wife and child. If Thai people with CKD no longer maintain their usual role, they may find it hard to accept their life with CKD. For example, children are expected to look after their elderly parents as much as they can and maintain their parents’ property (Kaewpimon & Hieu, 2008). If young Thai people become ill, the child’s role is compromised causing significant stress.

In the partner role, people receiving HD may no longer be able to contribute to the family income and may find their families become their caregivers. They may suffer feeling dependent and a burden on their family (Coyne, 2013). In addition, people receiving HD find it difficult to maintain their family relationships, which sometimes results in divorce (Hagren et al., 2001; Hagren et al., 2005; Ravenscroft, 2005; Clarkson & Robinson, 2010; Yodchai, Dunning et al., 2011). Divorce is a significant turning point that can make life more difficult for people receiving HD.

However, divorce may help relieve stress and reduce uncertainty for some people with CKD if they felt they were a burden on their family (Curtin et al., 2002). Although strategies that create distance in relationships can help people with CKD reduce their emotional distress, it could be a maladaptive process in the long term. Although the relationships between the six roles are vital to help Buddhist Thai people develop peaceful, harmonious lives, people receiving HD may struggle if they do not integrate their usual roles into their changed health status resulting in maladaptation to CKD/HD.

HD also affects work capacity and social activities. Not surprisingly, spending time on HD causes people with CKD to feel disconnected from other people. People receiving HD spend a lot of time in hospital for various reasons; for example HD treatment, travel
to and from treatment centres, waiting before and after HD treatment and re-cannulation (Lin et al., 2005; Hargren et al., 2005; Ravenscroft, 2005; Clarkson & Robinson, 2010). If people are unable to adapt to HD, they are likely to develop emotional distress.

**Emotional distress**

In the literature, shock, crying, feeling discouraged, feeling uncertain about the future and fear of death had a major impact when individuals were initially diagnosed with CKD and needed HD treatment (Lin et al., 2005; Moran, 2008; Yu & Petrini, 2010). HD treatment affected people’s spirituality and resulted in depression, lethargy and/or weakness (Clarkson & Robinson, 2010). Qualitative (Moran, 2008) and quantitative researchers (Langnak, 2008) found uncertainty was commonly reported.

Feeling uncertain arises from various factors such as symptom burden, diagnosis, treatment plan and financial problems (Moran, 2008; Middleton et al., 2012). For example, Yodchai, Dunning et al. (2011) and Lai et al. (2012) reported being on a waiting list for a KT caused great uncertainty because transplants are not readily available, and patients continued to depend on HD treatment. Some Thai people found it hard to receive a KT because having a KT is only available in 24 centers located in big cities such as Bangkok: Ramathibodi Hospital, Siriraj Hospital and Chulalongkorn Hospital (Praditpornsilpa, 2010). Thai people who live in rural areas may find it hard to access advanced treatment such as a KT and are more likely to develop uncertainty than people who live in big cities (Prekbunjun, 2004).

In addition, many researchers reported people living with CKD and its treatment for long periods of time had less uncertainty (Mok & Tam, 2001; Hay, 2005; Langnak, 2008; Ramirez et al., 2012). The length of time spent on CKD/HD might enable them to become accustomed to the HD routine and/or develop coping behaviours. Duration
on dialysis seems likely to predict uncertainty in people receiving HD treatment. People need time to help them learn and understand how to manage life in both positive and negative situations.

**Conceptual frameworks**

Adaptation refers to an individual’s capability of responding to physical, psychological and socioeconomic changes associated with chronic illness such as CKD. Adaptation is a central concept in Roy’s Adaptation Model (RAM). RAM was used as the conceptual framework in three quantitative studies (Tanyi & Werner, 2003; Burns, 2004; Hay, 2005) and one qualitative study (Scaife, 2006). Scaife (2006) employed a phenomenological design and included five participants in the study. People needed to develop a positive outlook, have support from their families and learn about CKD and its treatment in order to adapt. However, the researchers did not reflect on the key elements of RAM such as the physiologic-physical and role function modes. Thus, the researchers may not have used all elements of RAM to frame the research purpose and develop an interview guide or to collect and analyse the data. In addition, the small sample size may limit the generalisability of the results and therefore, further studies with a larger sample size would be beneficial to validate and extend study findings.

Some quantitative researchers used RAM to frame their studies (Tanyi & Werner, 2003; Burns, 2004; Hay, 2005). These researchers used questionnaires based on the key elements of RAM, which may limit the relevance of the information provided for people with CKD who participated in the study. RAM seems relevant to people with CKD receiving HD in Western countries. Because RAM is grounded in Western culture it might not capture the multidimensional viewpoints of Thai people receiving HD.
Differences in cultural beliefs, customs, healthcare systems and healthcare policies can influence Thai people with CKD’s perspectives, responses to chronic illness and its treatment and their coping techniques. Therefore, RAM triggered the current researcher to consider the adaptation process Thai people receiving HD use. The following section shows how people receiving HD manage their concerns associated with HD treatment.

Managing HD-related concerns
Coping is a central to the adaptation process of people receiving HD and enables them to cope with CKD and its treatment. The classic coping strategies people with CKD receiving HD use are: seeking useful support and avoiding ill health.

Seeking useful support
Many qualitative and quantitative researchers found people seek useful support when dealing with physical, psychological and socioeconomic issues. People receiving HD relied on religion and spirituality to help them overcome their negative life situations.

Religion and spirituality
Many qualitative and quantitative researchers found people receiving HD used religion and spirituality to manage/cope with their physical and psychosocial problems and improve their wellbeing and quality of life (Gilbar, Or-Han & Plivazky, 2005; Hay, 2005; Ibrahim et al., 2012; Ramirez et al., 2012; Thomas & Washington, 2012). Religion is an important part of Thai culture (Pargament, 1994). Buddhism plays a fundamental and significant role in mediating Thai people’s values and beliefs, perceptions and knowledge and provides guidance about how to live in the world. Religion and spirituality appear to be positive, powerful coping strategies that help people with CKD reorient their lives to manage and accept CKD/HD.
Religion and spirituality are central aspects of the adaptation process and enable people to cope with stressful situations. None of the papers reviewed addressed the relationship between religion and spirituality, especially in Thai people receiving HD, or how religion and spirituality affect Thai people receiving HD. Therefore, further study could focus on religion and spirituality as separate issues and explore whether they affect the way Thai people receiving HD adapt. Loved ones and healthcare professionals provide useful support that helps people with CKD cope with positive and negative events.

**Loved ones and healthcare professionals**

Support is not only received from the families of people with CKD or their loved one but also from healthcare professionals such as doctors and nephrology nurses. Information support from family and friends helps individuals receiving HD understand the disease and its treatment (Weil, 2000; Prekbunjun, 2004; Lin et al., 2005; Langnak, 2008; Saenhom, 2008; Mitchell et al., 2009; Clarkson & Robinson, 2010; Lai et al., 2012). Information support from their loved ones is likely to be a powerful source of support that helps people with CKD to learn to live with their chronic illness and its treatment.

Emotional support helps individuals with CKD cope with emotional distress, anxiety, uncertainty, fear of dying and depression and to accept CKD and its treatment (Prekbunjun, 2004; Mitchell et al., 2009; Clarkson & Robinson, 2010; Lai et al., 2012). People receiving various types of support are more likely to undertake self-care (Chokephichit, 2003). Likewise, Kara et al. (2007) found most people on HD had high levels of social support from family and friends, which helped them comply with food and fluid restrictions and adhere to other treatments. However, people on dialysis may be independent and require less support from other people. In addition, unwanted support
from family and friends can create tension/conflict; therefore, positive support helps people adapt to the disease and its treatment (Moulton, 2008).

**Avoiding ill health**

People with CKD receiving HD tried to avoid ill health to prevent the progression of CKD (Welch & Austin, 2001; Curtin et al., 2002; Takaki et al., 2003; Heiwe & Dahlgren, 2004; Hagren et al., 2005). For example, they chose appropriate foods and avoided salty foods and reduced intake of vegetables and fruits to manage the process of their disease (Chokepephichit, 2003).

In addition, many researchers reported that people with CKD avoided thinking about issues that caused them emotional distress such as fear of dying, which helped them avoid emotional suffering (Curtin et al., 2002; Heiwe & Dahlgren, 2004). Avoiding thoughts about suffering could help people with CKD receiving HD relieve their stress in the short-term; however, in the long-term, avoidance or denial can lead to depression. For example, people who used avoidance coping techniques such as distraction, daydreaming or sleeping were more likely to be depressed than people who were faced with their life crisis (Welch & Austin, 2001; Takaki et al., 2003). Avoiding ill health may be a cause of stress and inhibit individuals’ adaptation to life with CKD/HD. The methodological limitations of the included studies are described in the following section.

**Methodological limitations**

Methodological limitations of quantitative studies affect the ability to generalise the findings for several reasons. For example, in many of the included quantitative studies non-random sampling techniques were used, commonly convenience sampling, that might result in low quality data; consequently, the findings may not be generalisable to
Tsay et al. (2005) employed an adaptation training program (ATP) to help Taiwanese people with CKD cope with disease-related stress. A convenience sample of 57 eligible participants was randomised to experimental (ATP plus usual care) or control (usual care) groups. The key stressors included fluid restriction, transport issues, physical dysfunction, duration of dialysis treatment and being unable to perform physical activities. After three months, the intervention ATP had an effect on perceived stress (P=0.005), depression (P=0.001) and quality of life (P=0.02). However, the sample was recruited using a convenience technique from three outpatient dialysis units in Northern Taiwan; therefore, the findings may not be generalisable to other settings.

Other qualitative researchers also used convenience sampling to recruit participants in their studies (Weil, 2000; Hagren et al., 2001; Clarkson & Robinson, 2010). Convenience sampling is considered to be the least rigorous sampling method because it involves selecting the most accessible participants and therefore may not include participants who have specific experience and knowledge of the research area (Whitehead & Annells, 2007). Thus, convenience sampling may not elicit in-depth information; consequently, the findings may not be transferable to other people in the sampling population or to other settings. It is interesting to note that Tsay et al. (2005) conducted a randomised controlled trial (RCT) that included an experiment and a control group; however, the researchers recruited the sample from only one setting, which affects the ability to generalise their findings.
Most quantitative studies used cross-sectional designs, which limited the discovery of any changes in adaptation to CKD/HD over time (Takaki et al., 2003; Burns, 2004; Weisbord et al., 2007; Yeh & Chou, 2007; Ramirez et al., 2012; Thomas & Washington, 2012). A study at one point in time might not capture all aspects of the adaptation process of people receiving HD, longitudinal designs could help the researchers capture all aspects of adaptation process in future research.

Many researchers used Lazarus and Folkman’s stress and coping theory as the theoretical framework to explore coping strategies (Mok & Tam, 2001; Logan et al., 2006; Yeh & Chou, 2007; Ibrahim et al., 2009). Most quantitative researchers used the Jalowiec Coping Scale (JCS) to examine coping strategies in people on HD. Construct validity of the original JCS was established by a panel from the Midwest Nursing Research Society that yielded a high percentage of agreement. The reliability (Cronbach’s alpha) of the JCS was 0.86, which is considered to be reliable and acceptable (Gurklis & Menke, 1988). Although the original JCS has established validity and reliability, it might not be valid in different cultures (Mok & Tam, 2001; Yeh & Chou, 2007).

Ibrahim et al. (2009) also used the JCS to examine coping strategies in Indonesian people receiving HD. Some questions such as ‘chewing gum’ were excluded because it is unusual for Indonesian people to chew gum. ‘Drinking alcoholic beverages’ was also excluded for Muslim participants because it is ‘harum’ (Ibrahim et al., 2009).

Some researchers suggested the JCS needs to be modified and tested before being used with people with CKD in different cultures (Burns, 2004; Logan et al., 2006; Ibrahim et al., 2009) to help strengthen confidence in the validity of the findings.

The quantitative researchers used various questionnaires to measure stressors or HD-related concerns of people receiving HD such as the Haemodialysis Stressors Scale
(HSS), the Hospital Anxiety and Depression Scale (HADS) (Takaki et al., 2003; Ramirez et al., 2012) and the Cognitive Depression Index (CDI), which was used to examine depressive status (Weisbord et al., 2007).

The construct validity of the original HSS was tested by a panel of nephrology experts including a clinical psychologist and a nephrology nurse that reached a high percentage of agreement. The reliability (Cronbach’s alpha) of the HSS was 0.87, which was considered to be reliable and acceptable (Mok & Tam, 2001; Yeh & Chou, 2007). Although the HSS is reliable and valid and has been widely used; it might not address all HD-related stressors (Mok & Tam, 2001; Yeh & Chou, 2007). The HSS is a quantitative tool; therefore, it might not elicit in-depth accounts of the individual’s experience. Logan et al. (2006) reported some items on the HSS questionnaire were not relevant to people with CKD aged over 65. For example, items related to impaired ability to have children and the effect on ability to do their jobs.

Burns (2004) and Logan et al. (2006) recommended the HSS questionnaire be validated before use with other populations because an invalid questionnaire is likely to affect the study results. In addition, the HSS is a structured questionnaire that asks participants to respond to the same questions in the same order, which does not allow participants to respond to questions in their own words. Consequently, the researchers might have overlooked some potentially vital responses. In addition, some participants object to choosing from alternatives that do not precisely reflect their opinions, which could affect the study results. Therefore, in-depth interviews can help researchers explore individual’s life experiences associated with CKD/HD. Suggestions for the current study are described in the following section.
Suggestions for the current study

The literature review related to people with CKD adapting to HD treatment consisted of 30 original studies and seven Masters and PhD theses from 16 countries. The literature review about how people adapt to HD highlighted two major themes. HD-related concerns included physical symptoms, disturbed normal life and led to emotional distress. Managing HD involved seeking useful support and avoiding ill health. However, the concerns were ranked in different order of importance in each study (Mok & Tam, 2001; Welch et al., 2001; Takaki et al., 2003; Logan et al., 2006; Scaife, 2006). The difference in rank might depend on the differences in cultural beliefs, customs, healthcare systems and healthcare policies in each country. Additionally, the concerns are subjective and can only be assessed by the individual’s experience, which may result in inconsistencies between different studies’ findings.

Moreover, factors including age (Tanyi & Werner, 2003; Burns, 2004; Ibrahim et al. 2009), education (Ibrahim et al. 2009), time on dialysis (Burns, 2004; Ibrahim et al. 2009) and income (Prekbunjun, 2004; Ibrahim et al. 2009) seem to predict adaptation to CKD and its treatment. Interestingly, Burns (2004) suggested people’s coping abilities may be reduced in old age. In contrast, Tanyi and Werner (2003) reported advanced age was associated with effective coping. If people receiving HD have various health complications in old age, they may find it difficult to adapt to HD treatment. Older people with health conditions tend to depend on other people and may find themselves less useful, which could have psychological consequences.

There is strong evidence to suggest that individuals receiving HD experience many stressors and use various coping strategies in both developed and developing countries. In fact, studies conducted in different countries including the United States, Sweden,
Thailand, Taiwan, Canada, Ireland, the UK, China, Singapore, Hong Kong, Spain, Israel, Turkey, Indonesia, Malaysia and Brazil noted cultural, sociological and healthcare system differences that could influence the adaptation process.

Little is known about how culture influences the way Thai people adapt to CKD and HD. Consequently, the current researcher conducted a pilot study in Thailand to collect preliminary data about how HD affects Thai people with CKD to inform the study that is the subject of the current thesis (Yodchai, Dunning et al., 2011). The pilot study provided important preliminary data that confirmed the need for the current study and identified issues that required further study. Therefore, the purpose of the current study was to understand the processes Thai people receiving HD used to adapt to CKD and its treatment. The knowledge gained from the current study may help healthcare professionals to contribute to the adaptation process and help people receiving HD improve their quality of life. The following Table contains extracted data and quality rating scores for the 17 qualitative and 20 quantitative studies included in the review (see Table 3.2 and 3.3 on pages 86 to 104).
Table 3.2: Outline of the 17 qualitative studies included in the review: Note the table continues over 9 pages.

<table>
<thead>
<tr>
<th>Number</th>
<th>Author/Date</th>
<th>Journal/Design</th>
<th>Purpose/Method</th>
<th>Sampling population/ Sampling process</th>
<th>Main findings/Results</th>
<th>Quality rating score</th>
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<tbody>
<tr>
<td>1.</td>
<td>Weil (2000)</td>
<td>Nephrology Nursing Journal Qualitative research design</td>
<td>To explore the definition and sources of hope in people with stage five CKD requiring HD.</td>
<td>Participants were recruited from two hospitals.</td>
<td>Having hope helped participants accept and live with CKD and HD.</td>
<td>5.5/8</td>
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<td></td>
<td>The United States</td>
<td>Semi-structured interviews</td>
<td>Fourteen participants receiving HD: nine were males, five were females. Age range 43 to 81 years (mean 62.5 years).</td>
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<td>Participants were able to adapt to life challenges by families, friends, spirituality and technology.</td>
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<td>Being active helped participants feel useful and resulted in enhancing individuals’ hopes, whereas feeling unwell reduced individuals’ hopes.</td>
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<tr>
<td>2.</td>
<td>Hagren et al. (2001)</td>
<td>Journal of Advanced Nursing Interpretative qualitative design</td>
<td>To describe and characterise patients’ experiences of stage five CKD.</td>
<td>Participants were recruited from a dialysis unit in a hospital.</td>
<td>Participants regarded the HD machine as a life line. However, HD meant they needed to spend time in hospital receiving HD, which resulted in loss of freedom, dependence on caregivers and disrupted their marital, family and social life.</td>
<td>5.5/8</td>
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<tr>
<td></td>
<td>Sweden</td>
<td>Semi-structured interviews</td>
<td>Fifteen participants receiving HD: eight females and seven males. Age range 50 to 79 years (mean 62 years).</td>
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<td>Optimism and having autonomy relieved suffering.</td>
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<td>Number</td>
<td>Author/Date Country</td>
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<td>3.</td>
<td>Curtin et al. (2002) The United States</td>
<td>Qualitative Health Research Exploratory/ descriptive design</td>
<td>To examine processes that helped people receiving dialysis survive. Semi-structured interviews</td>
<td>Eighteen participants were recruited but the research setting was not stated. Ten males and eight females, age range 38 to 63 years.</td>
<td>Participants reported coming to terms with an uncertain future or fear of dying by avoiding long-term commitments such as getting married, having children and purchasing a house or car.</td>
<td>6.5/8</td>
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<tr>
<td>4.</td>
<td>Chokephichit (2003) Thailand</td>
<td>Master thesis Exploratory/ descriptive design</td>
<td>To explore self-care experiences of people with CKD receiving HD. Semi-structured interviews</td>
<td>Twenty-five participants were recruited from three HD units of the government hospitals in one province, in the East of Thailand. Sixteen females and nine males, age range 22 to 75 years (mean 43.49 years).</td>
<td>Participants understood their self-care enabling them to live with CKD/HD including: - having appropriate food - reducing CKD complications - preventing vascular access complications - maintaining family and social relationships. Participants used various coping strategies to manage their stressful event: - adhering to treatment - seeking information - setting goals - having self encouragement - maintaining hope.</td>
<td>6.5/8</td>
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<td>Number</td>
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<td>5.</td>
<td>Heiwe and Dahlgren (2004) Sweden</td>
<td>Advances in Physiotherapy Phenomenographic approach</td>
<td>To describe the coping strategies patients with CKD used to perform physical activities.</td>
<td>Participants were recruited from the nephrology outpatient, the HD unit and the outpatient unit at the Karolinska Hospital. Eighteen participants: pre-dialysis phase (n=5), receiving HD (n=8) and receiving PD (n=6) but the researchers did not provide the age range of participants and mean.</td>
<td>Participants used three coping strategies to manage physical activities in daily life: - Scheduling to cope with temporal stress. - Adjusting pace and avoiding health issue were used to cope with fatigue.</td>
<td>6.5/8</td>
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<td>6.</td>
<td>Prekbunjun (2004) Thailand</td>
<td>Master thesis Qualitative research design</td>
<td>To explore the spiritual experience of people with stage five CKD.</td>
<td>Participants were recruited from two hospitals. Twenty participants receiving HD: 12 females, eight males. Age range 20 to 60 years (mean 47.35 years).</td>
<td>Participants experienced spiritual distress including: - living with no future and feeling worthless - Arteriovenous (AV) access is a lifeline - depending on HD - Chronic kidney disease is a disease for rich but poor people die. Spiritual support encompassed: - seeing their family successful - spiritual support from family - living longer life - receiving a KT - support from government.</td>
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<td>Number</td>
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<td>7.</td>
<td>Hagren et al. (2005) Sweden</td>
<td>Journal of Clinical Nursing Qualitative research design</td>
<td>To explore the experiences of people receiving HD.</td>
<td>Participants were recruited from three hospitals. The study included 41 participants receiving HD. Twenty-six males and 15 females. Age range 29 to 86 years (mean=67.5 years).</td>
<td>Participants were discontented with healthcare professionals due to inadequate communication with doctors. Participants reported time consuming HD treatment and fatigue was stressful. They maintained and preserved their energy by avoiding partying and social activity.</td>
<td>6.5/8</td>
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<td>8.</td>
<td>Lin et al. (2005) Taiwan</td>
<td>Western Journal of Nursing Research Colaizzi's Phenomenological design</td>
<td>To describe the experiences of making a decision about HD among a group of Taiwanese with CKD stage five.</td>
<td>Participants were recruited from HD centres and community hospitals in Southern Taiwan. The study included 12 participants receiving HD. Six males and six females. Age range 28 to 53 years (mean=38.9 years).</td>
<td>Participants experienced emotional distress when they were diagnosed with CKD and needed HD. The most common forms of emotional distress were shock, denial, fear and anxiety. Participants reported family support and religious belief enabled them to accept CKD/HD.</td>
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<td>Number</td>
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<td>9.</td>
<td>Ravenscroft (2005) Canada</td>
<td>Nephrology Nursing Journal Interpretive descriptive design</td>
<td>To explore the perceptions of people with diabetes concerning their CKD. In-depth interviews</td>
<td>Participants were recruited from one community HD unit and two centre HD units. The study included seven participants: five females and two males, age range 35 to 87 years (mean was not reported).</td>
<td>Participants adjusted to living with CKD by managing and accepting CKD, which enabled them to have personal control over their life and live with hope.</td>
<td>6.0/8</td>
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<td>10.</td>
<td>Scaife (2006) The United States</td>
<td>Master thesis Phenomenological design</td>
<td>To explore the experiences of people with stage five CKD receiving HD. In-depth interviews</td>
<td>Participants were recruited from a HD centre, in a Midwestern urban setting in the United States. Five participants were included in the study, four males and one female, age range 41 to 70 years (mean was not reported)</td>
<td>Participants coped with CKD and HD by using positive thinking, support from their family and learning to live with CKD and HD.</td>
<td>5.5/8</td>
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| 11     | Lee et al. (2007) | Taiwan  | Journal of Clinical Nursing | Phenomenological design | To explore the fatigue experiences from people receiving HD perspectives. Semi-structured interviews | Participants were recruited at a HD unit in South Taiwan. The study included 14 participants. Four males and 10 females. Age range 26-72 years (mean=52 years). | Participants described three main types of fatigue:  
- physical  
- affective  
- cognitive.  
They managed fatigue by modifying their lifestyle, which helped them to accept and live with CKD/HD. 7/8 |
<p>| 12     | Dip (2008)        | Ireland | PhD thesis          | Phenomenological design | To explore the individuals’ experience of stage five CKD and HD treatment. Semi-structured interviews | Participants were recruited from a renal unit in Ireland. The study included 16 participants. Age range 30-66 years (mean was not reported) and the researcher did not provide the participant’s gender. | Participants were frustrated by spending time on HD and being on a KT waiting list. Participants coped with their emotional distress by living with hope. 6.5/8 |</p>
<table>
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<th>Number</th>
<th>Author/Date</th>
<th>Country</th>
<th>Journal/Design</th>
<th>Purpose/Method</th>
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<th>Main findings/Results</th>
<th>Quality rating score</th>
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<tr>
<td>13.</td>
<td>Mitchell et al. (2009)</td>
<td>UK</td>
<td>Journal of Renal Care</td>
<td>Qualitative positive psychology approach</td>
<td>To identify the factors that enable people with CKD to transit to HD treatment.</td>
<td>Participants used three main coping strategies: - considering treatment options - cognitive style such as positive reappraisal, optimism realistic expectations, acceptance and social comparisons. - social support from neighbours, family, friends and other people with CKD.</td>
<td>6.5/8</td>
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</table>

Semi-structured interviews

Ten participants were recruited in a NHS Renal Unit. Five were females, age ≥20.

Participants were recruited in two HD teaching hospitals in Wuhan, China.

The study included 16 participants. Ten males and six females. Age range 20-77 years (SD=8.62).
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<th>Number</th>
<th>Author/Date Country</th>
<th>Journal/Design</th>
<th>Purpose/Method</th>
<th>Sampling population/ Sampling process</th>
<th>Main findings/Results</th>
<th>Quality rating score</th>
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<tr>
<td>15.</td>
<td>Clarkson and Robinson (2010) The United States</td>
<td>Nephrology Nursing Journal Qualitative research design</td>
<td>To explore the lived experience of patients with CKD. In-depth interviews</td>
<td>Participants were recruited from a dialysis centre in Oklahoma (n=10), age range 26 to 85 years (mean was not reported).</td>
<td>Participants receiving HD felt their lives were restricted, limited social activity and depending on other people. They developed emotional distress, depression, fatigue and lacked energy.</td>
<td>6/8</td>
</tr>
<tr>
<td>16.</td>
<td>Yodchai, Dunning et al. (2011) Thailand</td>
<td>Journal of Renal Care Grounded theory</td>
<td>To explore how HD affects Thai patients with ESRD and understand their perspectives about adapting and depending on HD. Semi-structured interviews</td>
<td>Participants were recruited from a dialysis unit in Songkhla province, Thailand. The study included five participants: 3 males; 2 females, age range 24-66 years (mean= 45.40 years).</td>
<td>Coping strategies such as planning, adjusting and avoiding, believing in religion, superstition and living with hope were used to adapt to HD/CKD and to perform physical activity, maintain self-concept, role function and interdependence.</td>
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<td>Number</td>
<td>Author/Date</td>
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<td>Journal/Design</td>
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<td>17</td>
<td>Lai et al. (2012)</td>
<td>Singapore</td>
<td>Psychology Health and Medicine</td>
<td>Qualitative research design</td>
<td>To explore the lived experiences of people receiving HD.</td>
<td>Participants used social support especially information, and physical and financial support from family members, friends, co-workers and healthcare professionals to cope with their stressful event.</td>
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<td></td>
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<td>Semi-structured interviews</td>
<td>Participants were recruited from the National Kidney Foundation Singapore (NKF).</td>
<td>People receiving HD experienced emotional distress and HD complications.</td>
</tr>
</tbody>
</table>
Table 3.3: Outline of the 20 quantitative studies included in the review: Note the table continues over 10 pages.

<table>
<thead>
<tr>
<th>Number</th>
<th>Author/Date</th>
<th>Journal/Study design</th>
<th>Purpose/Method</th>
<th>Sampling population/ Sampling process</th>
<th>Main findings/Results</th>
<th>Quality rating score</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Mok and Tam (2001) Hong Kong</td>
<td>Journal of Clinical Nursing</td>
<td>No specific study design</td>
<td>To determine the stressors and coping methods people receiving HD in Hong Kong used and compare the results to Western countries. Questionnaires including the Haemodialysis Stressor Scale (HSS) and the Jalowiec Coping Scale (JCS).</td>
<td>Participants were recruited from three outpatient HD centres. The study included 50 participants. Thirty males (60%) and 20 females. Age range 36-55 years (mean 62 years).</td>
<td>People receiving HD reported fluid restriction was stressful. They also reported food restriction, itching, fatigue and cost as causes of stress. Participants used more problem-orientated coping strategies than affective-orientated coping strategies to manage their stress.</td>
</tr>
<tr>
<td>2.</td>
<td>Welch and Austin (2001) The United States</td>
<td>Journal of Advanced Nursing</td>
<td>No specific study design</td>
<td>To examine relationships among stressors, coping and depression and test the mediating role of coping in people receiving HD. Questionnaires included the Centre for Epidemiologic Studies Depression Scale (CES-D) and the HSS and the Coping Strategy Indicator (CSI).</td>
<td>Participants were recruited from two Midwest, dialysis clinics: one at a university hospital and one in community. The study included 103 participants, age range 20 to 82 years (mean=55.6 years).</td>
<td>The results show at time one, psychological stressors were significantly associated with problem-solving, social support and avoidance coping. Participants who used avoidance coping and had high psychological stress at time one suffered from depression at time two. Psychosocial stressors and depression were related to avoidance coping.</td>
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<tr>
<td>Number</td>
<td>Author/Date</td>
<td>Country</td>
<td>Journal/Design</td>
<td>Purpose/Method</td>
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<td>3.</td>
<td>Takaki et al.</td>
<td>Japan</td>
<td>Behavioral Medicine</td>
<td>To access the interactive effects of stressors, coping with stress and self-efficacy on depression and anxiety in people receiving HD.</td>
<td>Participants were recruited from four medical facilities in Japan: the Yuuai Clinic in Saitama, the Bousei Tanashi Clinic, the Tokyo Kensei Hospital and the Nishi Clinic in Tokyo.</td>
<td>Participants with itching had low self-efficacy suffered more depression and anxiety than participants without itching.</td>
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<tr>
<td></td>
<td>(2003)</td>
<td></td>
<td>Cross-sectional design</td>
<td>Questionnaires including the Hospital Anxiety and Depression Scale (HADS), the Self-Efficacy on Health-Related Behaviours Scale and the Coping Inventory for Stressful Situation (CISS).</td>
<td>The study included 453 patients receiving HD treatment for more than one year. Age range 21.1 to 88.7 (mean=60.2).</td>
<td>Participants who reported a high degree of emotional-oriented coping were more anxious than participants who did not itch.</td>
</tr>
<tr>
<td>4.</td>
<td>Tanyi and Werner</td>
<td>The United States</td>
<td>Clinical Nursing Research</td>
<td>To examine the relationships among adjustment, spiritual wellbeing and self-perceived health in women with stage five CKD.</td>
<td>Participants were recruited from five outpatient HD centres in five out patients centres in the United States.</td>
<td>The majority of women reported their health was good. In addition, Well-being Scale and Self-Perceived Health were positively and significantly associated with overall of Psychosocial Adjustment to CKD.</td>
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<td></td>
<td>(2003)</td>
<td></td>
<td>Descriptive-correlational design</td>
<td>Questionnaires including the Psychological Adjustment to Illness Scale-Self-Report (PAIS-SR), the Spiritual well-being Scale (SWB) and the Your Health and Illness questionnaire.</td>
<td>Sixty-five women, age range 24 to 82 years (mean=57.54 years).</td>
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<td>5.</td>
<td>Burns (2004)</td>
<td>The United States</td>
<td><em>Applied Nursing Research</em></td>
<td>Cross-sectional design</td>
<td>To identify problems and coping strategies of African Americans on HD and describe relationships among demographic characteristics, coping and psychosocial and physiologic characteristics.</td>
<td>Participants were recruited from a HD centre in a south eastern city in the United States. The study included 102 African Americans with stage five CKD receiving HD. Forty-six males and 56 females, slightly more than half the participants were younger than 60 (n=56, 55%). Age range 26 to 80 years (mean=54.60 years).</td>
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<td>6.</td>
<td>Devins et al. (2005)</td>
<td>Canada</td>
<td>American Journal of Kidney disease</td>
<td>Randomised Controlled Trial (RCT)</td>
<td>To examine long-term survival after predialysis psychoeducational interventions and to examine survival differences between early referral nephrology and late referral to nephrology.</td>
<td>Participants were recruited from Montreal and Calgary in Canada. The study included 335 people with CKD: 172 were randomly assigned to receive predialysis psychoeducational interventions (63.0% men; mean age, 50.8 years) and 163 participants assigned to usual care (62.1% men; mean age, 52.7 years).</td>
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<td>Number</td>
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No specific study design | To examine the association among mental adjustment and coping strategies (emotion and problem focused) and psychological distress.  
Questionnaires including the COPE, the Mental Adjustment to Cancer (MAC) and the Brief Symptom Inventory (BSI) scales. | Participants were recruited from two hospitals in Northern Israel.  
The study included 60 people with stage five CKD. Forty-seven males and 13 females. The mean age was 53.5 (SD=12.77). | Participants used fighting spirit, problem focused and older people had less psychological distress. | 5.5/7 |
| 8.     | Tsay et al. (2005) | Taiwan | Journal of Advanced Nursing  
A two-group, RCT | To examine the effects of an adaption training program (ATP) for people with stage five CKD on coping with stressors.  
Questionnaires including the HSS and the Beck Depression Inventory (BDI). | Participants were recruited from three outpatient dialysis units in Northern Taiwan.  
The study included 57 people with CKD including 33 participants randomly assigned to ATP group and 27 participants assigned to usual care. Thirty females and 27 males; mean age was 50.725 years (SD=14.10). | The key stressors included:  
- fluid restrictions  
- transport issues  
- physical dysfunction  
- duration of dialysis treatment  
- unable to perform physical activities.  
After three months the intervention ATP had an effect on perceived stress ($P=0.005$), depression ($P=0.001$), and quality of life ($P=0.02$). | 7/8 |
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<tr>
<th>Number</th>
<th>Author/Date</th>
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<th>Quality rating score</th>
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<tr>
<td>9</td>
<td>Hay (2005)</td>
<td>The United States</td>
<td>Thesis, Descriptive, correlational design</td>
<td>To examine the effects of age, income, gender, education, the duration of dialysis, functional health status, spirituality, powerlessness and depression on quality of life of older people with stage five CKD perspectives.</td>
<td>Participants were recruited from two outpatient dialysis clinics in West Central Georgia and East Central Alabama.</td>
<td>The role function, self-concept and interdependence modes all had significant and direct effect on quality of life.</td>
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<td>Questionnaires including the Inventory of Functional Stature-Dialysis (FIS-D), the Religious Coping Scale (R-COPE), the Life Satisfaction Index-Z (LSI-Z), the Center for Epidemiological Studies-Depression (CES-D) and the Health-related Powerlessness Scale (HRPS).</td>
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<td>10</td>
<td>Logan et al. (2006)</td>
<td>Canada</td>
<td>Journal of Advanced Nursing, Descriptive, correlational design</td>
<td>To identify the types of stressors and coping strategies older people receiving HD use to manage stressful events.</td>
<td>Participants were recruited from two sites: one was located in a tertiary care hospital and another setting was equipped with 24 dialysis stations. The study included 50 participants: 28 males; 22 females, age range 66 to 90 years (mean 76.4 years).</td>
<td>Duration on HD, lack of energy and limited social activities were the most bothersome stressors. Optimistic was most frequently used to manage life-changing events: having a sense of humour and looking on the good side.</td>
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<td>11.</td>
<td>Sa-Ngakul (2006)</td>
<td>Master’s thesis</td>
<td>To examine perceived self-efficacy in health-promoting behaviours of people receiving HD.</td>
<td>Participants were recruited from two sites: HD units at the Priest’s Hospital and Renal unit of Police General Hospital.</td>
<td>The mean overall health-promoting behaviours was ‘rather good’ level. The mean of nutrition behaviour, interpersonal relationships, spiritual growth, physical activity and stress management were <em>rather good</em> (health promoting score range=2.50-3.49). Age, education level, family income, and self-efficacy were predictive of health-promoting behaviours (38.1%, $R^2=0.381$, $p&lt;0.001$).</td>
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<td></td>
<td>Thailand</td>
<td>Descriptive, correlational design.</td>
<td>Questionnaires including the perceived self-efficacy in health-promoting behaviours and the health-promoting behaviours of HD patients.</td>
<td>The study included 132 people receiving HD. Sixty-nine males and 63 females, age range 18 to 67 years (mean = 40.98 years).</td>
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<td>12.</td>
<td>Kara et al. (2007)</td>
<td>Journal of Nursing Scholarship</td>
<td>To examine Turkish people’s non adherence to food and fluid restrictions and the level of perceived social support.</td>
<td>Participants were recruited from three HD centres in Ankara, Turkey.</td>
<td>Most participants were non-adherent to food and fluid restrictions. People of younger age, married and low level of support from family and friends were significant factors affecting fluid non-adherence.</td>
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<td>Turkey</td>
<td>Descriptive, correlational design.</td>
<td>Questionnaires including the Dialysis diet and Fluid Non-adherence Questionnaire (DDFQ) and the Multidimensional Scale of Perceived Social support (MSP).</td>
<td>The study included 160 participants (57.5% male). Age range 20 to 84 years (mean 47.3 years).</td>
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<td>13.</td>
<td>Weisbord et al. (2007) The United States</td>
<td>Nephrology Dialysis Transplantation Cross-sectional design</td>
<td>To compare the prevalence and severity of depression and symptoms of African American and Caucasian people receiving HD.</td>
<td>Participants (n=160) were recruited from three dialysis units in Allegheny County. Eighty-two were Caucasians (60 males and 22 females, (mean age=65 years). Seventy-eight were African Americans (63 males and 15 females, mean age=59 years).</td>
<td>Both African-Americans and Caucasians reported high symptom burden and symptom severity. Racial differences were significantly associated with spiritual and religious beliefs. African-Americans were more likely to regard spiritual and religious beliefs as more important than Caucasians.</td>
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<td>14.</td>
<td>Yeh and Chou (2007) Taiwan</td>
<td>Psychosomatic Medicine Cross-sectional design</td>
<td>To investigate stress-related to HD and the relationship between stress and coping strategies in people with CKD.</td>
<td>Participants were recruited from five medical centres: regional hospitals (n=5), community hospitals (n=10) and independent HD centres (n=7). The study included 2,642 participants 1,228 males 1,414 females (mean=57.39 years).</td>
<td>People with CKD experienced stress related to physical symptoms, dependence on medical staff and blood vessel problems such as arteriovenous (AV) fistula block and not enough blood flow. Participants used emotion-oriented, support seeking, avoidance and isolated thoughts (getting away from the issues or think of something else) to manage life with HD.</td>
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<td>15.</td>
<td>Langnak (2008)</td>
<td>Thailand</td>
<td>Master’s thesis</td>
<td>To examine the level of uncertainty and the relationship among stimuli frame (duration of HD, number of complication and severity of complications), structure provider (education level of people on HD and perceived support from nurse) and uncertainty in people with CKD receiving HD.</td>
<td>Participants were recruited from a HD unit in the Kidney Foundation of Thailand, Priest hospital. The study included 150 participants, 80 males; 70 females, age range 20 to 70 years (mean 45.47 years).</td>
<td>Participants reported moderate uncertainty. Duration of HD and education level was negatively associated with uncertainty level. People receiving HD for a long time and those with high education as well as perceived high level support from nurses had little uncertainty.</td>
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<td>16.</td>
<td>Saenhom (2008)</td>
<td>Thailand</td>
<td>Survey research</td>
<td>To examine the quality of life of people with end stage renal disease.</td>
<td>Participants were recruited from Khon Kaen Hospital, Thailand. The study included 43 participants, 27 males; 16 females, age range 24 to 73 years (mean 52.84 years).</td>
<td>Overall of participants’ quality of life was moderate (82.9 out of 130). 37.2% of participants felt unhappy associated with cost and health status. 55.8% of participants felt happy associated with family caring and understanding and good health service. Social relationship reported good level among monks but low level among wageless people, farmers and housekeepers.</td>
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<td>17.</td>
<td>Ibrahim et al. (2009) Indonesia</td>
<td>Thai Journal of Nursing Research Descriptive design</td>
<td>To examine the relationships between coping and quality of life among Indonesians receiving HD.</td>
<td>Ninety-one participants receiving HD were recruited from three HD units in Bandung.</td>
<td>Quality of life was negatively associated with affective-oriented coping, but was not significantly associated with problem-solving coping (p &lt; 0.05).</td>
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<td>18.</td>
<td>Ibrahim et al. (2012) Malaysia</td>
<td>Asian Social Science Cohort study</td>
<td>To determine the influence of illness perception and religious coping strategies on health-related quality of life (HRQoL) and to identify predictors of religious coping on illness perception and HRQoL.</td>
<td>Individuals receiving dialysis (PD or HD) were recruited at outpatient facilities affiliated with the University Kebangsaan Malaysia Hospital, Dialysis patients at Jalan Ipoh, Kajang and Cheras and those in the care of the Batu Pahat Johor Medical Centre.</td>
<td>Illness perception and religious coping strategies were significantly associated with HRQoL (p &lt; 0.01). Individuals who had positive religious coping strategies perceived their illness to be less chronic, had good personal control, experienced fewer consequences and had a better understanding of the illness (p &lt; 0.01).</td>
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| 19.    | Ramirez et al. (2012)  | Brazil      | Journal of Psychosomatic Research | Cross-sectional design                                                       | To investigate the association among positive religious coping, religious struggle psychological distress and HRQoL.  
Questionnaires including the Hospital Anxiety and Depression Scale (HADS), the Brief RCOPE (religious coping) and the World Health Organisation Quality of Life (WHOQOL). | Participants were recruited from three outpatient HD units in Fortaleza.  
The study included 170 people receiving HD: 109 males and 61 females. Participant’s mean age was 48.40 years (SD=14.19).  
Participants receiving HD used religious coping and religious struggle techniques to manage life with CKD. Religious struggle is a negative coping technique related to individual’s tension and/or conflict in self and other people.  
Positive religious coping strategies were associated with HRQoL. However, religious struggle (tension or conflict in self and other people) was associated with depression ($r = 0.43; P < .0001$) and anxiety ($r = 0.32; P < .0001$). | 6.5/7               |
Questionnaires including the Measure of Religious Involvement, the Medical Outcomes Study Social Support Survey and the Medical Outcomes Study 36 Short Form Health Survey (SF-36v2). | The study included 176 African Americans receiving HD from four HD units.  
Eighty-six males and 90 females. Age range 20-85 years (mean=55 years).  
Social support was significantly associated with the emotional and physical health of African Americans ($P < 0.05$). | 6/7                 |
Chapter summary

Chapter three described the basis of the literature review, the search strategy used to identify relevant literature, the search aim, the databases searched, the search terms used and the selection criteria. In addition, Chapter three described the critical appraisal process used to assess the quality of each study. Data analysis and synthesis and a summary of the key findings were also described and discussed. The following Chapter presents the methodology and methods used in the current study.
Chapter 4

Methodology and methods
Chapter introduction

Chapter four is presented in two parts; part one provides a brief overview of qualitative research, the key elements of qualitative research, as well as the basic characteristics and methods used to ensure rigour in qualitative research. Part two describes the data collection tools, the data collection process and the interview process used in the current study. Part two also indicates how bias was managed during data collection and data analysis. Lastly, the ethical considerations are discussed.

Part one

Brief overview of qualitative research

Qualitative approaches were reviewed to set the context for the current study. ‘Qualitative research’ is a broad term that is difficult to clearly define (Avis, 2005). A commonly accepted definition of qualitative research refers to ‘multi-method in focus, involving an interpretive, naturalistic approach to its subject matter’ (Denzin & Lincoln, 1998, p.3). Denzin and Lincoln’s definition informed the methods used in the current study as such individual interviews were undertaken to gain insight into the experiences and perspectives of Thai people receiving HD.

Qualitative research encompasses various approaches such as phenomenology, ethnography, ethnomethodology, grounded theory and biographical and historical methods (Denzin & Lincoln, 1998). Each qualitative approach has a specific philosophical framework largely based on anthropology, psychology and sociology, but they share common philosophical elements and a similar purpose: to describe, explain and understand people’s perspectives and life experiences (Denzin & Lincoln, 1998; Speziale, 2007). The key principles of qualitative studies were applied in the study and data were collected using semi structured interviews.
Key elements of qualitative research

Each qualitative research approach provides different information about people’s perspectives and life experiences, although they share three key elements: ontology, epistemology and methodology (Guba & Lincoln, 1994).

**Ontology** refers to the nature of ‘reality’ (Healy & Perry, 2000, p.119). An ontological question is ‘what is the form and nature of reality and what can be known about it?’ (Guba & Lincoln, 1994, p.108). The ontology underpinning the current study was how Thai people with CKD adapt to HD.

**Epistemology** refers to the relationship between the existing knowledge and the researchers (Healy & Perry, 2000). An epistemological question is ‘what is the nature of the relationship between the knower or would-be knower and what can be known?’ (Guba & Lincoln, 1994, p.108). The epistemology underpinning the current study was guided by stories from the literature review and a pilot study undertaken to identify what is already known about CKD and HD in Thailand and to identify the gap in the literature concerning these issues.

**Methodology**: methodology and method refer to different issues in qualitative research. Methodology refers to a general qualitative approach researchers use to explore the ‘reality’ under study, whereas method refers to a set of procedures and research techniques used to collect and analyse the data (Strauss & Corbin, 1998; Healy & Perry, 2000; Silverman, 2006). A methodological question is ‘how can the inquirer (would–be knower) go about finding out whatever he or she believes can be known?’ (Guba & Lincoln, 1994, p.108). In the current study, the researcher used a qualitative approach, employing semi-structured interviews to collect data from Thai people with CKD to acquire information about how they adapt to HD.
Basic characteristics of qualitative research

Qualitative research is usually conducted in a natural setting and the context in which the phenomenon occurs is considered to be a part of the phenomenon itself (Denzin & Lincoln, 1998). The researchers make no attempt to place experimental controls on the phenomenon being studied. However, the researchers do attempt to interpret phenomena in terms of the meaning people give to them (Morse & Field, 1995; Speziale, 2007). The current study was conducted in Thailand: in two hospitals, patient’s homes and workplaces, which represent the natural settings in which the key informants, people with CKD, live and receive treatment. Qualitative research enabled the researcher to understand and interpret people’s experiences about the effect CKD and HD had on their lives and how they adapted to and lived with CKD and its treatment.

Qualitative research produces text rather than numerical data. Textual data includes transcripts of interviews, free text comments on a questionnaire, observation and field notes and video evidence. Significantly, textual data enables participants to express their thoughts and beliefs in their own words using their own terminology (Morse & Field, 1995). The researcher used individual interviews, questionnaires, field notes and audio recorded interviews to collect the data from participants.

Qualitative research is subjective, interpretative (inductive and deductive) and generates data that describe the phenomena of interest (Streubert & Carpenter, 1995). An important aspect of qualitative research is that it enables researchers to develop theory from the data. Theories can be developed from the data while data collection is in progress or after data analysis is completed (Morse & Field, 1995; Devers, 1999). Collecting and analysing qualitative data enabled the researcher to develop a theory or model that
described the adaptation process Thai people receiving HD experienced as they learned to live with CKD and HD.

Quantitative researchers focus on controlling variables, standardised testing and statistical data (Morse & Field, 1995; Devers, 1999; Creswell & Miller, 2000). Although qualitative research focuses on the subjective and utilises language and description, qualitative research is considered to be valid because it draws on different techniques from quantitative research to demonstrate ‘rigour’ or ‘trustworthiness’ (Davies & Dodd, 2002). The following section discusses rigour in qualitative research and shows how the researcher ensured rigour in the study.

**Rigour in qualitative research**

Trustworthiness is one aspect of rigour. Many authors describe ‘rigour’ as referring to the quality of qualitative enquiry that is applied to evaluate the quality of qualitative research (Lincoln & Guba, 1985; Denzin & Lincoln, 1998; Morrow, 2005; Polit & Beck, 2004; Whittemore, Jaser, Guo & Grey, 2010). Ensuring studies are rigourous is important to increase confidence that the study findings reflect the participants’ perspectives. Various strategies were used in the current study to enhance rigour (see Table 4.1 on pages 111-112) (Krefting, 1991; Mays & Pope, 1995; Davies & Dodd, 2002; Chiovitti & Piran, 2003; Horsburgh, 2003).
### Table 4.1: Strategies used to enhance rigour in the current study: Note the table continues over two pages.

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<th>Criteria/Strategies</th>
<th>Strategies applied in the current study</th>
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<td><strong>Credibility</strong></td>
<td>• Data were analysed independently, then a supervisory team meeting was held to consider the preliminary analysis and discussion to reach consensus.</td>
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<td>• The study process and findings were discussed with the supervisory team.</td>
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<td>• The interview transcripts were returned to participants to check for errors in the information. A summary of findings was also returned to participants requesting they provide additional comments and information.</td>
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<td>• The interviews were tape-recorded to secure an accurate account of the conversation.</td>
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<td>• The researcher was involved in a training activity program including interview training with her associate supervisor and analysing data using NVivo program with an expert.</td>
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<td>• Sample selection, the study setting, methods of data collection and analysis were clearly described.</td>
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<td>• Purposive sampling was used to target people receiving HD in order to provide relevant information for the study purpose and to ensure transferability of the findings to other Thai people receiving HD.</td>
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<td>• The interviews were conducted and data transcribed verbatim by the same researcher.</td>
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<td>• Field notes recorded the researcher’s observations and non-verbal responses during interviews.</td>
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<td>• Field notes recorded the researcher’s observations and non-verbal responses during interviews.</td>
</tr>
<tr>
<td></td>
<td>• The researcher wrote memos to record her ideas during data analysis.</td>
</tr>
<tr>
<td></td>
<td>• Sample selection, the study setting, methods of data collection and analysis were clearly described.</td>
</tr>
<tr>
<td></td>
<td>• Purposive sampling was used to target people receiving HD in order to provide relevant information for the study purpose and to ensure transferability of the findings to other Thai people receiving HD.</td>
</tr>
<tr>
<td></td>
<td>• The interviews were conducted and data transcribed verbatim by the same researcher.</td>
</tr>
<tr>
<td></td>
<td>• Field notes recorded the researcher’s observations and non-verbal responses during interviews.</td>
</tr>
<tr>
<td></td>
<td>• The researcher wrote memos to record her ideas during data analysis.</td>
</tr>
</tbody>
</table>

**Credibility** refers to the truth of the findings (Morse, 1994). Credibility can be achieved by:

- *Triangulation* refers to using multiple sources of information and perspectives to minimise systematic bias (Holloway & Wheeler, 2002). The main types of triangulation encompass sources (people and resources), methods (interviews, observations, focus group and questionnaires), researchers (research team or single researcher) and theories (Letts et al., 2007). Inter-rater reliability is used when an analysis is conducted by two or more researchers to establish the consistency of findings (Kitto, Chester & Grbich, 2008).

- *Peer debriefing or peer review* refers to the process in which the researcher discusses the research and findings with their colleagues who have experience of qualitative research (Lincoln & Guba, 1985).

- *Member checking* refers to the process where the researchers seek to validate data by returning the interview transcripts to the participants to ensure that they reflect the participants’ point of view (Lincoln & Guba, 1985).

**Transferability** refers to the extent to which the findings are confirmed by or are applicable to other settings or groups. Transferability can be enhanced by thick description (Lincoln & Guba, 1985; Sandelowski, 1986). *Thick description* is vital to qualitative studies. The researchers provide clear information about the research setting, the participants, the methods and the processes (Holloway & Wheeler, 2002).

**Dependability** is achieved by ensuring the findings are credible. One of the processes used to achieve dependability is maintaining an audit trail, including using field notes and memos to clearly document the researcher’s assumptions, decisions, choices and insights (Lincoln & Guba, 1985). Reflexivity is also a vital part of the audit trail. *Reflexivity* is an assessment of the influence of the researcher’s own background, perceptions, and interests in the qualitative research process which can be achieved by using journals and memos (Krefting, 1991).
<table>
<thead>
<tr>
<th>Criteria/strategies</th>
<th>Strategies applied in the current study</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Confirmability</strong> refers to the researcher’s ability to produce evidence to enable other researchers to confirm the findings (Morse, 1994). It also depends on clearly describing the methods so other researchers can replicate the study. Confirmability can be achieved through the audit trail (Lincoln &amp; Guba, 1985).</td>
<td>• The confirmation committee examined the logic of the decisions made throughout the study process. • The researcher asked her colleagues who have experience of qualitative research to review the process and findings.</td>
</tr>
<tr>
<td><strong>Methodological integrity</strong> refers to selecting the method to suit the aims of the study and appropriately applying the method (Liamputtong, 2009). Methodological integrity is met when the researchers describe their decisions and the process of the study.</td>
<td>• The conceptual framework was clearly described. • Semi-structured individual interviews were an appropriate method to answer the study questions.</td>
</tr>
</tbody>
</table>
| **Representativeness** refers to sampling approaches. In qualitative research, statistical representativeness is not a major requirement (Horsburgh, 2003). The two types of samples used in qualitative research encompass:  
- *Maximum variation sampling* where the researcher tries to study a phenomenon by finding a setting or people that represent the greatest differences in that phenomenon use different ages, cultural backgrounds and status (Al-Busaidi, 2008).  
- *Homogenous sampling*, the researchers select a small homogenous sample with the purpose of describing some particular subgroup in-depth (Al-Busaidi, 2008). | • Purposive sampling was used to recruit participants in the current study. • Heterogeneous samples were included in the study. Both genders were eligible to participate in the study if they met the inclusion criteria: started dialysis six months or more before the interview, aged 18 years or older, were medically stable and had no acute medical problems such as shortness of breath, nausea and vomiting and cardiac arrhythmias, were mentally competent to give informed consent to participate in the study and were Thai nationals. |
| **Saturation** refers to the redundancy of information and confirmation of previously collated data, in which no new information is forthcoming from new data (Morse, 1994). | • After approximately 16 interviews were completed and analysed very little new information emerged, but four more interviews were conducted to be sure data were complete. Therefore, data saturation was reached after 20 interviews. |
Researchers need to address many forms of bias in order to enhance the quality, trustworthiness, plausibility and credibility of the findings. Bias is discussed in the following section.

**Bias in qualitative research**

Bias is a major concern when designing and undertaking both qualitative and quantitative studies because bias can affect the quality of the data collected and the capacity to maintain and achieve trustworthiness (Polit & Hungler, 1999; Polit & Beck, 2008). Bias can be introduced in any aspect of the study including when the study is being designed, in the methods, by the researcher, the data collection process such as questionnaires, individual subjects, the overall sampling process and the data analysis (Polit & Beck, 2004). Researchers need to consider all forms of bias because it distorts the study findings (Chenail, 2011). The researcher and the sample selection process and data analysis are common areas where bias occurs in qualitative research (Polit & Beck, 2004).

**Researcher bias**

The researcher plays an important role in qualitative research and can be considered a ‘data collection instrument’ because the researcher is the observer, interviewer and/or interprets various aspects of the data (Lee, 1992; Avis, 2005; Speziale, 2007). Researchers are involved in every step of the study process and their potential to introduce bias occurs at each step and needs to be considered from the initial planning stages and throughout the study, including during data collection, analysis and interpretation (Avis, 2005).

A qualitative researcher is subjective, inductive, interpretative and generates data to describe the phenomena of interest (Speziale & Carpenter, 2003). Bias can occur during data collection if the researcher gives participants a clue about what they are
hoping to hear or expect to hear (Wengraf, 2001). Likewise, bias can occur when researchers allow their own perceptions and beliefs to intrude into the data analysis (Streubert & Carpenter, 1995; Corbin & Strauss, 2008; Chenail, 2011). Reflexivity is an important technique that helps researchers minimise their own bias. Reflexivity refers to an acknowledgement by the researchers that their own actions and decisions would affect the meaning and context of the individual’s experiences (Horsburgh, 2003). As indicated previously, the researchers are an essential part of the study process, which may influence participants’ responses if researchers lack concern about their own position. Significantly, the researchers need to acknowledge their own experiences, beliefs, and individual history in order to enhance their study findings.

Reflexivity is enhanced by researchers using journaling and memos to record and declare their assumptions and potential ideas that could influence participants’ responses (Krefting, 1991). Reflexivity in the current study was achieved by the researcher reflecting on her roles while collecting, analysing and interpreting data, which could enhance the quality of the study. In the past, the researcher has worked in an intensive care unit, but not in the Haemodialysis Unit at Hatyai hospital, which was one of the data collection sites. The researcher had no current relationship with potential participants. If the researchers do not reflect on their roles, bias can occur at various points in the study such as in the process of sampling.

**Sampling bias**

Sampling bias is a crucial issue in both qualitative and quantitative research and can occur in most sampling processes (Coyne, 1997; Morse, 2000). Qualitative inquiry focuses on developing an in-depth understanding of the phenomena (Morse, 2000).
Random sampling is of less concern in qualitative research. There are four main types of qualitative sampling:

- Convenience sampling, which is the weakest sampling form because it is easy to recruit accessible participants, who may differ from the rest of the population (Polit & Hungler, 1999). Thus, convenience sampling can result in low quality data and/or may not elicit in-depth information; consequently, the findings may not be transferable to other people in the sampling population or to other settings (Marshall, 1996; Polit & Beck, 2004).

- Snowball sampling or network sampling refers to gathering information from a few people who refer other people who meet the eligibility criteria such as friends, relatives, colleagues or other significant contacts until the sample size is obtained. Although snowball sampling is often used, it is open to sampling bias (Whitehead & Annells, 2007).

- Theoretical sampling is a data collection process, whereby the researcher simultaneously collects, codes and analyses the data in order to decide whether other data needs to be collected and the type of data needed (Whitehead & Annells, 2007; Chen & Boore, 2009). Theoretical sampling is commonly used in grounded theory, and is vital to the inductive and deductive process. The inductive process involves generating theory from the data whereas the deductive process entails purposeful sample selection to check the emerging theory (Chen & Boore, 2009).

- Purposive (purposeful) sampling or judgement sampling is the most common qualitative sampling method; people are recruited because they know about the study topic (Marshall, 1996). Purposive sampling was used in the current study because participants had insider knowledge about the issue under study:
living with CKD and HD. The method used in the current study is discussed in the following section.

**Part two**

**Methods used in the current study**

The researcher used individual interviews to collect data about the experience of CKD and HD from Thai people in Songklanagarind Hospital and Hatyai Hospital.

**Sampling population**

The research was undertaken in Thailand. People with CKD receiving HD were recruited from two tertiary care hospital HD units located in Songkhla Province in Southern Thailand during January and February 2012.

**Research setting**

1. **Songklanagarind Hospital**

Songklanagarind Hospital is the largest hospital in Southern Thailand and trains healthcare professionals such as medical and nursing students and has approximately 1000 beds. The hospital specialises in cancer, cardiology, neurology and renal care. Approximately 36 people were receiving HD in the dialysis centre at the time of the study. Twenty females aged between 29 and 86 years and 16 males aged between 40 and 86 years.

HD treatment was delivered in two sessions per day: one in the morning and one in the afternoon, Monday to Saturday. People with CKD receiving HD were able to select whether they received HD in the morning (8.00 am-1.00 pm) or in the afternoon (1.00-6.00 pm). People with CKD received HD treatments two or three times a week, each HD session averaged four to five hours.
2. Hatyai Hospital

Hatyai Hospital provides care for individuals referred from community and district hospitals from 14 provinces. It has approximately 600 beds. Approximately 16 people were receiving HD in the hospital at the time of the study: six females aged between 52 and 74 years and ten males aged between 22 and 75 years. HD services were similar to those provided in Songklanagarind Hospital. HD treatment was delivered in two sessions per day: one in the morning (8.00 am-12.00 pm) and one in the afternoon (1.00-4.00 pm), Monday to Friday. People with CKD received HD treatments two or three times a week, each HD session averaged four to five hours. Both hospitals are government operated. The hospitals are well-known to the public and both are located in the same province.

Sample selection

The researcher used purposive sampling to recruit participants who had CKD and were able to provide the necessary information to address the study aim. Females and males were eligible to participate in the study if they met the inclusion criteria.

Inclusion criteria

- Started dialysis six months or more before the interview, to ensure they had knowledge and experience of the issue under study.
- Aged 18 years or older because the study focused on adult and older people.
- Were medically stable and had no acute medical problems such as shortness of breath, nausea and vomiting and cardiac arrhythmias, which may induce cardiac arrest during the interviews.
- Able to give informed consent to participate in the study because they were capable of making their own decisions and judgments related to the study.
- Were Thai nationals because the study focused on Thai people on HD.
Exclusion criteria

- Started HD less than six months before the study commenced, which limited their experience of the issue under study.
- Younger than 18 years because the study focused on people aged 18 and over.
- Physically or psychologically unable to participate in the study because they lacked the ability to provide information.
- Not a Thai national because the study focused on Thai people.
- Not able to give informed consent due to lack of capacity to make decisions.

Sampling procedure

The researcher introduced herself to the nephrology nurses, doctors and other staff in each hospital, explained the purpose of the study and how the interviews would be conducted. The researcher asked a nephrology nurse who knew the patients to determine whether patients from the respective hospital HD databases met the inclusion criteria.

Nursing staff informed potential participants about the study and ascertained whether they were interested in participating. If potential participants indicated they were interested in participating in the study, nursing staff gave their names to the current researcher. The researcher gave individuals who met the inclusion criteria and indicated they were interested in participating in the study a plain language statement about the study in Thai, explained the information and answered any questions the person had in Thai (see Appendix C).

The researcher left the plain language statement and consent form with potential participants to read and make a decision about whether to participate in the study. After approximately one week the researcher contacted potential participants and
asked whether they agreed to take part in an interview. People who confirmed their participation signed a consent form before being interviewed. Participants were free to choose the venue where the interviews would be conducted.

**Data collection tools and data collection process**

**Questionnaire**

A questionnaire was used to collect demographic data from participants and/or from their medical records. The questionnaire was completed by the researcher and included two parts:

- General demographic data including, age, gender, marital status, religion, education level and socioeconomic status were collected from participants.
- Health information, including current treatment, comorbidities and complications associated with HD treatment were extracted from the medical record with the participants’ and nursing staff’s permission (see Appendix D).

General demographic and health information were collected from participants before the interview commenced.

**Interview guide**

Data about people’s experiences of living with CKD and HD and how they adapted to being diagnosed with CKD/HD were collected using in-depth individual interviews and open-ended questions. An interview guide was developed using *adaptation* as the conceptual basis to frame the research questions. Data from a pilot study (Yodchai, Dunning et al., 2011) and a review of relevant literature related to people receiving HD and the methods they used to cope with CKD/HD informed the development of the interview guide. The questions concerned experiences, the effects of HD on peoples’ lives and how they coped with CKD/HD (see Appendix D).
The interview processes

The researcher began to collect data from participants in Songklanagarind Hospital and then continued to collect data from participants in Hatyai Hospital. The interviews were conducted in a private room in the hospital or another place the participants desired; approximately one hour was allowed for each interview. The researcher interviewed participants once, unless there was a reason for the interview to be stopped or rescheduled, in which case, the researcher invited the participant to continue the interview at a later date.

Good communication was essential to collecting quality data and depended on the researcher creating rapport with participants. The researcher is a Thai national; thus, the interviews were conducted in the Thai participant’s native language. The researcher started the interview by greeting participants in a respectful manner and saying ‘Sawasdee ka’ while smiling and introducing herself to the participant. *Sawasdee ka* means hello in Thai. Rapport was considered to be established if participants smiled, responded to the greeting in a relaxed manner and answered in a calm voice. If participants showed they were nervous or anxious, the researcher continued building rapport by talking about a general topic until they felt relaxed.

After building rapport, the researcher again explained that the purpose of the interview was to gain information about Thai people’s experiences living with CKD and HD. The researcher also reminded participants they could stop the interview at any time and would be given an opportunity to ask questions.

The researcher asked permission to audio record each interview before beginning the interview. The researcher asked participants to describe their experiences of being diagnosed and living with CKD first, then she asked about HD treatment and how
they adapted to life with CKD and HD treatment. When necessary, probing and clarifying questions were used to explore issues participants raised such as:

- ‘Can you tell me about …?’
- ‘Can you give me an example of that?’
- ‘What was that like?’
- ‘What did that mean to you?’
- ‘How did you feel about…?’
- ‘Can you describe or tell me more about…?’

These types of questions helped gather in-depth information about how participants lived with CKD and HD. The researcher was careful not to disclose her views about CKD/HD to participants to minimise the researcher’s effect on participant’s responses. Participants were not rushed or pressured to respond.

The researcher used non-verbal language such as nodding, eye contact and verbal cues such as saying ka (ka is a polite word Thai women use to end a conversation and to show their politeness) to encourage participants to continue talking and to show her interest in hearing their stories. The researcher listened to participants’ responses in an active non-judgmental manner to enhance the accuracy and authenticity of the data. She controlled her facial expressions and maintained a neutral non-judgmental manner during the interviews.

If a participant exhibited emotional distress such as anger, frustration or crying during the interview, the researcher asked the participant whether they wanted to have a break or stop the interview. If the participant wished to continue the interview the researcher waited until they regained their composure before continuing the interview.
At the end of the interview the researcher confirmed whether the participant required
further support or counselling. If so, the researcher referred them to a qualified counsellor who provides a free service in each hospital.

After each interview was completed, the researcher asked the participant for permission to contact them again at a later date if she needed to clarify issues emerging in the transcript during data analysis, ask more questions, or ask the participant to comment on the transcript and the summary of the findings. Participants were free to agree or disagree to being contacted a second time. If participants indicated they were willing to be interviewed again, contact details were requested. The researcher ended the interview by saying Khob-Khun-Mark-Ka, which means thank you very much in Thai.

The researcher wrote field notes immediately after each participant left the room while details were still fresh in her mind. Field notes recorded non-verbal information such as a description of the physical appearance of the participant, the way they talked and other non-verbal information that could not be audio-recorded. The researcher also wrote about her reflections on the interview and the information the participant provided. She also reflected on whether the way she asked questions and responded to the participant could have influenced the participant’s responses.

All interviews were transcribed verbatim by the researcher. After one or two weeks, the researcher distributed the transcript to the participants in a sealed envelope the next time they attended the hospital for dialysis treatment. Participants were asked to check the transcript to ensure the information accurately reflected the conversation and captured their experiences. The researcher asked participants to give their comments back to her when they attended dialysis treatment the following week.
Once participants agreed the information was accurate, the researcher was careful to preserve the meaning of participants’ words when she translated the information from the Southern Thai dialect and Thai formal language into English to enable her Australian supervisors to read and analyse the transcripts. The researcher also received advice from a Thai English teacher from the Language Institute in Thailand and an English teacher in Australia to ensure the interviews were translated as accurately as possible in order to preserve the integrity of the data. After approximately 16 interviews were completed and analysed very little new information emerged. However, four more interviews were conducted to be sure data were complete. Data saturation was reached after 20 interviews.

**Data analysis processes**

NVivo 9 (© QSR International) computer program was used to manage the data. Large amounts of textual data in the form of transcripts and field notes were entered directly into the NVivo 9 (© QSR International) computer program for analysis. Analysis was conducted according to Ritchie and Spencer’s atheoretical method of qualitative data analysis (Ritchie & Spencer, 1994).

Five key data analysis stages were:

- familiarisation
- identifying a thematic framework
- indexing
- charting
- mapping and interpreting.
**Familiarisation**: the purpose of familiarisation is to enable the researcher to become immersed in the data. The researcher listened to the audio-recording and read and reread the transcripts and the field notes to become familiar with the data in order to list key ideas and emerging words and themes.

**Identifying a thematic framework**: the thematic framework was identified by entering short phrases, ideas or concepts that emerged in the familiarisation stage into the NVivo 9 (© QSR International) computer program. The data indicated that participants experienced various major changes such as ‘being diagnosed with CKD,’ ‘realising dialysis would help them survive’ and ‘getting married to subsidise the cost of HD.’ Those codes were therefore clustered into a concept named ‘turning points.’ In addition, participants felt CKD moved along a continuum from one stage to another such as ‘being diagnosed with CKD,’ considering treatment options and accepting and living with dialysis.’ Those codes were clustered into a concept named ‘transitions,’ which resulted in the generation of categories and sub-categories. Memos were also used to create categories. Devising and refining the thematic framework involved both logical and intuitive thinking and discussing ideas and concepts with the principal supervisor who is a skilled qualitative researcher. These steps helped the researcher confirm the data throughout the analysis, interpretation and writing processes.

**Indexing**: the researcher made judgments about the meaning and comparative importance of the information and comparisons within and among transcriptions of individual interviews. The indexing reference was represented by various codes in the NVivo 9 (© QSR International) computer program.
**Charting:** quotes were transferred from their original context and rearranged under the newly developed themes. Each passage from the transcripts and field notes was charted and referenced to the original text for further examination and possible quotation when writing up the findings and to preserve the integrity of the data.

**Mapping and interpreting:** the findings were mapped and interpreted as a whole to answer the priori research question and explain the emergent themes. The following section describes how the researcher controlled her bias during data collection, data analysis and interpretation.

**Managing bias during data collection, data analysis and interpretation**

The researcher adopted several strategies to enhance rigour and manage bias during data collection. Before conducting the study, the researcher attended qualitative workshops and undertook training in conducting qualitative interviews with her associate supervisor who has experience in qualitative research. The researcher also received advice from her Thai supervisor who is experienced using qualitative methods and was able to provide feedback about the first three interviews during data collection in Thailand. Thus, the researcher gained experience conducting qualitative interviews before she conducted most of the interviews, which helped minimise potential researcher bias.

The researcher attended qualitative data analysis workshops to learn how to analyse qualitative research using the NVivo 9 (© QSR International) computer program that helped her manage the information efficiently. In order to control researcher bias, the researcher wrote memos to record her ideas and decisions during data analysis. In addition, the researcher used investigator triangulation by having her supervisors, who were knowledgeable about qualitative methods, analyse each interview independently.
and then discuss their analysis with each other and the student researcher to reach consensus and confirm the data analysis and interpretation was as accurate as possible.

The following section is an example from the list of the nodes at an early stage of data analysis.

Licensee: NVivo version 9    Created 3/8/2012 (9.10 AM.)

**Node: Diagnosis stage**

1. First diagnosed.
   1.1 Did not realise the impact of the disease on their life (10 sources).
   1.2 Realising the impact of CKD on their life (10 sources).

2. Responding:
   2.1 Emotional distress (19 sources).
   2.2 Accepted (1 source).

3. Coping strategies during diagnosis stage.
   3.1 Social support:
      3.1.1 Family (10 sources).
      3.1.2 Friends (2 sources).
   3.2 Religion and spirituality:
      3.2.1 Accepted CKD (2 sources).
      3.2.2 Karma (2 sources).
   3.3 Preparation:
      3.3.1 Healthcare professionals (3 sources)
      3.3.2 Hospital choices (1 source).
      3.3.2 Seeking information (1 source).

At the end of the data collection the list contained 221 nodes.
Member checking was conducted after data analysis to manage one source of potential bias. Member checking was undertaken by mailing a summary of the findings to each participant and asking them to comment on the summary to ensure the researcher’s interpretation of the data reflected the participant’s views and ensure the participants were able to recognise their collective experiences of HD. Member checking also enabled participants to provide further comments about living with CKD and HD to strengthen the completeness of the study findings.

**Ethical considerations**

The study was approved by Deakin University Human Research and Ethics Committee (2011-240) and by both hospitals in Thailand: Songklanagarind Hospital (EC:54-338-19-2-3) and Hatyai Hospital (No. 2/2011) before data collection commenced (see Appendix E). Key ethical considerations encompass right to refuse to participate, informed consent, privacy and data security.

**Plain language statement and informed consent**

A plain language statement and consent form explaining the purpose of the study, what participation involved the names of the researchers and the method of contacting the chief investigator was approved as part of the ethics approval process. Time was taken to answer all participants’ questions about the study, to ensure they understood what participation involved and that they were fully informed, only then did they sign the consent form. Participants had the right to refuse to participate or to withdraw from the study at any time until data were analysed, without affecting their relationship with the researchers or the hospital. The interviews were audio-recorded with permission.
Privacy

Each interview was conducted in a private room. The researcher provided each participant with a unique code to protect their identity. For example, the acronym P1F/M means that ‘P’ participant, ‘1’ the first participant, ‘F/M’ refers to gender: Female or Male. The codes are used throughout Chapter five, the study findings, and will be used in publications and presentations arising from the study.

In addition, transcripts and consent forms with the participants’ real names were kept separate from the data in a locked cabinet in the Research Office at Deakin University. Participants are identified by a code in the thesis, all publications and presentations arising from the study and only group data will be reported. Participants were individually re-identifiable to enable the researcher to contact them, if there was a need to re-interview them at a later date. Computer-based data were password protected and access to data was limited to the PhD student and her supervisory team. All audio-recordings were secured in accordance with Deakin University’s guidelines, which stipulate a minimum retention period of six years after the study is completed or published, after which they will be destroyed.

Chapter summary

Chapter four was divided into two parts; part one provided a brief overview of qualitative research, key elements of qualitative research, basic characteristics of qualitative research and rigour in qualitative research. Part two described the data collection tools, data collection process, interview process, how bias was managed during data collection, and data analysis. The ethical considerations were also discussed.
Chapter 5

Study findings
Chapter introduction

Chapter five presents the study findings in two parts: part one encompasses the response rate, participants’ demographic data and health information. Part one also describes the findings that suggest Thai people went through three transitional stages as they adapted to living with HD: being diagnosed with CKD, considering treatment options and accepting and living with HD. Part two shows a synthesis of the findings, which resulted in a model for adaptation that emerged from the interviews and comments on the summary of the findings from participants.

Part one

Response rate

People receiving HD in two Thai hospitals were given a week to decide whether they would like to participate in the study. If they indicated they were willing to participate, they were asked to sign and return a consent form. Twenty four of the 52 people invited consented to participate. One participant withdrew from the study before the interview commenced but did not give a reason for withdrawing. Three other participants were not able to be interviewed: one developed dyspnoea on the day of the interview and two could not be interviewed because the interview room was not available at the scheduled time and they did not make another appointment. Therefore, 20 people participated in the study.

Demographic data

Participants were aged between 23 and 77 years: mean = 53.7 (± 16.38 SD), median = 55 and mode = 40. Ten were females, 17 were Buddhist and three were Muslim. Duration of their CKD ranged from three to 21 years: mean = 9.75 (± 5.21 SD), median = 8.5 and mode = 8. Duration of HD ranged from two to 13 years: mean 6.20 (± 3.40 SD) median = 6
and mode = 3. Sixteen participants had HD treatments twice a week and four participants had HD three times a week. Participants were using between five and 20 medicines per day: mean 10.75 ($\pm$ 3.77 SD), median = 10 and mode = 10. Nineteen participants used western medicines and one participant used a combination of western and traditional Thai medicine. Other demographic data are shown in Table 5.1.

Table 5.1: Demographic data of the 20 people receiving HD who participated in the study.

<table>
<thead>
<tr>
<th>Demographic characteristics</th>
<th>Raw scores</th>
<th>Percent of n=20 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>13</td>
<td>65</td>
</tr>
<tr>
<td>Never married</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary School</td>
<td>5</td>
<td>25</td>
</tr>
<tr>
<td>High school</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>College/University</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Employment status</td>
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<td></td>
</tr>
<tr>
<td>Not employed</td>
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<td>50</td>
</tr>
<tr>
<td>Government employee</td>
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<td>25</td>
</tr>
<tr>
<td>Farmer</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Business person</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Treatment payment options</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Government reimbursement</td>
<td>14</td>
<td>70</td>
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<tr>
<td>National health security office</td>
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<td>25</td>
</tr>
<tr>
<td>Social security fund</td>
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</tr>
<tr>
<td>Income (baht/month)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No income</td>
<td>5</td>
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<td>10</td>
</tr>
<tr>
<td>&gt; 20,001</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Comorbidities</td>
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<td></td>
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<tr>
<td>Hypertension</td>
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<td>70</td>
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<tr>
<td>Heart disease</td>
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<td>25</td>
</tr>
<tr>
<td>Diabetes</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>
Turning points and transitions that occurred as participants adjusted to the need for HD

Face-to-face, in-depth individual interviews using open questions were conducted at two public hospitals in Songkhla Province, Thailand during January and February 2012. Eighteen participants were interviewed; two participants requested the interview be stopped prematurely because of other commitments. Consequently, two interviews were continued at a later date. Two participants became upset and cried during the interview but elected to continue the interview when asked whether they would like to stop the interview or withdraw from the study. The duration of the interviews ranged from 40 to 120 minutes: mean = 69.30 (± 19.05 SD), median = 65.50 and mode = 64.05.

Interviews were undertaken at the hospital (15), participant’s home (four) and participant’s work place (one). All interviews were undertaken in private rooms. The researcher used open questions and prompts and probing questions in response to the individual’s answers to elicit further information about people’s experiences of living with HD and how they adapted to and coped with CKD and HD.

Each transition included one or more turning point. Turning points are significant events that usually indicate transition is about to occur. Although turning points were common among participants, they occurred at different times for individuals. The main turning points participants identified were:

- being diagnosed with CKD
- realising CKD would have a major impact on their lives
- realising dialysis would help them survive
- moving from a rural area to the city to access HD
- changing hospitals
• getting married to subsidise the cost of HD
• finding a job and/or becoming unemployed.

Three main transitions that explained people’s experiences as they adapted to life with HD emerged from the interviews. The three main transitions were:

1. Being diagnosed with CKD, which meant changing from a healthy person to a person with CKD.
2. Considering treatment options. Once participants accepted the diagnosis of CKD they realised they needed dialysis (HD or PD) to survive. They also knew a kidney transplant (KT) was a possible treatment option, but most participants realised they were unlikely to receive a KT.
3. Accepting and living with dialysis. Most participants chose HD as their first choice, but four participants initially chose PD and changed to HD after being treated with PD for varying lengths of time. Ultimately, all participants accepted they would have to live with HD for the rest of their lives.

Participants used two main coping styles during each transition: health-adjustment and health-behaviour. Health-adjustment coping styles refer to the decisions an individual makes to control and manage significant events to help them make sense of their experiences, in this case CKD and HD. Health-behaviour coping styles refer to behaviours related to illness or the individual’s ability to manage life transitions. These two coping styles encompassed specific coping strategies in four areas:

1. religion
2. spirituality
3. self-management
4. social support.
Being diagnosed with CKD signified a major life change and heralded the beginning of life with CKD. Participants indicated the diagnosis of CKD was a stressful event and found it difficult to accept they had CKD. The diagnosis represented the change from being a healthy person to a person with CKD. Participants described numerous physical, emotional and socioeconomic effects when they negotiated life transitions and finally accepted the diagnosis of CKD.

**Transition one**

**Being diagnosed with chronic kidney disease**

Some participants described visiting a hospital (not the hospital where the research was conducted) for several years and being treated for diseases such as hypertension, diabetes, pyelonephritis and lupus before they were diagnosed with CKD. These diseases are actually underlying causes of CKD and should have triggered a renal function assessment, although it is costly and not offered for free to Thai people. Thus, the renal function assessment could be offered for free to all Thai people. One participant said:

> I thought I was not well. I used to be plump but kept losing weight. My younger colleagues asked why I was so thin but they said it was good. It had been like that for a long while and I started to feel tired—could not do much so I went for an examination at the hospital. The doctor said there was nothing wrong. I went many times until the last time when I couldn’t hold on any more so I went to a clinic. The doctor examined me and said I had kidney disease. [P8F]

Two participants said they stopped consulting doctors because they did not realise that their disease such as lupus could progress to CKD. One of the three participants with diabetes refused insulin injections because she was afraid of needles.
Further, she felt doctors did not clearly inform her that she was at high risk of developing CKD if she did not control her diabetes, as the following quote shows:

*I had diabetes before I had kidney failure. The doctor suggested that I had injections [insulin injections], but I was afraid...I dared not inject myself so I opted for medicine... The doctor did not explain it [need to control blood glucose] to me...See, I had not been treated for my kidney failure at all. When I first knew about it [CKD]. I was in the last stage of the kidney failure already.* [P16F]

The previous statement may not be strictly correct; it is possible the woman had high blood glucose for a significant period of time, which led to CKD. If she had accepted insulin injections, she might have prevented or delayed CKD because insulin improves the likelihood of achieving optimal glycaemic control and significantly decreases the risk of CKD.

Some participants were still trying to come to terms with the diagnosis of CKD while they were feeling unwell. Four participants sought health advice and visited the hospital several times, but indicated the doctor did not treat their CKD. As a result, some participants reported that they did not trust their doctors and stopped visiting the hospital because they felt their doctor did not listen to their concerns. They sought medical advice from other hospitals in the city where they hoped to find knowledgeable doctors who would listen to their concerns and be able to diagnose their health problem.
Eventually, they discovered they had CKD and realised it would have a major impact on their lives as the following quote shows.

_I thought I was not well. All of a sudden I became thinner and thinner. Before, I used to be plump but I kept losing weight ...I went to the hospital many times because I was tired. The doctor examined me and said there was nothing wrong_ [she spoke louder and her face showed anger and disappointment with the doctor].

_When I could not hold on any more, my friend told me to go to hospital in the city [the study hospital for treatment]...So we all [her and her family members] came._

_The doctor said that I had kidney disease and admitted me to hospital._ [P8F]

Moving to another hospital was a significant turning point for some individuals. The move helped them develop trust in doctors who demonstrated a level of respect by listening to their health concerns. In addition, identifying their health issues helped most participants realise CKD had a negative impact on their lives. Most participants indicated they were ‘shocked,’ when they were first diagnosed with CKD. For example, one male described the day he was informed he had CKD:

_The day I was told by the doctor that I had kidney disease, I was really shocked._ [P7M]

Thai people often tease each other by using spoonerisms. Some participants used spoonerisms to make sense of what ‘kidney failure meant. Participants indicated they were terrified of the words kidney failure (tai waai) because with a small change in pronunciation, kidney disease in Thai becomes early death (taai wai). Participants confirmed the meaning of CKD with the doctors thinking they would die soon without dialysis. Some participants became emotionally distressed, cried a lot, felt discouraged and uncertain because they believed they would die soon.
For example:

*Do you know what you are sick with? I guessed that I was sick with kidney failure. Kidney failure means early death and that I would die soon. The doctor said I was right... I was so worried.* [P3F]

One participant accepted CKD the day he learned the diagnosis because he regarded himself as ‘a mentally strong person.’ He felt being mentally strong helped him accept CKD and adapt faster than other people. He said:

*I am a mentally strong person. Usually, I am not discouraged by anything. When I knew I had kidney disease, I told myself that I would not give in. I will live with it [CKD].* [P10M]

Inner-strength was a powerful coping mechanism that helped some participants accept CKD and search for new meaning in their lives with CKD. Participants who gradually accepted CKD took various periods of time to accept the diagnosis, generally about six months; however, some people took three years or more. Participants used various coping strategies to come to terms with and accept the diagnosis of CKD.

**Strategies participants used to cope with the diagnosis**

As mentioned earlier, most participants used health-behaviour and health-adjustment coping strategies to cope with the diagnosis of CKD (see Figure 5.1 on the next page).
 Asking ‘why me?’

When participants were diagnosed with CKD, they began to search for an explanation for why they developed CKD as illustrated in following quote:

*Why do other people not suffer from renal disease? Why me?* [P19M]

Most participants described the diagnosis of CKD as a major life-changing event that triggered changes and began the transition to adapting to the change, accepting the diagnosis and integrating CKD into their lives. They used religious and spiritual beliefs to make sense of why they developed CKD.
Religious and spiritual explanations

Religious and spiritual beliefs and practices were important coping mechanisms for most participants and helped them understand and accept CKD. Participants mentioned two main religions.

Buddhism

Buddhism is the national religion in Thailand and encompasses many principles and ritual practices. Numerous Buddhist teachings, especially the relationship between rebirth and karma, deeply influence Thai people’s daily life including when they are ill. Buddhist participants believe in rebirth in five realms: heaven, human, animal, hungry ghost, and hell.

Karmic disease

Karma refers to previous volitional acts, which can be physical, spoken or thought, and are either good or bad. Buddhist participants believed the ‘law’ of cause and effect influences karma: doing a good deed begets good karma while a bad act results in bad karma. Karma in the current life affects future lives.

Some Buddhist participants adopted Buddhist teachings and reflected on their past actions to determine whether the way they behaved in the past predisposed them to CKD. In fact, most Buddhist participants felt ‘bad karma’ or ‘bad deeds’ transformed into ‘bad luck,’ ‘fate’ and ‘destiny’ in the form of CKD: that is, participants regarded CKD as a punishment for sins committed in a past life. Hence, it is possible that Buddhist participants believed CKD was ‘a karmic disease;’ which enabled them to resign themselves to and accept CKD.
For example:

*I never thought I would have kidney disease. I was unhappy I had it. There were so many things that were forbidden. I tried to accept it and thought people were born to pay for what they did in their past lives* [bad karma]. *I don’t know in which life I did something wrong so I have to pay for bad deeds in this life. Well, I’ll just let it be.* [P15F]

One female participant tried to come to terms with and accept she had CKD by adopting a philosophical approach to life with CKD, she said:

*I could accept that I had this disease* [CKD]. *At the beginning I was so stressed. I didn’t know what to do, how to take care of myself until I made up my mind by telling myself ‘whatever happens, will happen,’ I will live with it* [CKD]. [P4F]

Religious and spiritual beliefs helped participants find meaning in life with CKD. In fact, another challenge participants faced was how to reduce their bad deeds. Buddhist participants knew past bad karma could not be cancelled out but they believed accumulating numerous good deeds in the present life would positively influence the future and could alter their life for the better. Hence, another coping strategy Buddhist participants used was making merit to store up ‘good deeds’ for the future and improve their current lives.
**Merit making**

Merit making (*tham-bun*) has long been the most important way to accumulate good karma and positively influence current and future lives among Buddhists. Several participants made merit while they were sick in an attempt to balance their bad karma. They believed if they made enough merit they would receive good health in return. Most participants made merit using various common Buddhism practices. Participants who were able to go to the temple (*wat*) offered food, clothing and medicines to the monks on Buddhist Sabbath days. Participants who were unable to go to the temple gave alms to the monks when they appeared in front of their homes. Some participants poured water (*kruat-nam*) to transfer merit to other beings and invite all creatures to share the merit after they gave alms to monks. They also prayed for forgiveness for wrongful acts that led to bad karma to correct their faults and accumulate good deeds. For example:

> I will invite those [humans or animals to whom they had done wrong in previous lives] who make me suffer to come and receive the merits I make, asking them not to cause me pain to let me live comfortably. If I feel pain, I won’t be able to live.
> 
> *After the merit making, I’ll pour water to invite all creatures to share the merit.*
> 
> *That makes me feel good, comfortable and I sleep well.* [P18F]

Donating to charity was another form of making merit. Some participants donated money to poor people or beggars. Buddhist participants believed they could not live without merit (*bun*); therefore, as bad deeds were inevitable, they needed to store merit in the present life to compensate for their possible wrongful acts in their current and future lives.
For example:

*I think to myself that if I have a chance, I will donate dialysis machines to [the hospital] wherever they need them. I want to help to restore lives [by merit making]. My little happiness now is that I want to help anyone when I can. I take it that giving is the happiness I can get now.* [P16F]

Most Buddhist participants stored merit or did good deeds and avoided committing sins (shown in Figure 5.2) such as killing animals or committing suicide. Most participants believed suicide was a great sin that would transform into very bad karma and make their future lives worse. One man said:

*I live my life the way the religion tells me to because we consider committing suicide a great sin.* [P12M]

![Diagram](image)

*Figure 5.2: Participants living with CKD needed to balance their bad karma by accumulating more merit.*
Fourteen participants tried to come to terms with their CKD by reading Dharma books, which were a powerful source of solace.

**Reading Dharma books**

Dharma books are usually related to Buddhist teachings such as the law of karma, meditation and chants and are available in temples, book stores and on the Internet.

Younger, male participants in particular, turned to religion to enhance their inner strength and resolution to deal with CKD. Some learned from Dharma books, which helped them understand life as part of the birth-aging-illness-death continuum. That is, they regarded death as a natural part of life. Most participants were hospitalised several times with uraemia, which caused uncertainty and fear of dying. Reading Dharma books helped participants find meaning and purpose in their lives. For example:

*Dharma books let me understand life and calm down. I will see the way-out.*

[P1M]

Praying and chanting was another way of coping using religion and spirituality.

**Praying and chanting to save life**

Buddhist participants prayed in front of a Buddha statue or image. Two prayers, the *Shinabunshorn prayer* and the *Burapharatsaming prayer*, are common Buddhist prayers that people chant to Buddha asking him to save their lives and for a good life. One elderly participant said:

*I chant all the prayers and I chant the Burapharatsaming prayer too. The Burapharatsaming prayer says may the illnesses that are a burden in the heart and soul be gone.* [P3F]
Some participants incorporated Thai traditional beliefs such as ‘lucky’ days and numbers in their prayers. Thai people believe nine is a lucky number because it signifies going/moving forward. In addition, Thursday is Teacher’s day, which has been a lucky day in Thai traditional culture since ancient times. Normally, Teacher’s Day, falls on the first Thursday of June each year. People are expected to respect and worship teachers for their kindness, on Teacher’s Day. Some Thai people also believe every Thursday is an auspicious day. One Buddhist female said:

I always pray the special prayer called Shinabunshorn every Thursday.
Actually, people can say this special prayer everyday starting on Thursday.
So I say it nine times! Number nine is a lucky number that will make your wishes come true. This is my hope for recovering. [P20F]

Chinese participants also prayed to the Goddess of Mercy (Jao-Mae-Kuan-Yin) because they believed she was able to protect them from crises. Although they respected Buddha, they also respected and relied on the Goddess of Mercy and prayed to her to save their lives. One participant said:

I respect Jao-Mae-Kuan-Yin [Goddess of Mercy] and I offer her fruit not meat.
Sometimes I make a vow to the Goddess Kuan Yin to help me recover. [P15F]

People commonly worship the Goddess of Mercy by offering her fruit rather than meat because they believe the Goddess of Mercy has great compassion for animals. Some participants were unable to pray for themselves because they were seriously ill. These participants described how their family members offered prayers and made votive offerings on their behalf or vowed to become a nun in return for saving their loved ones.
For example, one Buddhist participant said:

> My relatives are also supportive in terms of morale...When I was in the hospital, my relatives grasped my hand and said we will become nuns if I got over the disease and I raised my hands to perform a wai [to salute with joined palms]. So we planned if I am well enough to stay at the temple, may be next year [2013]...It might be a temple close to my house. We have not discussed details of how long we will be nuns, but it will not be permanent.  [P4F]

Some Buddhist participants believe in supernatural powers and spirit worship. Spirit worship helped participants cope with fear and uncertainty and to accept their CKD. Making a vow to Pran-Boon was a significant form of spirit worship participants described.

**Making a vow to Pran-Boon**

Pran-boon is a key actor who represents a symbolic hero or achievement in Manora literature. Manora has six sisters who have similar graceful attributes. One day, Manora and her sisters went swimming at the Anodat pool, Pran-Boon met Manora and he captured her and presented her to the King named Suthon. Manora married the King and Pran-Boon was rewarded.

This popular story is part of Manora literature and is portrayed in several forms of entertainment such as a Manora dancing, which is popular in the South of Thailand. Pran-Boon is a joker who first acts to get the audience’s attention and makes them laugh. More significantly, Pran-Boon has been respected for centuries because he was the character who was able to capture Manora. Consequently, Pran-Boon has become an ancestor spirit that some participants worshipped and asked to cure their CKD. Participants worshiped Pran-Boon in various ways: some placed a Pran-Boon mask
on a shelf in their homes; others carried a small Pran-Boon mask with them to protect
them or save their lives. For example, one elderly participant described:

...We have believed Pran-Boon [ancestor spirit] for a long time, since before
we were born- we ask please come and blow away bad things to help me to
recover-don’t let me die. [P3F]

Most Buddhist participants knew CKD is an incurable disease but felt praying and
making vows on their own or with their families enhanced their good health, saved their
lives, helped them maintain a sense of personal control and reduced uncertainty. Once
participants felt in control, they were able to move forward in the adaptation process.
Islam was another prominent religion influencing participants in the study.

Islam

Three Muslim participants followed Islamic religious beliefs and practices to cope
with CKD. Like Buddhists, most Muslim participants viewed health, illnesses,
suffering, and dying as a natural part of life and felt CKD was a test set by God (Allah);
consequently, they accepted CKD patiently. Muslim participants also described life and
death as being ‘up to Allah’ because they believe death does not happen except by
God’s will. Therefore, death is part of their journey to finally meet Allah. Like
Buddhists, most Muslim participants, felt their CKD was a result of their sinful
behavior or a form of punishment for their sins. For example:

Since the day the doctor told me that I suffered from an incurable disease
[CKD], I came to terms with it [CKD] by thinking that it is my sin. I have to
pay for this sin. [P12M]
Family members prayed for participants who were not able to plead with Allah themselves. For example, a Muslim participant described being unconscious and admitted to the intensive care unit. Her husband and relatives helped her by praying and making votive offerings to Allah so she would survive. She actually recovered from her critical condition and her family felt their prayers were answered. She said:

_Oooh! many days I was unconscious, maybe a week or so. I thought I was dead. I lay there like that. They [her family and relatives] prayed asking for me to wake up... After I regained consciousness, we killed goats and made offerings to God...I believe in it [asking Allah to save my life]. [P8F]_

There are some differences between the two religions: Buddhism is a flexible and powerful guide people use to help them cope with CKD whereas God controls the way the individual adjusts and behaves in Islam. Consequently, people make their own decisions about how they will respond to and accept CKD based on their cultural and religious beliefs. Self-protection was another coping strategy used by participants.

**Self-protection**

_The Chinese Zodiac_

Some participants used the Chinese Zodiac (bpee-nak-sat-chin) to protect them from misfortune and serious illness. The Chinese Zodiac is shown in Figure 5.3 on the next page. Most participants believed their animal year to be a good or bad year (chong). Some participants said if the present year was incompatible with their birth year, bad luck would follow. Some participants believed an individual would have bad luck if other people; for example, doctors and nurses’ birth year was incompatible with their own and could lead to treatment errors.
In addition, some participants believed their birth year brought them bad luck or serious illness if the present year was incompatible with their birth year. Consequently, some participants tried to protect themselves from bad luck in various ways such as donating coffins to the temple and praying to the Tai-Sui, the Chinese God of Destiny, to protect their lives. One woman said:

*Based on Chinese superstitious practice, this year [2012] is a bad year for me. This year is the Dragon, which collides with the year of the Dog [she was born in the year of the dog]. So, people born under the sign of the dog will be greatly affected according to the Chinese zodiac system... There are five ways to alleviate bad luck. I chose to donate coffins and to worship a Chinese God ... So I could have peace of mind.* [P20F]

![Chinese Zodiac](http://webboard.pooyingnaka.com/photo/Pooyingnaka20080118_123011.jpg)

*Figure 5.3: The Chinese Zodiac is based on a twelve year cycle and each year is represented by an animal sign. Participants used the Chinese Zodiac to predict and protect themselves from misfortune and illness (adapted from: http://webboard.pooyingnaka.com/photo/Pooyingnaka20080118_123011.jpg accessed 9/04/2012).*
Some participants used U-Bakong’s Times to protect themselves from accidents associated with travelling to and from the hospital for HD.

**U-Bakong's Times**

U-Bakong was a soldier who brought the Myanmar armies to attack Chiang Mai in the era of King Rama I (1784). U-Bakong was captured and while he was imprisoned, he taught his soldiers ‘U-Bakon’s Times’ to help them escape and return to Myanmar. Some of his soldiers did not escape, and they taught the Thai prison officers about U-Bakon’s Times. Subsequently, U-Bakong's Times has been passed from generation-to-generation and is now very popular in South-East Asia, especially Thailand (see Table 5.2).

Some participants said there were good and bad times in each day and they used U-Bakong's Times to predict the safest times to travel to protect themselves from accidents. For example one participant said:

> Before I left the house, I would check for the auspicious time that’s safe and good. They call it U-Bakong’s time… That’s what I did before I moved here for haemodialysis because I wanted to make sure that there wouldn’t be any danger or mishap during the trip, like bombing or unexpected accidents.

[P18F]
Table 5.2: Table of U-Bakong’s times Thai people use to check whether the time of day is auspicious or inauspicious before making a journey (adapted from: http://www.myhora.com/upload_files/Image/contents/ubagong1_print.jpg and translated by researcher).

<table>
<thead>
<tr>
<th>Time</th>
<th>Morning</th>
<th>Late morning</th>
<th>Noon</th>
<th>Afternoon</th>
<th>Evening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day</td>
<td>06.01 hrs.</td>
<td>08.24 hrs.</td>
<td>10.49 hrs.</td>
<td>13.13 hrs.</td>
<td>15.37 hrs.</td>
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<tr>
<td></td>
<td>08.25 hrs.</td>
<td>10.48 hrs.</td>
<td>13.12 hrs.</td>
<td>15.36 hrs.</td>
<td>18.00 hrs.</td>
</tr>
<tr>
<td>Night</td>
<td>18.01 hrs.</td>
<td>20.25 hrs.</td>
<td>22.49 hrs.</td>
<td>01.13 hrs.</td>
<td>03.37 hrs.</td>
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<tr>
<td></td>
<td>20.24 hrs.</td>
<td>22.48 hrs.</td>
<td>01.12 hrs.</td>
<td>03.36 hrs.</td>
<td>06.00 hrs.</td>
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<td>Thursday</td>
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<td>Saturday</td>
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<td>●●</td>
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<td>●</td>
</tr>
</tbody>
</table>

*One dot* suggests refraining from going as you will lose in your endeavor.

*Two dots* mean that you should move quickly since you will be lucky.

*Without any dot* suggests prosperity and absence of mishaps.

*A cross* suggests inauspicious; if you make a journey, you will meet with loss.

*Four dots* suggest affluence and fortune. You should be quick to move to gain victory.
Comparing CKD with other diseases was another coping strategy participants used to come to terms with CKD.

**Comparing CKD with other diseases**

As participants began to come to terms with the fact they had CKD, they began to change the way they viewed the disease, and often compared CKD to other diseases. Most participants felt it was better to have CKD than some other fatal or serious diseases such as AIDS or cancer and were aware of people with such diseases and felt they caused more serious pain and suffering than CKD. Comparing CKD with other diseases also helped some participants come to terms with the severity of CKD, made them feel more positive and helped them find meaning in their current health status. For example,

> *I have to really accept it [CKD] and think that having kidney disease is better than having cancer. I don’t know if it’s true or not, but I know that it [CKD] is not suffering as much. I feel extremely tired. People who have cancer have pain and it’s terrible. My next door neighbor has cancer and it’s so painful that she lies down and cries. So I compare and think that if a person has diabetes, he can have an infected wound on his hand or somewhere but with kidney disease, it’s nothing, right?* [P14M]

**Establishing social support**

Establishing social support was another positive approach participants described. Most participants received support from family members, friends, colleagues, health professionals and neighbours. Participants described three main types of support: physical, emotional and using alternative treatment.
Physical support

CKD affected participants’ ability to perform usual daily activities. Consequently, they relied on family members and friends for help to undertake activities such as providing physical support; for example, preparing food, assisting with personal hygiene, taking them to hospital and other places such as the temple to pray. One single male participant said:

They [his parents] have helped me many times such as they take me to the hospital, take care of me at home and give me a tepid sponge bath when I have a fever. When I first suffered from kidney failure, I could not take care of myself. Now, I am fine with it [CKD]. I can take care of myself. [P11M]

Most participants’ families supported and helped them cook or set a menu for them. However, most participants felt a ‘renal diet’ was unappetising. Consequently they ate foods not recommended including food from shops and/or restaurants. Although participants were appreciative of the family’s good intentions and efforts to help them manage, family conflict ensued when participants did not adhere to food and fluid restrictions. One participant’s comment clearly illustrates such conflicts:

My close relatives and friends and children reminded me of that [diet and fluid]. Sometimes when I did not believe them, they were angry. Everybody was hurt and unhappy. They always buy food for me but tell me not to eat it a lot. They don’t let me drink. Like, at home, there is no ice because my children do not buy it. So I put a bottle of water in the freezer and shook it when water was turning to ice... and my daughter came around behind me snatched it and threw it away. I felt exactly like a child whose lollipop was snatched away. I felt very hurt. With her good intention, she did that. I want to go, they say no. I want to eat, they say no, something like that. [P16F]
The controlling words and actions family members and health professionals used made some participants feel like children and/or that their family members and health professionals acted like ‘the police.’ Some participants felt their family members and friends were sometimes ‘overly helpful’ and made them feel they were not allowed to do anything for themselves. One participant said:

\[I felt useless... I feel they [friends] think I am not capable of doing anything.\]

\[They just won’t let me do anything because they think that I am disabled.\]

[P1M]

These negative consequences of unnecessary or inappropriate support affected the relationship between participants and family members and friends and inhibited participant’s acceptance of CKD and the adaptation process. Emotional support was also important to most participants.

**Emotional support**

Most participants described relying on emotional support from family members and friends to help them cope with CKD. Emotional support involved understanding (kao-jai), sympathising (hen-jai) and encouraging (kam-lang-jai) participants. Families and friends sympathecised and encouraged participants with words, prayers and phone calls, which made them feel loved and cared for and helped them cope with the challenges of living with CKD. Most participants appreciated such positive feedback from their family and friends, but deep down they knew their CKD was incurable.
Thus, participants tried to ‘put on a brave face’ rather than openly discuss the incurable nature of CKD, as one participant’s poignant comment shows:

I accepted the fact I had kidney disease. I had my mum and dad to support me. My friends too, they cheered me up and told me to fight it, saying that it will be gone. I was feeling okay and I did not worry too much about it...My mum and I are very close and she always tells me that she will be with me and that the illness will be gone. My mum is supportive in terms of morale. She told me not to think too much about the illness... I know that it won’t be gone. [P5F]

Putting on a brave face might help participants maintain their morale in the short term, but in the long term it could have a negative impact and delay acceptance of CKD. In addition, information support that participants received from several sources, but mainly their families, was vital to help participants find traditional Thai medicine.

**Using traditional Thai medicine**

Families and friends also provided information about complementary and alternative medicines. Some families tried to persuade participants to use traditional Thai medicine and/or travel to a temple where other people had been ‘cured’ of CKD by using traditional Thai medicine. Some participants followed their families and friends advice and used *ya-mor*, a traditional Thai medicine available from the temple (*wat*) in an attempt to cure their CKD. *Ya-mor* is made from roots of trees mixed with herbs and is prepared by boiling the ingredients in a pot.
Other participants obtained ya-mor from monks, or lay people in villages or rural areas who taught them how to prepare ya-mor. One participant said:

_The day that I was told by the doctor I had kidney disease. I was so discouraged. After that my in-law's friend called saying that if I had kidney failure, I should go to the temple. So we [participant, his wife and children] went to Ratchaburi province that night... I went there without belief but it was better than sitting around doing nothing. It was like encouragement. I had ya-mor ...It consists of many kinds of barks and turns black after being boiled. It’s very bitter and hard to swallow. It tastes terrible. I drank one glass a day. It [ya-mor] didn’t do any good to treat the disease [CKD]. [P7M]_

_Ya-mor_ did not cure participants but it did help them manage the emotional distress associated with CKD, remain positive and enhanced their self-care. All participants who used ya-mor eventually accepted renal replacement therapy (RRT). Realising RRT would help them survive was an important turning point and indicated participants were ready to consider other treatment options.
Once participants realised they needed RRT to survive they carefully considered the types of RRT available: peritoneal dialysis (PD), haemodialysis (HD) and kidney transplant (KT). Thus, the next major transition in the adaptive process was considering treatment options.

**Transition two**

**Considering treatment options**

Deciding whether or not to start RRT is the first of many decisions participants confront when their kidney function declines. The majority of participants knew two forms of dialysis treatment were available in Thailand: PD and HD, but did not know they could have HD at home. Some participants were able to make a decision quickly while other participants found it difficult to choose between PD and HD.

**Strategies participants used to choose between PD and HD**

Participants used two main strategies to choose a treatment: obtaining information and considering costs. Participants obtained information about the benefits and risks of each dialysis treatment, costs, how each treatment would affect their work responsibilities and their self-image before they decided on PD or HD. Participants obtained information from various sources including peer education sessions, healthcare professionals, caregivers, other people, the Internet and books. The strategies participants used to consider their treatment options are shown in Figure 5.4.
Figure 5.4: The process participants used to consider treatment options and make treatment decisions. All participants were receiving HD during data collection. Sixteen participants commenced HD. Four participants began PD but transferred to HD prior to participating in the study. One participant commenced HD and subsequently received a KT.
Obtaining information support

Peer education

Most participants had an opportunity to observe other people receiving dialysis and the other treatments they discussed with healthcare professionals before they chose between PD or HD. Observing other people receiving RRT and being able to ask them questions was a form of peer education that gave participants access to valuable firsthand information. Most participants indicated that discussing treatment with peers helped them understand what HD or PD involved and made them feel more confident to make a decision. One participant said:

*I wanted to have PD* [after discussing options with the doctor]. *However, I decided to take a look at how HD is done at the hospital and became interested in it* [HD] *and now I still have HD.* [P7M]

Healthcare professionals

Objective, factual information helped relieve people’s fears and worries that dialysis would disrupt their lives in areas such as work, socialising and travelling. For example, one participant who was concerned dialysis would prevent her travelling abroad said:

*The nurse consoled me. The nurse said it was okay. I could go anywhere with it* [HD], *even abroad. The nurse told me that, so I was a bit relieved. It made me feel better.* [P16F]

Participants regarded doctors as knowledgeable authorities because they had studied in the biomedical field. Some participants indicated the doctors had the knowledge and technology to detect what was going on inside their body. When participants needed to go to hospital they had confidence in the fact that the doctors would help
relieve their suffering and save their lives. Consequently, some participants stated ‘they put themselves in the doctor’s hands.’ For example, one female participant who was happy to follow her doctor’s recommendations said:

*I believe in the doctor. I trust his experience. I put myself in his hands...so, I am fine... I have HD* [P20F]

Some participants indicated doctors act as knowledgeable guides whereas participants are followers. Consequently, participants relied on doctors’ advice and did not ask questions because they put their faith in their doctors. Some participants tried hard to be ‘good patients’ in the hope they would receive good assistance to help them combat their life threatening and incurable illness. One participant explained why he believed his doctors’ advice:

*I usually believe in a doctor. Wherever doctors have suggested treatment, I usually follow their advice because I have no idea how to take care of my sickness. I am not a doctor. I do not have any medical knowledge. So, whatever the doctor says, I simply do as instructed. I will never argue or resist. I cannot do that. If I do not recover, I will try again. I cannot sit still. I need to get treatment. Otherwise, I will die.* [P17M]

Other participants tried to be ‘good patients’ by searching for knowledge and asking doctors questions to gain more information about their disease and its treatment. These participants took responsibility for ‘their health.’ One participant reported how she sought information:

*...I got information through searching the Internet and asking doctors.* [P20F]
**Considering costs**

Financial issues were a major concern for many participants, especially those from lower income families, and influenced their treatment choices. Most participants knew HD treatment would be costly until the end of their lives; therefore, the cost of RRT had a significant influence on participants’ decision to accept PD or HD. Participants experiencing financial difficulties found it difficult to make a decision but chose PD because it was cheaper than HD. Participants with adequate financial resources were generally less stressed than those with financial constraints. Four participants said that, if they had to die, they would simply accept dying because they could not afford treatment. One participant said:

*Upon learning renal disease was incurable, this really drove me to despair. It is hard to describe my feelings. If I had to choose between life and death, I would choose to die as I would not recover...I do not think I can afford it [HD treatment]. [P19M]*

Consequently, four participants initially chose PD. Sixteen participants who commenced HD needed considerable financial resources to pay for HD treatment and obtained financial support from three main sources: government reimbursement for civil servants, social security funds and national health security office funds. The government reimbursement for civil servants covers 100 percent of RRT and supports old age pensioners, civil servants and/or their parents, partners or children’s benefit schemes.

Some participants married so they could afford HD treatment. Marriage helped them adapt faster than usual because of the physical, moral and financial support their partners provided.
For example,

*My husband asked me to marry him so that I could be reimbursed for the treatment fee from his benefits* [government reimbursement]. *In fact, I had this kidney disease before I got married. When my husband knew that I had CKD, he consulted the doctor at X Hospital and decided to marry me so that I could gain health benefits from his job at the public hospital. I consider myself very lucky but he is not.* [P2F]

Most participants knew they needed long-term HD treatment and felt they would become a burden and worried their families would not be able to support them in the long term. Hence, some participants decided to sell land they inherited (*moradok*) from their parents. Consequently, they were unable to pass the *moradok* on to their children, which made them feel sad and regretful. Although selling their property made them feel guilty about depriving their children of their inheritance, it enabled them to pay for HD. For example:

*My relatives would not be able to support me financially ... I would have to pay a lot every month. I would give up. I sold my four rai of land and received almost a million baht. Within two years, I spent it all [on HD]. Oh! I sold my land shortly after I was diagnosed because I didn’t know where to get the money [for treatment] from. I regret it because it’s my parents’ heritage... I have no land for my children or grandchildren because I sold all the land I had.* [P12]

Not surprisingly, financial constraints caused participants to worry about the future. HD treatment in Thailand commonly costs between 1,500-2,000 baht per session. Even though participants sold their land, they did not have enough to support
themselves and pay for HD. As a result, some participants and their family members sought outside financial support. Some participants borrowed from organisations such as the Helping Teacher Fund. Others asked nursing staff whether they could have HD treatment and pay at a later date. One male participant said:

*I did suppose that if I go to have haemodialysis today, I will tell the staff at X hospital [private hospital] that I will pay for the treatment later. Then sometime the next morning, I will come to pay the expenses. I will never be in debt for months. That was the only money matter.* [P1M]

Charity organisations were another source of financial support for some participants; however, it is difficult to obtain support for charities because of the large number of people with CKD seeking financial support from charity organisations and the lack of funds.

**Factors that influenced treatment options**

Four participants chose PD because it could be undertaken at home or in their work place and meant they did not need to be absent from work to attend HD sessions. PD enabled some participants to manage their work responsibilities and their treatment. Unfortunately, two of the four participants suffered infections such as peritonitis; each participant had three infections in five years of PD treatment before they changed to HD. Participants stated they felt HD gave them a second chance of survival. For example:

*I cannot be treated by the peritoneal dialysis anymore because I got peritonitis with fibrosis, so treatment with peritoneal dialysis is useless...then I had to be treated by haemodialysis.* [P1M]
Two other participants stated they had no choice because they required PD as an emergency treatment for renal failure. Consequently, they had PD for a short time before changing to HD treatment because they were concerned about infection and their body image. One of these participants said:

_The doctor pierced my abdomen immediately for PD because I couldn’t breathe [oedema]…When I was better, the doctor asked me to choose PD. I said ‘no’ because I have to work. How can I spare the time to do it? Do I do it for the kids to watch? So I said ‘no’ and I chose HD._ [P8F]

Most participants knew kidney transplant (KT) was a treatment option. However, the knowledge did not significantly influence their choice because they were aware they were unlikely to receive a KT for various reasons such as:

- lack of donor organs
- concerns about donor’s health issues
- not meeting KT criteria
- inadequate funding support
- concerns about the need for immunosuppressive therapy
- travel problems because KT was only available in the capital city.

Most participants felt being on the transplant list made them feel hopeless because the chance of having a KT was remote. One participant who received a KT said it was like ‘winning a lottery’, ‘winning the first prize’, ‘a fluke’, ‘the jackpot’ and ‘luck.’
As one participant explained:

... I know kidney transplant will be very difficult... It’s like winning the first prize in a lottery to get a kidney that’s compatible. A rare chance! I hope for a fluke. [P10M]

One participant said having a KT made her dreams come true. She had HD treatment for three years before she received a KT, which functioned well for 11 years. Unfortunately, she lost hope again when she rejected the kidney and recommenced HD to survive. She said:

I changed to have haemodialysis for three years. After two years [HD], I applied for a kidney transplant... I had been waiting for a kidney transplant for a year before I received a kidney transplant. It [HD and KT] was all together about 14 years... My weight kept increasing and my body was swollen. Then I could not eat. I felt nauseous and vomited...I was told all of my symptoms might be the result of renal rejection. I felt very uncomfortable, so I requested haemodialysis. I could not endure it any more. [P20F]

Therefore, HD treatment gave some individuals flexibility, balance in their lives and helped them maintain hope.
Participants changed from being individuals living a normal life to individuals who accepted living with HD, which was a major part of their adaptation process. Most participants indicated it was not easy to accept living with HD, and described numerous challenges.

**Transition three**

**Accepting and living with haemodialysis**

Accepting and living with HD was a significant journey during which participants encountered numerous physical, emotional and socioeconomic challenges including HD procedures and complications and complying with treatment.

**Physical effects-related to HD**

Most participants described physical effects related to HD including pain, muscle cramps, low blood pressure, headache, heart problems and seizures during HD treatments. Pain occurred during HD treatment, usually when needles were inserted in the arteriovenous fistulae and as several participants were afraid of needles, they experienced more pain than for other people.

**Needle pain**

During HD treatment, large bore needles connected to special tubing are inserted into the individuals’ arteriovenous fistula. Blood travels to the dialyser via an arterial needle to remove uraemic toxins and fluid and the cleaned blood is returned to the individual via the venous needle. Even though inserting the needle does not take long, participants regarded it as a negative, painful experience. Some participants’ biggest fear was that the needle would cause an aneurysm in the blood vessel when it was inserted. Some participants reacted to pain by screaming, clenching their teeth and kicking their feet: others closed their eyes so they would not have to watch the needle being inserted.
Most participants who reported pain when needles were inserted said staff technique was the main cause of the pain. Participants regarded some nurses as being ‘heavy handed’ (*mue-nak*) when they pierced the access vessel. Novice staff were the most likely to be ‘heavy handed’ because they were less experienced. One participant said:

*Once they pierced me [inserted the needle], it was swollen. I told the nurse that it was painful. The nurse then stopped immediately. It [his arm around the access site] was black and blue... My vascular access could be used but she pierced too deeply, missing the middle of my vessel. Maybe, this was because she was new. It took her a while to learn the formula [technique].* [P12M]

Participants felt there was a difference in the pain when male staff inserted needles and said male nurses were gentler than female nurses, but needle insertion still hurt. For example:

*It hurts when a needle is inserted. I think, it depends on the technique used by a nurse. At the X hospital, male nurses did a much better job than here. While the male nurse was inserting the needle, it hurt a little. In fact he applied slight pressure while inserting the needle.* [P19M]

Some participants stated that using local anaesthetic such as a xylocaine injection before inserting the needle helped relieve the pain. However, most nursing staff did not use xylocaine injections before they inserted the needle. Some nurses suggested participants buy their own local anaesthetic gel to apply to the skin before the needle was inserted. However, nursing staff did not always insert the needle in the area where the anaesthetic was applied.
Consequently, participants still suffered from needle pain. For example:

*I screamed. It was exceedingly painful. The needle was a number 16, only a bit smaller than a nail, right? The nurse pierced the flesh, right? Why wouldn’t it hurt? It does every single time. But when the nurse used it [local anesthetic] it still hurt because the nurse pierced the skin in the wrong spot. I bought a tube and used it once and not again. I have lost interest now. I will bear the pain.* [P16F]

Most participants did not complain about the pain or the care they received and said they were fine, even when they felt pain and were suffering. Despite the pain, some participants said they did not try to select a nurse who caused them less pain during the needle insertion because they did not want to upset other nursing staff and wanted to show they were ‘good patients.’ In addition, a complication associated with arterovenous cannulation technique was haemorrhaging.

**Haemorrhaging**

Some participants haemorrhaged during HD treatment mostly due to nursing staff carelessness. According to the HD protocol, the needle should be inserted before and taken out after HD treatment. Although removing the needle did not take long, it worried some participants. For example, one participant worried about becoming disconnected from the dialysis machine and haemorrhaging, which had occurred once when a novice nurse accidentally pulled out the wrong catheter. The participant said:

*...And that morning the nurse accidentally pulled out the wrong catheter...so the blood splashed all over me. I was scared of blood so I had a convulsion and I got spasms and bit my tongue, too.* [P2F]
Another participant described how a nurse forgot to tape the catheters into place after inserting the vascular access, which resulted in haemorrhage and frightened the participant who said:

_Once, while having dialysis, the needle came out. I was unaware of bleeding until I noticed a lot of blood. A nurse forgot to put on a plaster [after inserting the needles]. This made me really scared._ [P19M]

To avoid conflict and maintain harmony in their interpersonal relationships, most participants did not complain when they were not satisfied with the quality of care nurses provided. A complication related HD treatment, that caused participants to worry, was septicaemia.

**Septicaemia**

Septicaemia did not occur very often but most participants knew septicaemia was a serious complication of HD treatment and they were very concerned about developing septicaemia, even though it can be treated. In fact, five participants did develop septicaemia and were admitted to hospital for several days, which added to the cost of the care. One male participant stated:

_I don’t like infection. I used to have an infection from haemodialysis. The nurse took me off the haemodialysis immediately before she transferred me to ICU [intensive care unit]. I was unconscious for two months at the hospital. Everybody thought that I was dead. That was a very severe infection._ [P1M]
Moreover, six participants were afraid of dying from septicaemia. One participant reported a previous experience with septicaemia in a private hospital where healthcare professionals could not treat his/her septicaemia due to inadequate staffing and lack of a septicaemia care protocol. Consequently, he was transferred to another hospital. A participant who developed septicaemia described his loss of confidence in the hospital where the septicaemia occurred saying:

*Haemodialysis was almost done and I started shivering and the staff moved me to another hospital for the treatment because this hospital could not treat it [septicaemia]...I thought that the staff may make a mistake. I lost my confidence and so I moved to another hospital.* [P10M]

Emotional effects-related to adhering to HD had a vital impact on participant’s daily life, as participants described.

**Emotional effects-related to adhering to HD**

Most participants indicated that adhering to HD treatment, especially controlling food and fluid intake, was very challenging, often disrupted their life style, and challenged their values and attitudes to diet and medicines.

**Diet challenges**

Adjusting to a ‘renal diet’ was a major change for most participants and was very difficult to incorporate into their lives. Some participants took a year to accept and manage the renal diet: others took three years or more. Some participants, particularly those who changed from PD to HD, needed to adapt to their diet restrictions because managing the diet on PD was less stressful than the diet required for HD.
Participants who started RRT with PD reported that PD removed fluid and waste products every day, whereas HD only removed fluid and waste products every two or three days. Consequently, participants needed to be concerned about having a ‘well-balanced diet’ once they commenced HD. One participant who changed from PD to HD said:

*Food intake has quite some effects on me. I used to eat a lot and every kind of food when I was receiving peritoneal dialysis. But with haemodialysis, I had problems with fluid volume excess.* [P1M]

Some Chinese participants who drank a lot of tea or coffee found it difficult to reduce their tea or coffee intake. One participant said:

*In the past, well, I’m a son of Chinese parents. I drank tea all the time…I still drink tea and coffee every day, but I try to drink less.* [P15M]

Most participants indicated limiting their food and fluid intake was especially difficult in social and work situations because watching others eating delicious food was emotionally upsetting. Although some participants knew various foods were forbidden, they kept satisfying their needs by continuing to consume some of their favourite foods and fluids. One participant described his feeling when he saw his friends eat:

*Going on a diet by limiting food and water is the most difficult because when I see they [his friends] are eating delicious food that I am not allowed to eat, I really want to eat that food. I have to eat it a little.* [P12M]

Some participants were not able to accept the renal diet, and felt like ‘everything is forbidden.’ Therefore, participants often gave up and did not adhere to HD treatment.
In addition, some participants believed to ‘die when full is better than to die when hungry.’ One participant said:

…I was so worried about food. So, it would be better for me to die when I am full than when I am hungry. [P15F]

Most participants found each HD treatment stressful and felt the doctors or nurses were checking up on them because they always asked them what they ate the previous day if they were overweight and their laboratory tests showed abnormally high levels of potassium and phosphate. Most participants knew health professionals had good intentions when they reminded them about diet, but they felt frustrated and upset that they were not a ‘good patient.’ For example,

I could not control food for six months now. The nurse said that I had a small build and wondered how I can eat a lot. Nurses told me to reduce my food intake otherwise it will cause problems. I am trying to control it [diet], but it is not easy. [P5F]

Embarrassment was another form of emotional distress some participants described.

**Body image issues**

Many participants were embarrassed and concerned about their body image because of the changes in their bodies due to CKD and HD treatment. Common changes were darkening of the skin, hair loss and ‘ugly’ vascular access site scars. A female participant frequently referred to her scars and dark skin and emphasised how these body changes caused her distress. A male participant also became frustrated and distressed when other people did not understand his ‘big ugly scar.’
He said:

\[
I \text{ began to wear a long-sleeved shirt from the first day I had haemodialysis.}
\]

\[
I \text{ don’t want to talk about it [vascular access scar] very much. I’m annoyed.}
\]

\[
One \text{ person after the other will ask and I don’t want that to happen. Some people might ask whether I have AIDS or something like that. [P6M]}
\]

Most participants used antihypertensive medication to manage their blood pressure, a common cause and complication of CKD. Hypertension is due to various factors such as sodium and water retention, increased vascular resistance from renin-angiotensin system activity, and must be controlled to reduce further kidney damage. However, one side effect of antihypertensive medications such as Minoxidil is excess body hair. One participant said she ‘looked like a monkey’ because she had excess body hair:

\[
You \text{ see, that hair is growing on my face. This made me look like a monkey. I have to shave it. There is a large amount of hair growing on my body. I was told if I took this medicine [antihypertensive medicine], body hair would grow. [P20F]}
\]

She became resigned to and accepted the excess hair growth because she knew it was important to control her blood pressure but still felt bad. Socioeconomic constraints also caused stress.

**Socioeconomic effects**

Most participants felt HD affected their basic role in the family, especially their capacity to perform the role of head of family, parent, wife, husband or child. Most participants tried to come to terms with their changed family roles as well as life with HD.
**Changed family roles**

Participants described being tired after HD treatments and after engaging in their usual activities, which affected their family roles. Men regarded themselves as the head of the family and believed ‘the man is an elephant’s front legs’ (chang-thao-nar) who takes responsibility for the family as a whole. Once men commenced HD, their family role changed from being independent to depending on family members for personal health care and often for financial support. The following comment clearly demonstrates one man’s distress at his changed role.

*The rubber I collect is not my own. It comes from my wife’s plantation. I depend on her. I haven’t planted my own rubber. When I wanted to start a rubber plantation, I suffered from kidney disease. I can’t do it now. I can’t tap rubber myself. She [his wife] can’t tap rubber alone too. She has to bear a large burden. I feel upset sometimes that I can’t help her. Instead of me helping her, she has to help me. She has to be a leader. In fact, the family leader should be me but she has to do my duty.*  [P12M]

Some male participants could not perform their role as the head of the family, which had a big effect on their self-esteem and compromised their self-confidence. CKD and HD also led to changes in women’s roles and self-esteem. Thai women are expected to be virtuous caregivers in the family according to Thai cultural constructs. Some women participants described how HD affected their ability to be the ‘ideal Thai woman,’ that is, a home maker, respectful, obedient and helpful to her husband and provides her husband with children. Thus, HD often led to regret and guilt for women participants.
One woman simply stated:

*Deep in my heart I’m sorry for him [her husband]. I can’t do things for him. I can’t give him children. He has a very kind heart, he helps me with everything.* [P2F]

Sexuality was an important issue for some participants and their partners. Female participants described how their interest in sex declined and men described having erectile dysfunction (ED) and difficulty reaching orgasm. These sexual difficulties were a consequence of the physical and emotional effects of CKD and/or the consequences of treatments such as antihypertensive medications; for example, alpha and beta blockers, potassium-sparing diuretics/aldosterone-receptor blockers. Sexual dysfunction had a significant effect on participant’s body image, relationships with their partners and their self-concept. For example, one man described how ED affected him psychologically:

*But after being discharged from the hospital after I had oedema, we still had sex but I could not reach orgasm because my organ relaxed. My wife was irritated. She said if I couldn’t do it, I just go to sleep [laughing]. I’m stressed, somewhat, but not to the point of irritation. I feel hurt sometimes about what my wife said. I want to be happy making love but I can’t now.* [P10M]

Some women participants were concerned about their inability to fulfil their husband’s sexual needs when they did not have intercourse as usual. Some women participants suggested their husbands have sexual relationships with other women as a way to pay their husbands back for their kindness. Suggesting their husband have a relationship with another woman was painful for these women but they regarded it as a form of honoring their husbands and fulfilling their roles as the ideal caring and compassionate Thai woman. However, the women said their husbands did not take up
their suggestion to have sexual relationships with other women, which reassured them and bolstered their self-worth. One woman said:

*I don’t know; he [her husband] is kind of too good to be true. He might have been a Buddhist monk in his past life, I think ... If he had affairs with other women, I would not be mad with him... I might get furious at first but not for very long I think. I know that I have taken more liberties than him for a very long time; I should give him some favour in return.* [P2F]

CKD and HD also affected relationships with boy or girlfriends, which sometimes became increasingly distant. Four participants met their boy or girlfriends just before they were diagnosed with CKD and learned they needed HD treatment. Participants and their partners adapted to the changed relationship in various ways including avoiding making marriage plans and suggesting their boy or girlfriends see other people. In addition, participants indicated they did not want their partners to suffer as a consequence of their CKD. One female participant said:

*I used to have a boyfriend, but when I became sick we did not have time to seriously talk about our relationship. After having renal disease, nobody has come into my life. I have fewer chances to meet people.* [P20F]

Two participants were not in a relationship at the time of the interview and had lost hope of finding a new partner. They were resigned to being single for the rest of their lives, but felt they could live peacefully without needing to worry about other people.

Some participants said they intended to repay gratitude owed to their parents. For example, children are expected to show gratitude (*katanyu-gatawatee*) and pay back their parents for giving them life and raising them. Thai people are expected to
constantly repay gratitude through kind and generous behaviour such as taking care of older parents. Some participants felt distressed because CKD and HD made it difficult or impossible for them to repay their parents (*bunkhun-poor-maae*). Thus, their obligations as children were unfulfilled, which created regret and guilt and sometimes affected their ability to adapt to and accept HD. The dilemma was highlighted by one female participant who said:

> The most important impact was that I needed to have my parents look after me instead of what I should do for them. Yeah, that’s the thing that affects me the most... This upset me quite a lot... I’m still feeling sorry but not as much as I was before. I’m the only daughter of the family. [P2F]

HD also had a profound effect on participants’ ability to fulfill their hopes and dreams.

**Unfulfilled hopes and dreams**

Some participants felt hopeless about their future when they realised they might no longer be able to fulfil their hopes and dreams. For example, one participant felt she would not be able to continue attending university and achieve her dream of having an education. She withdrew from her course at the Teacher’s College when she commenced HD treatment because she lacked energy, was fatigued, anaemic, had headaches, nausea and vomiting, which made studying very difficult, as she said:

> I was stressed because I was doing my Master’s at the Teacher’s College. I tried to think about what I should do. First I wanted to drop my study for a while but my husband said it didn’t look possible for me to go back to my study. So I resigned. I was absolutely disappointed because I wanted to finish my study as intended. [P9F]
The woman’s previous statement shows she made a difficult life changing decision at a low point in her life when she was vulnerable. Her decision was influenced by her husband who supported her spiritually.

Some participants’ employers were considerate of participants’ health and capacity to work and enabled them to change their work duties so they could continue working. Some employers also allowed participants to leave the workplace to attend doctor’s appointments, which participants regarded as demonstrating significant support, compassion and empathy. Other participants resigned from their jobs because they did not want to be a burden at work:

> When the doctor made an appointment or when I had to come for HD, I had to arrange a substitute teacher. I had to leave my class. It became a burden for other teachers. I resigned so they could fill my position with somebody else.

[P10M]

Resigning from their jobs was a big change for these participants as well a major transition from being an employee to being unemployed. Resigning from their jobs helped some participants reduce guilt and gave them time to manage their CKD and HD. The processes participants used to cope with CKD and HD treatment is shown in Figure 5.5.
Strategies participants used to accept and live with haemodialysis

In the early transition stages, people diagnosed with CKD developed emotional and various physical problems. They needed social support to help them to deal with CKD/HD. When people moved on to the last stage, and were able to perform self-care they were more independent. Participants used religious and spiritual beliefs and practices and self-management to cope with the physical, emotional and socioeconomic effects of HD. In order to control their emotions, some participants adopted positive affirmations to deal with the frustration associated with diet and fluid restrictions.
‘Don’t be a lotus flower under the water’

Buddhist participants adopted Buddhist teachings such as ‘Don’t be a lotus flower under the water’ to cope with diet challenges. One participant said:

I have a motto I keep in my mind, ‘don't be a lotus flower under the water.’

[P16F]

Buddhist teaching uses the lotus as a metaphor for peoples’ level of learning and understanding. Different parts of the lotus plant represent different learning levels. There are four levels. On the first level, the lotus flower is above the water and gets the sunlight and suddenly blooms. At level one people are fast learners. On the second level, the lotus is just breaking the surface of the water, a metaphor for average learners who need more practice to be able bloom like a lotus flower. The lotus is under the water, is a metaphor for people who have knowledge, need to practice, and are encouraged to understand that one day they could grow upwards, break the surface and bloom. The lotus roots are buried in mud is the fourth level and represents people who are unable to understand or learn. Lotus on the floor of the pool becomes food for fish and tortoises and will not grow upwards or bloom. The metaphor is depicted in Figure 5.6.
Figure 5.6: In Buddhist teaching the lotus flower represents a metaphor for individual’s level of learning and understanding (From: http://dhammaathand.diaryclub.com/images/20100114_2209.jpg accessed 5/04/2012).

Self-management

Participants often changed their way of life to accommodate HD by self-managing the effects of HD in everyday life.

Learning to use blood test results

Participants normally had a blood test every month to check blood urea nitrogen, creatinine, potassium, calcium, fasting blood glucose, alkaline phosphatase, phosphorus, sodium, albumin, total protein, haematocrit and haemoglobin, all of which are indicators of HD adequacy and overall health status. Doctors and nurses interpreted the results of blood tests and advised participants to avoid certain foods when indicated by the results. Participants indicated they learnt to interpret blood test
themselves over time, which helped them self-manage their diet. Participants also learned to use ‘medical terminology,’ which gave them a sense of ‘belonging’ to the health team. One female participant said:

…after the blood test results show high levels of potassium, I know what I must not eat. I’ll know and manage myself. [P18F]

Some participants also learnt to manage food and water restrictions through experience.

**Learning from previous experience**

Some participants were hospitalised with pulmonary oedema, which caused them great suffering. Consequently, they learned how to manage their water consumption to avoid pulmonary oedema in the future, which gave them a sense of control. For example, one female participant said:

… I drank too much water and it was difficult for me to breath. I was hospitalised two to three times last year because of excess water in my abdomen… I tried to reduce my water intake. Being hospitalised at that time made me more careful to take better care of myself. [P15F]

Thus, being able to control diet and fluid intake was empowering for many participants.

**Rewards for past achievement**

Some participants put a lot of effort into managing their food intake and controlling the associated restrictions. If they were able to control their food and water consumption appropriately, participants rewarded themselves by eating their favorite
food. Self-reward enhanced participant’s tolerance of water limitation. For example, one female participant said:

... I don’t drink water in the afternoon and will drink again at home in the evening. When I come home and there is some dessert, I’ll have it and drink water to reward myself after being able to abstain from drinking the whole day. [P9F]

Participants who had long experience managing food and water restrictions were likely to cope better than participants with less experience. However, over time, the latter also became ‘experts.’ The following section describes the process of ensuring rigour in the current study.
Part two

Member checking used to enhance rigour in the study

Part two summarises the information the researcher obtained from the interviews and participants’ comments about the summary of findings she compiled and forwarded to participants for member checking. Member checking was an important part of validating the data. The researcher sent the following summary of findings to the participants in order to verify the researcher’s interpretation of the data.

Summary of the findings

Twenty people participated in the interviews; following is a summary of the information the researcher obtained during data analysis. People receiving HD went through four main phases as they adapted to having HD.

Phase one: Coping with the diagnosis of renal disease

People described how they had to face the diagnosis of chronic kidney disease. Participants described how they felt emotionally distressed at the diagnosis. Common forms of emotional distress were shock, crying, sadness, discouragement, stress, worry, depression, fear of death and uncertainty about the future.

Participants tried to find ways to reduce the emotional distress and face the diagnosis and treatment needed to manage their renal disease. They began to ask themselves why they developed renal disease, asking ‘why me?’ to vent their emotional distress. Participants also felt having renal disease was personal and caused by their karma, which they could not deny or escape. In addition, participants compared themselves to others whom they felt were less fortunate. Most participants felt having renal disease was much better than having other diseases such as AIDS and cancer.
Participants said they eventually realised they had to accept the situation and cope with it. Participants highlighted that emotional support from their family and friends (kam-lang-jai) helped them cope with the diagnosis and accept the disease. Most participants tried to treat themselves with traditional Thai medicine, but stopped after they realised it did not work and would not cure their renal disease and they needed dialysis treatment.

**Phase two: Preparing for dialysis treatment**

People realised they would require dialysis treatment to sustain their life and understood that two forms of dialysis treatment were available: peritoneal dialysis and haemodialysis. Participants chose one of these dialysis forms after they received information from nursing staff and doctors. Family and friends also influenced the choice of dialysis treatment. Participants who chose peritoneal dialysis said free treatment and difficulty traveling to/from the hospital for haemodialysis treatment were the main reasons they chose peritoneal dialysis. However, after having peritoneal dialysis for two to three years, most participants developed an infection and changed to haemodialysis.

Participants who chose haemodialysis from the beginning did so because they trusted their doctors and nurses who relieved their fear of haemodialysis and because they felt safer having haemodialysis in hospital. Elderly participants chose haemodialysis because they worried about developing an infection if they had peritoneal dialysis. Most participants also managed the expensive cost of haemodialysis treatment by using their own and their family’s government welfare entitlements.

**Phase three: Having to depend on haemodialysis**

Participants described many physical, emotional and socioeconomic effects of haemodialysis. The most frequent physical effects were muscle cramps, tiredness or
lacking energy, shortness of breath, headache, itching, trouble falling asleep, pain, change of skin colour, hair loss, weight loss, swelling in legs, nausea/vomiting, dry skin, constipation, dry mouth, difficulty becoming sexually aroused, vascular access problems, decreased interest in sex and septicemia.

Participants experienced numerous emotional effects such as fear of death, feeling useless, loss of dignity, fear of social isolation or social rejection, embarrassment, sadness, depression and felt dependent on nursing staff and doctors. Participants were concerned about the socioeconomic effects such as cost, interference with their job, transportation to and from the dialysis unit, having to plan vacations where they could access haemodialysis centres, which limited their travel options, and duration of treatment.

Participants used various strategies to cope with the physical, mental and socioeconomic effects of haemodialysis. Participants who became tired or lacked energy said they avoided attending social activities, having sex and having children. Participants also avoided exposing parts of their body because of scaring, skin darkening, their vascular access becoming larger, and hair loss, which they tried to hide by wearing a long-sleeved clothes and head scarfs.

Most people were concerned about the time spent undergoing haemodialysis. Participants used schedules and plans to manage their activities, traveling to and from the dialysis unit, holidays and their religious practices. For example, participants made up for lost prayer time while they were on haemodialysis and they also managed their medication regimen by skipping medicines at noon when they needed to fast.

Many people used positive thinking to cope with the duration and frequency of haemodialysis and the need to travel to hospital so often. For example, they thought
positively that ‘haemodialysis is part of duty’ like part of their job. Participants also said activities such as reading books, watching TV, listening to music and sleeping while they were on haemodialysis helped them ‘kill time.’

Moreover, participants relied on social support from family and friends, who helped them manage the social isolation associated with haemodialysis. However, haemodialysis also meant family roles and responsibilities in their workplace changed. All participants felt they received good quality help and care from nursing staff and doctors. However, some participants felt some nursing staff and doctors did not appreciate the pain associated with accessing the vascular access for haemodialysis treatment, bleeding caused by clamping the wrong catheter and forgetting to tape the catheter into place, which caused worry and fear. Most participants said they became used to and accepted these things to maintain a good relationship with nursing staff and doctors.

Another way participants coped with the physical, mental and socioeconomic effects of haemodialysis was through their spiritual beliefs and religious practices. For example, reflection on their karma and sustaining their life by merit making such as offering alms to monks, donating money and donating a haemodialysis machine to the hospital, to manage their stress. Participants also used prayer to relieve their fear of pain and help them sleep as well as praying for a kidney transplant.

Many participants trusted in God, who decides how and when they would die, which helped them cope with their fear of dying. Most participants read Dharma books because they helped them understand life. Participants used different practices according to their religious beliefs. Buddhist participants vowed to become a nun and vowed to ‘Pran-Boon’ while Muslim participants made vows to God by offering
things such as a boiled chicken, a bottle of whisky, young coconut, bowls of rice, areca nuts and betel leaves and money, if they recovered from illness.

Participants also used traditional Thai protection processes such as ‘Lucky time’ (U-Bakong’s time), for example, when traveling to/from the dialysis unit to protect them from any danger or mishaps during the trip. Others relied on the ‘Chinese Zodiac’ to protect them from bad luck and misfortune.

**Phase four: Living with haemodialysis**

Participants’ realised haemodialysis improved their symptoms and well-being despite the difficulties, and appreciated the benefits of haemodialysis. For example, it improved their appetite and maintained their life. Most participants were ‘on hold’ while they waited for a kidney transplant. If they could not receive a kidney transplant they would have to live with haemodialysis for the rest of their lives. They also hoped living with haemodialysis would go well and without complications.

Many people were satisfied with their family life and felt they had ‘nothing to worry about’ and that haemodialysis could help them ‘see the future of their love ones’. Participants managed life with haemodialysis by ‘living day-by-day or year-by-year’ without knowing how many years they would live. Participants shared their experiences of living with haemodialysis with other people such as family, friends, neighbours and pupils to educate them about the disease in the hope of protecting them from renal disease.

**Comments on the summary of findings**

Seventeen of the 20 participants provided comments about living with HD (see Table 5.3). None of the 17 participants disagreed with the summary of findings and three participants did not return the comments for unknown reasons.
Table 5.3: Participants’ comments on the summary of findings (n=17): note the table continues over two pages.

<table>
<thead>
<tr>
<th>Participant (number)</th>
<th>Comments (n=17 of 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Mostly information relates to my experiences. Nothing to add. Thank you.</td>
</tr>
<tr>
<td>2.</td>
<td>Thank you for sending the summary of the findings. I think the information is similar to my experience about living with renal disease and being treated with haemodialysis. Having renal disease is suffering but I can live with it. Significantly, we need to accept it and take it as part of our life.</td>
</tr>
<tr>
<td>3.</td>
<td>Thank you to the research team that undertook the research on patients with renal failure. Renal failure is a disease that causes the patient to suffer greatly as they cannot travel or stay away long and they also experience pain when they undergo haemodialysis each time. However, when people have renal failure they need to accept it and then they will be happy and peaceful and be able to share their experience with medical students and other people to gain knowledge and experience in daily life to protect them from renal failure. Patients were also very proud. Thank you very much.</td>
</tr>
<tr>
<td>4.</td>
<td>The information in the summary reflected my experience of living with renal failure and haemodialysis. I also would appreciate if the information, which I provided in the study that would be beneficial to other people.</td>
</tr>
<tr>
<td>5.</td>
<td>Yes, it reflected my experiences about living with renal disease and haemodialysis. I have nothing else to add. Thank you for sending the summary of findings.</td>
</tr>
<tr>
<td>6.</td>
<td>The summary of study mostly reflected my experiences. Thank you.</td>
</tr>
<tr>
<td>7.</td>
<td>I think that other peoples’ experiences are the same as my experiences.</td>
</tr>
<tr>
<td>8.</td>
<td>According to reading the summary of findings the research found after reflecting on the experience of kidney disease, I think that my experience is the same as other patients. Consequently, I was inspired and had hope and peace of mind knowing that there are many people like me. ‘Fighting and strong in life.’</td>
</tr>
<tr>
<td>Participant (number)</td>
<td>Comments (n=17 of 20)</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------------------</td>
</tr>
<tr>
<td>9.</td>
<td>Yes, other patients are similar to me. So, it is not only myself that suffers like this. I will live with kidney disease and its treatment. Thank you for sending this letter.</td>
</tr>
<tr>
<td>10.</td>
<td>I think the summary of findings is mostly like my experiences about living with kidney disease and dialysis. I have no more information to add. Thank you.</td>
</tr>
<tr>
<td>11.</td>
<td>The letter that I received reflected my experiences. Thank you</td>
</tr>
<tr>
<td>12.</td>
<td>Thank you to the research team. I think that the information reflects my experiences.</td>
</tr>
<tr>
<td>13.</td>
<td>Yes, other peoples’ experiences are similar to mine. I would like to thank all of research team for undertaking this project.</td>
</tr>
<tr>
<td>14.</td>
<td>Yes, it reflected my experiences. Thank you.</td>
</tr>
<tr>
<td>15.</td>
<td>Yes, the summary of findings is really similar to my experiences. I did not know other patients have experiences like me. So, I will fight on with renal disease.</td>
</tr>
<tr>
<td>16.</td>
<td>Thank you so much for sending the summary of findings. The summary of findings is close to my experiences. I will try to practice and live with renal failure. Thank you so much and I would like to praise the researcher team for undertaking this project.</td>
</tr>
<tr>
<td>17.</td>
<td>The summary of findings reflected my experience. Having renal failure is suffering. However, we need to accept renal failure, life with positive thinking, no tension and we can live with it.</td>
</tr>
</tbody>
</table>
Field notes were used to enhance rigour during the study

Field notes are the written account of the researcher’s thoughts and observations related to the interview and include participants’ facial expressions, participant’s body language, emotions, the environmental surroundings, the researcher’s own response to the participant during the interview and any factors that may have affected the researcher during the interview that cannot be recorded on a tape. The researcher used field notes in order to capture data that could not be recorded on tape during the interviews.

The researcher used data from the field notes to confirm emerging categories during data analysis. For example, data from the field notes confirmed the information from the transcript regarding people with CKD who developed emotional distress when they knew they had CKD as follows:

...While she talked about having kidney disease, she was silent and looked down to the floor for a while and started crying. [P3F: field notes]

Research outcomes

The main outcomes of the research were:

- A model that explains how Thai patients with CKD adapt to depending on and living with HD (see Figure 5.7).
- Information about Thai people’s experiences and perspectives of living with HD.
- Information that can be used to inform nursing education programs for people with CKD.
Figure 5.7 explains the way Thai patients adapted to haemodialysis (HD). Adaptation is a process in which Thai patients moved through the three transition stages. The model shows participants negotiated three transitions. Each transition included a turning point that motivated participants to adapt to and cope with the CKD and HD. Being diagnosed with CKD was the first transition to life with CKD. Participants used two coping styles: health-adjustment and health-behaviours, which encompassed specific coping strategies in four areas. These coping strategies in four areas were religion, spirituality, self-management and social support, which participants used to deal with physical, psychological, socioeconomic and cultural influences.

Chapter summary

Chapter five described the study findings, which were presented in two parts. Part one included demographic data and health information and described the results of interviews undertaken with people receiving HD. The findings suggest people went through three transitional stages as they adapted to living with HD: being diagnosed with chronic kidney disease, considering treatment options and accepting and living with HD. Part two presented a synthesis of the findings which resulted in a model for adaption that emerged from the interviews and comments on the summary of findings from participants.
Chapter 6

Discussion and conclusions
Chapter introduction

Chapter six discusses the key findings that describe the way Thai people receiving HD adapted to having CKD and requiring HD treatment. Key findings related to the consequences of haemodialysis and classic coping strategies Thai people used to manage CKD and its treatment. In addition, models and theories related to the adaptation process are discussed. Chapter six also explicates the strengths and limitations of the study, outlines recommendations for nursing practice, education and research, and presents conclusions.

Key findings

The key findings are discussed in two parts:

- Consequences of haemodialysis:
  - changes in family and social roles
  - food and fluid restrictions
  - financial issues
  - needle pain.

- Key coping strategies:
  - religious and spiritual beliefs and practices
  - having strong social support
  - self-managing CKD and HD
  - positive thinking
  - denial.
Consequences of haemodialysis

The information from 20 Thai participants with CKD receiving HD treatment revealed that participants suffered from psychological, socioeconomic and physical effects associated with CKD and its treatment. Psychological, social and economic effects included anxiety, stress and depression due to their inability to adapt to and cope with various difficulties such as changes in family and social roles, food and fluid restrictions as well as financial issues.

Changes in family and social roles

Thai culture played an important role and influenced the adaptation process in the current study. Current participants developed emotional distress that was influenced by cultural values and beliefs related to the role of head of the family, gender, children, and public perceptions of HD. In Thai culture children are expected to demonstrate gratitude by paying their parents back for the care they received in childhood by caring for their parents when they become old or ill. When young participants in the current study developed CKD and received HD, the child’s role was compromised causing significant spiritual distress.

People receiving HD often experience conflict or role deprivation when they are diagnosed with CKD. The current study is consistent with Abdoli et al., (2011) who found Iranian people with diabetes regarded their daughters as crucial sources of support for their families. If an Iranian daughter became ill, she was unable to maintain the traditional daughter role of supporting her family, which caused spiritual distress. The current and other studies also found CKD and HD affected parents’ roles, especially the mother’s ability to be a good ‘mum,’ because mothers on HD could not perform everyday activities with their children due to fatigue. Consequently, they felt regretful
and guilty (Martin-McDonald, 2003; Lee et al., 2007; Wadd, King, Bennett & Grant, 2011; Al Nazly, Ahmad, Musil & Nabolsi, 2013). Likewise, Thai men regard themselves as the head of the family and believe ‘the man is an elephant’s front legs’ and takes responsibility for the family as a whole, which is consistent with Iranian culture in which men take the role of the sole breadwinner to support the family (Rambod & Rafii, 2010).

The current study and other researchers found males with CKD are unable to perform usual daily activities and work, which reduces their ability to earn money. Consequently, they viewed themselves as ‘less of a man’ (Hagren et al., 2005, p. 298; Rambod & Rafii, 2010; Al Nazly et al., 2013). Men or fathers with CKD might feel powerless, worthless and have low self-confidence because men regard work as a symbol of masculinity (Kastrouni et al., 2010; Al Nazly et al., 2013). These findings suggest men with CKD might view themselves as ‘disabled’ or ‘weak,’ which could impair their ability to integrate CKD and its treatment into their life.

The current participants also reported CKD and HD affected their social role. Participants found it very painful when people commented about their misfortune at having CKD. Consequently, they stopped socialising and attending ceremonies and festivals to avoid placing themselves in a position where other people would notice their ‘big ugly scar’ and comment about their misfortune at having CKD. Similarly, Hagren et al. (2005) found 41 people receiving HD tried to avoid discussing their health issues with other people during social activities because they felt overwhelmed by the diagnosis of CKD. Avoiding discussing their CKD can help people manage emotional distress and prevent anger. However, avoiding discussion of their CKD can be considered a passive coping technique people with CKD use to manage their
emotional distress. If people with CKD avoid discussing their CKD for a long time, they may develop anxiety and depression (Hagren et al., 2005; Wolf & Mori, 2009).

**Food and fluid restrictions**

The current and other researchers found people receiving HD experience physical and psychological effects due to food and fluid restrictions, which people find onerous, as their health status worsens if they do not comply (Hyre et al., 2008; Weisbord et al., 2008; Clarkson & Robinson, 2010; Lindberg & Fernandes, 2010; Rayment & Chow, 2010; Keskin & Engin, 2011; Horigan, 2012; Al Nazly et al., 2013). In addition, people receiving ‘short daily dialysis’ tended to be non-adherent to fluid restriction because they felt they could consume large amounts of any food and drink they desired (Rayment & Chow, 2010). These researchers suggest people with CKD who frequently received HD felt less frustrated than other HD recipients. People with poor food and fluid control are considered to be maladaptive because of the associated negative long-term health complications such as cardiovascular disease, a leading cause of death (Welch & Davis, 2000; Pang, Ip & Chang, 2001).

The individual’s choice not to follow food and fluid recommendations also contributes to anxiety and stress. The current participants felt they were not ‘good’ patients because nursing staff had frequently re-educated them about the adverse effects of not adhering to food and fluid restrictions. Healthcare professionals have good intentions for people with CKD when they educate them about how to manage their food and fluid intake. However, people with CKD feel regretful, stressed and depressed, which can lead to distance in the relationship between them and health professionals.

Khalil, Frazier and Lennie (2011) found depression in people with stage five CKD contributes to non-adherence to food and fluid constraints. Likewise, Christensen and
Ehlers (2002) found people with depressive symptoms such as hopelessness, cognitive distortions and fatigue often have negative expectations of the future that can affect their ability to perform self-care and lead to non-adherence to medicines, food and fluid restrictions. Non-adherence to medicines, food and fluid restrictions and psychological effects often occur simultaneously and exacerbate each other. Healthcare professionals need to recognise that depression can be a cause and result of medicines, food and fluid non-adherence.

It is interesting to note that Muslims receiving HD felt frustrated when they were unable to fast during Ramadan because they had to attend dialysis appointments and often felt unwell (Al Nazly et al., 2013; Bayhakki, 2013). However, Muslim participants in the current study avoided fasting because they had health problems that might worsen as a result of fasting. Consequently, they made donations to the poor instead, which is considered an alternative to performing their religious practice.

Even though Muslims with health conditions can be exempt from fasting because of the risk to their health (Lundberg & Thrakul, 2011), other researchers found Muslims on HD attempted to fast, but found it hard to continue fasting (Al Nazly et al., 2013; Bayhakki, 2013). Some Muslims with CKD reported that the fasting month helped them control their food and fluid intake (Al Nazly et al., 2013; Bayhakki, 2013). This may be true because during the Ramadan fast, no food and fluid consumed in the day time; consequently, people consume less food and fluid. Although Muslim people receiving HD could not complete their fasting period, they tried to fast as long as they could to conform to their religious practice (Al Nazly et al., 2013; Bayhakki, 2013). Consequently, Muslims receiving HD gain physical and emotional benefits because
they can perform their religious practice like other Muslim people (Lundberg & Thrakul, 2011; Al Nazly et al., 2013; Bayhakki, 2013).

**Financial issues**

Financial issues were a major concern for the current participants especially people from low income families who faced significant financial burdens. Other researchers found people with stage five CKD from low income families regard CKD as a ‘rich person’s disease’ because treatment is costly (Prekbunjun, 2004; Prakongsai, Palmer, Uay-Trakul, Tangcharoensathien & Mills, 2009; Rambod & Rafii, 2010). For example, the current researcher and Prekbunjun (2004) found some Thai people with stage five CKD were concerned they would die because they could not afford the cost of HD in the long-term. As a consequence, most people receiving HD relied on their families for financial support because they could not work, which made them feel they were a burden on their families and resulted in impairment of their wellbeing and quality of life (Prekbunjun, 2004; Al Nazly et al., 2013).

In contrast, Van, Duangpaeng, Deenan and Bonner (2012) examined the relationship between factors such as monthly income, comorbidity, time on dialysis treatment, social support and health-related quality of life (HRQOL) in Vietnamese people receiving HD. Only monthly income was not significantly related to HRQOL \( (p>0.05) \). Van et al. (2012) maintained monthly income was not significantly related to HRQOL; however the association is difficult to determine because participants did not provide exact monthly income. Participants in Van et al.’s (2012) study may have sought financial support from several sources such as family, friends and charity organisations to reduce their financial burden.
If people with stage five CKD received HD without charge, they could enhance their wellbeing and quality of life. Even though HD treatment was free for Indonesian people, they still had financial problems that impaired their quality of life because they needed to spend their money on treating other health complications, medications and travelling to and from hospital (Al Nazly et al., 2013; Bayhakki, 2013). The inconsistency among studies concerning financial problems is a complex issue influenced by various factors such as employment status, income and treatment payment options (Jha, 2004; Lin et al., 2005; Mitchell et al., 2009; Prakongsai et al., 2009; Clarkson & Robinson, 2010; Lai et al., 2012).

Payment options for renal replacement therapy (RRT) are important because they could inhibit or help people with CKD adapt to the disease and its treatment. For example, RRT is free and accessible in Iran (Mahdavi-Mazdeh et al., 2007). However, in the current study RRT cost was a significant issue because HD was not available for all Thai people with stage five CKD. In developing countries such as Thailand the government should consider policies to reduce HD cost for all Thai people. In addition, the Thai government could implement policies that focus on primary prevention such as an early screening program for all Thai people, and develop effective healthcare services to improve people with CKD’s health status and their quality of life. Additionally, practicing nurses can play an important role in educating individuals about the leading causes of CKD to enable them to self-manage their health condition and possibly help them delay further kidney damage.

**Needle pain**

Participants in the current study suffered negative outcomes, particularly needle pain when needles were inserted during HD treatments. Other studies also show people
receiving HD worry about needle pain and that needle pain causes emotional distress (Davison, 2003; Lin et al., 2005; Shayamsunder, Patel, Jain, Peterson & Kimmel, 2005; Herlin & Wann-Hansson, 2010; Lai et al., 2012; Adib-Hajbaghery, Molavizadeh & Alavi, 2012; Al Nazly et al., 2013). It is interesting to note that some participants in the current study reported a great deal of needle pain was due to fear of needles rather than actual pain. Some people may have had negative experiences from needle-related medical procedures in the past that caused fear of needle-related pain. If not addressed, fear of needles can cause anxiety in the future.

Fear of needle-related pain and needle ‘phobia’ are different concepts; needle ‘phobia’ refers to the strong feeling of fear associated with needles (Szmuk, Szmuk & Ezri, 2005). Some people may avoid medical treatment involving needles, which could result in serious health problems. For example, some participants with diabetes in the current study refused insulin injections because they were afraid of needle pain, eventually they developed stage five CKD. The current and other researchers found people with diabetes feared insulin injections because they thought injecting themselves might be painful (Peyrot et al., 2005; Szmuk et al., 2005; Alagiakrishnan & Sclater, 2012). People with diabetes also regard insulin injections as inconvenient and complicated, as well as being afraid of hypoglycaemia and the social embarrassment of injecting in public (Rasmussen, O’Connell, Dunning & Cox, 2007). If people with diabetes delay initial insulin therapy, it may result in long-term negative outcomes such as future kidney damage (Cox & Mohr, 2003; Fu, Qiu & Radican., 2009).

Pain also occurred because local anaesthetic was not used prior to the cannulation. Three cannulation techniques are commonly used to insert the needles: buttonhole,
rope ladder and area puncture (Evans, 2012). The ‘buttonhole technique’ refers to a process where needles are inserted into a fistula for HD in exactly the same needle tract, angle, direction and depth at every cannulation, it causes less pain (Flynn & Linton, 2011; Evans, 2012). There are several reasons for using the buttonhole technique: patient preference for self-cannulation and patients who are unable to have the rope-ladder technique because of short fistulas (Flynn & Linton, 2011). The ‘buttonhole technique’ requires a different procedure to the rope-ladder technique, which allows for individual differences in site selection, needle direction and angle; therefore, enabling healing between sessions (Evans, 2012). Area puncture technique requires repeated needle insertions in one or two sites and carries the potential risk of aneurysm and it is no longer recommended (Evans, 2012).

Many studies show the ‘buttonhole’ and ‘rope-ladder’ techniques are widely used; especially the ‘buttonhole’ technique (Evans, 2012). For example, people receiving HD using ‘buttonhole’ and ‘rope-ladder’ techniques felt less pain and fear of cannulation (Smyth, Hartig & Manickam, 2013). Smyth et al. (2013) indicated injecting local anesthetic before inserting venous access needles in both techniques influenced pain and fear ratings due to vasoconstriction. Bayhakki (2013) found that, although Indonesian people receiving HD did not report needle pain, they did report pain due to HD-related muscle cramps. The muscle cramps associated with HD were caused by various factors such as low blood pressure, changes in plasma osmolality, hypomagnesium and hypoxia, where the muscles of the lower extremities, abdominal muscles, arms and hands were affected. Thus, muscle cramps need to be managed to help people with HD enhance their quality of life.
Pain is subjective and pain perception is influenced by an individual’s experience of pain and types of needle such as blunt and dull needles (Doss, Schiller & Moran, 2008). In addition, the researcher may influence participants’ responses to their experiences of pain such as the researcher giving participants a clue about what they are hoping to hear or expect to hear and how questions were asked (Wengraf, 2001), which may account for inconsistencies between different studies.

Participants in the current study also indicated the nursing staff’s cannulation technique caused patients pain. The needle insertion technique and care of the vascular access site could be improved using continuing nursing education and developing a standard protocol for vascular access care. In addition, patients could be given the option to use local anaesthetic to help relieve pain (Evans, 2012).

**Key coping strategies**

Coping emerged as an important part of the adaptation process in the current study. Key coping strategies emerged:

- religious and spiritual beliefs and practices
- having strong social support
- self-managing CKD and HD
- positive thinking
- denial.

**Religious and spiritual beliefs and practices**

Participants in the current study mainly relied on religious and spiritual beliefs and practices to help them understand why they developed CKD and required HD treatment. Religion has an important influence on how Thai people adapt to the burden of chronic illnesses. Religion provides a philosophy and cognitive framework
that can reduce suffering and help people find meaning in illness (Koenig et al., 2001; Phillips et al. 2009; Naewbood et al., 2012; Ting & Ng, 2012). Buddhists in the current study believed their past sins contributed to their current illness, which is consistent with research into other chronic illnesses in Thailand such as cancer (Junda, 2004), diabetes (Sowattanangoon, Kotchabhakdi & Petrie, 2009) and stroke (Thongbaiprasath, Wannapornsiri, Suntayakorn & Siripronpibul, 2007; Ting & Ng, 2012). Thai Buddhists believe committing sin in present or past lives will result in bad karma and different forms of suffering such as pain, disabilities and diseases (Dala, 2000; Klausner, 2000; Sucitto, 2008). Belief in karma can help people with chronic illnesses and suffering explain their situation, find meaning and purpose in their lives and eventually accept the reality that their lives include incurable diseases (Phillips et al., 2009).

Religion can help people to minimise suffering through traditional practices: worship, rituals, moral guidance, story-telling and festivals (Burkhardt & Nagai-Jacobson, 2002; Padela et al., 2012). It is interesting to note that Buddhists in the current study believed they could not escape their bad karma; consequently, they used various practices such as praying, chanting, making merit to mitigate past sins and manage stressful events. Similarly, Chinese Buddhists in Malaysia believed bad karma caused their health issues (Ting & Ng, 2012). Chinese Buddhists relieved their pain and suffering by performing meritorious acts such as meditating and asking for blessings from Buddhist monks and nuns (Ting & Ng, 2012). Religious practices help people to recover and minimise emotional distress if they are diagnosed with incurable diseases (Dossey, 2010). People with chronic illness know their disease cannot be cured; they perform religious practices to maintain hope that their life will improve. Thus, religious practices have positive effects and positively influence the adaptation process for people
with chronic diseases because it helps them find balance and develop a sense of control over their lives.

The current and other studies also found Muslims with CKD viewed illness and suffering as a test set by God (Allah) and prayed to God for relief (Abdoli et al., 2011; Padela et al., 2012; Bayhakki, 2013). Other research suggests Muslims have a God-centric perspective wherein God’s will is paramount, and God can bestow health or illness (Abdoli et al., 2011; Padela et al., 2012; Bayhakki, 2013). When a Muslim person believed God willed they would develop CKD and HD, they accepted CKD, because they believed their life was in God’s hands (Rambod & Rafii, 2010; Ramirez et al., 2012). Therefore, Muslims with CKD accepted the disease and its treatment with patience and positive thinking because they trusted God knew best and believed only God can bring healing (Rassool, 2000).

In the current and other studies Muslim participants sought a cure by praying to God, supplication, reciting the Quran, and consulting Imams (Muslim leaders) who gave them spiritual support and motivated them to take care of their bodies by performing self-care (Padela et al., 2012). Likewise, Abdoli et al. (2011) found Iranian Muslims with diabetes undertook self-care because they believed their body was a gift from God and they had a responsibility to take good care of it. Similarly, Thai Christians believed their body was God’s temple, which they needed to look after to the best of their ability to improve their health (Naewbood et al., 2012). Religion appears to be an important factor that influenced self-care for people with chronic illness (Lundberg & Thrakul, 2011).
Having strong social support

Having strong social support was important to participants in the current study, particularly support from family members, and enabled them to adapt to CKD and HD. Other studies show people with CKD obtained support from various sources, mainly family members, friends, healthcare professionals and other people with CKD on dialysis (Patel et al., 2005; Cukor et al., 2007; Rambod & Rafii, 2010). These previous studies highlighted the fact that family members such as husbands or wives, parents and children are a major source of social support for people receiving HD and help them enhance their quality of life (Revenson et al., 1991; Rambod & Rafii, 2010; Lai et al., 2012). Thus, family members appear to be a buffer to stress and enhance physical and psychological wellbeing, particularly when people with CKD experience both positive and negative situations (Rambod & Rafii, 2010).

Although people with CKD appreciated the help family caregivers provided, they felt guilty about being a burden to the family (Lin et al., 2005; Fan et al., 2008; Mitchell et al., 2009; Calvey & Mee, 2011; Suri et al., 2011; Lai et al., 2012; Al Nazly et al., 2013). Caregivers needed to provide various types of support: driving to and from the dialysis unit and other medical appointments, maintaining individual hygiene and providing meals (Kara et al., 2007).

Numerous duties such as these are known to exhaust caregivers resulting in depression and impaired quality of life (Kara et al., 2007; Suri et al., 2011). Spouses and other family members report distress and exhaustion from supporting their family members (Ziegert & Fridlund, 2001; Aasen, Kvangarsnes, Wold & Heggen, 2012; Çelik, Annagur, Yılmaz, Demir & Kara, 2012). Çelik et al. (2012) reported Turkish caregivers of people receiving HD experienced poor sleep quality and used sleep
medications more than the people they cared for. Çelik et al. (2012) suggested educational, social and psychological support may enhance the sleep quality of both people receiving HD and their caregivers.

While support is generally regarded as beneficial, some participants in the current study felt stressed when they felt they received too much support or unwanted support. Caregivers want to protect loved ones, which can have positive or negative effects on the receivers and the caregivers (Linnarsson, Bubini & Perseius, 2010). Some participants in the current study felt support represented an attempt to control their lives and felt disempowered because they were ‘not allowed to do anything.’ Consequently, a negative impact occurred in the relationship between participants and their caregivers that could affect self-care. There is a strong need for caregivers to listen to their loved one with CKD and attempt to understand their needs and encourage them to remain involved in their self-care.

The current and other studies also found people with CKD wanted relevant information to enable them to understand stage five CKD and its treatment (Mitchell, et al., 2009; Clarkson & Robinson, 2010; Lai, et al., 2012). People with CKD begin with little or no knowledge about CKD and its treatment; gradually their knowledge increases through experience, reading and regular educational updates (Calvey & Mee, 2011). It is interesting to note that peer support was also a significant source of information in the current and other studies (Morton, Howard, Webster & Snelling, 2010; Griva et al., 2012). Sharing information represented opportunities for people with CKD to learn from people living with CKD and its treatment and help them deal with the burdens of CKD and HD (Symister & Friend, 2003). In addition, peer support helps people with CKD see how others cope (Thomas-Hawkins &
Zazworsky, 2005). Thus, social support is important because it helps people with CKD cope and manage their life threatening condition and enhance their quality of life (Halter & Varcarolis, 2010; Rambod & Rafii, 2010).

**Self-managing CKD and HD**

Self-care is ‘a process of adaptation in response to learning about oneself and about ways to live well with illness’ (Kralik, Price & Telford, 2010, p. 197). The current and other studies suggest people receiving HD manage CKD and its treatment by controlling food and fluid, exercising, adhering to medications and attending physician’s appointments (Levin et al., 2008; Lundberg & Thrakul, 2011). People with CKD who engage in routine and consistent self-care have better outcomes: improved physical, psychological, social wellbeing and quality of life (Welch & Davis, 2000).

The current and other researchers found people with CKD find self-care is time consuming and challenging because it requires time to adapt and learn how to perform self-care tasks (Thomas-Hawkins & Zazworsky, 2005; Mitchell et al., 2009). People living with CKD need to make positive efforts to manage chronic illness successfully and participate in their health care to prevent CKD complications, control symptoms and reduce the disturbance CKD can cause their lives (Rothman & Wagner, 2003; Curtin, Mapes, Schatell & Burrows-Hudson, 2005; Thomas-Hawkins & Zazworsky, 2005).

In addition, to perform self-care activities, people with CKD need to build self-efficacy, change behaviours, manage medical aspects, interpret and manage symptoms, live with emotions and use resources (Thomas-Hawkins & Zazworsky, 2005; Levin et al., 2008). Particularly, building self-efficacy, as individuals need to
believe and have confidence in their own ability in order to develop knowledge and skill to improve their health status (Thomas-Hawkins & Zazworsky, 2005; Baumann & Dang, 2012; Jutterström, Isaksson, Sandström & Hörnsten, 2012). It is important to strengthen self-efficacy among people with CKD through empowerment and encourage them to be active in their own care. Active participation in care decisions is central to effective self-care; thus, self-care enables people with CKD to adapt to the disease and its treatment (Thomas-Hawkins & Zazworsky, 2005; Lindberg & Fernandes, 2010).

Self-care declines when people feel tired or fatigued, develop psychological distress such as depression, possess inadequate knowledge and face financial burdens (Thomas-Hawkins & Zazworsky, 2005; Lindberg & Fernandes, 2010; Baumann & Dang, 2012). The current and other studies suggest people with CKD who feel unwell eventually rely on their family members or friends to engage in activities. Consequently, they compromised their self care and felt stressed about being a burden to their families (Lin et al., 2005; Fan et al., 2008; Mitchell et al., 2009; Calvey & Mee, 2011; Suri et al., 2011; Lai et al., 2012; Al Nazly et al., 2013).

Additionally, self-care can decline when people with CKD have irrational thoughts, which can be defined as using illogical thought processes (Williams, Manias & Walker, 2009). Williams et al. (2009) used in-depth interviews to explore how irrational thought affected people’s adherence to medicines used to treat diabetes-related kidney disease. Convenience sampling was used to recruit 23 Australians with diabetes-related CKD. Participants reported having irrational thoughts that contributed to erroneous or underestimated risk assessment of CKD. Williams et al. (2009) recommend people with CKD perform the self-care they need to understand
and adhere to treatment because it can help them to manage CKD and the adverse effects of its treatment.

**Positive thinking**

Current and other studies found people depending on HD often felt shock, fear and great uncertainty about the future (Hagren et al., 2001; Calvey & Mee, 2011). Although emotional distress manifested itself when individuals were initially treated with HD, it enabled people with CKD to survive, which was a positive outcome of HD. Positive thinking was a significant coping technique that helped the participants adapt to life with CKD and its treatment. Other researchers found people regarded the HD machine as a ‘lifeline,’ which is not surprising because it replaces kidney function and keeps people alive and therefore provides hope (Hagren et al., 2001; Prekbunjun, 2004; Hagren et al., 2005; Calvey & Mee, 2011; Bayhakki, 2013).

Hope refers to an individual’s expectation about a situation remaining good or improving in the future (Weil, 2000; Burkhardt & Nagai-Jacobson, 2002; Chiu et al., 2004). Hope is essential to adaption, to life turning points and has a positive influence on health outcomes such as reducing stress (Weil, 2000). Stress is an essential adaptive mechanism, but prolonged unrelieved stress results in burnout or maladaptation. Unrelieved stress can trigger hyperglycemia, cardiovascular disease and hypertension, which are key underlying causes of CKD (Pryor, 2008; Ashfield, 2010). Thus, maintaining hope could help buffer stress for people receiving HD and help them improve their health status (Davison & Simpson, 2006).

Hope arises from an individual’s faith, relationships with other people, feeling needed and having goals (Baldacchino & Draper, 2001). The current and other studies suggest hope for people with CKD is associated with having a KT and putting trust in
the doctors and God (Davison & Simpson, 2006; Moran, Scott & Darbyshire, 2011). Hope of having a KT helps people with CKD engage confidently in life or continually receive HD without despair (Moran et al., 2011).

Hope can be impaired if people’s beliefs and expectations are not fulfilled or are not consistent with reality. For example, individuals with CKD felt hopeless due to the disease and dialysis complications and because they knew other people with CKD who were dying (Weil, 2000). Moran et al. (2011) interviewed 16 people receiving HD in Ireland and found they felt uncertain about the future because they had been on a KT waiting list for a long time and had no idea when or whether they would receive a KT. If individuals can maintain hope, they are more likely to adapt successfully and find meaning and purpose in life. Thus, hope is positively related to health for people with CKD, it empowers or encourages people facing life challenges to move forward and have better lives.

**Denial**

Participants in the current and other studies were overwhelmed at the initial CKD diagnosis and found it hard to accept they had CKD and needed HD (Lin et al., 2005; Ravenscroft, 2005; Krespi, Bone, Ahmad, Worthington & Salmon, 2008; Coyne, 2013). The current and other research suggests denial was used to deal with emotional distress for people with CKD when they were initially diagnosed with disease and needed HD (Williams et al., 2009). Denial refers to unacknowledged unpleasant facts that guard the patients from perceiving the real situation (Buetow, Goodyear-Smith & Coster, 2001). It is interesting to note that in a study in Belgium, people with CKD reported the degree of denial of the severity of CKD and complications were inversely correlated with anxiety and depression (Jadoulle, Hoyois & Jadoul, 2005). However,
denial can prevent the obtaining of new information; consequently, it can affect an individual’s decision-making resulting in errors (Whitehead & Russell 2004).

For people with CKD, denial can lead to unresolved physical and psychological problems that impair the adaptation process and self-care as well as increase the risk of poor health outcomes. Kaltsouda et al. (2011) found greater use of emotional defensive coping techniques such as denial is associated with more depressive symptoms and impaired quality of life in people with CKD in Greece. The researchers suggest the adverse effects of denial coping technique were likely related to CKD stage and the time when CKD was diagnosed (Kaltsouda et al., 2011). Thus, healthcare professionals could be aware of long-term denial and assess coping techniques used for people with CKD and depressive symptoms at the initial CKD diagnosis.

In addition, denial can occur when people with CKD are discouraged because they felt CKD is an incurable disease. For example, Portuguese people with CKD denied HD because they could not see a cure and preferred not to waste time, as a result they developed emotional distress and impaired their quality of life (Ridder, Geenen, Kuijer & Middendorp, 2008; Barbosa & Valadares, 2009).
Key models and theories related to study findings

The process Thai people used to adapt to CKD and HD treatment is consistent with some models and theories: Lazarus and Folkman’s stress and coping theory (1984), Roy’s Adaptation Model (1984), Leininger’s Theory of Culture Care Diversity (1991) and Bridges’s Transition Theory (2009). Participants in the current study went through several life transitions, triggered by various turning points as they adapted to and accepted CKD and HD therapy. The current findings highlight the three transitional stages of adaptation process outlined by Bridges (2009): being diagnosed with CKD, considering treatment options, and accepting and living with HD.

Bridges (2009) described three phases of transitions: ending, neutral zone and new beginnings. Most participants in the current study felt a sense of loss in the ending phase when they were diagnosed with CKD and realised they needed dialysis treatment to survive. Participants had a range of concerns in the neutral zone; disorientation, fear of dying and uncertainty about the future. Participants required time to learn how to cope with and manage their CKD and HD treatment. Participants who were able to adapt to CKD and HD found meaning and purpose in their changed health status and entered the phase in which they were able to live with CKD.

Likewise, Charmaz (2006) used grounded theory to explore how people with chronic illnesses view and act toward their illnesses. One hundred and sixty five participants were interviewed in Northern California, in the United States. Participants experienced a sense of loss related to their chronic illnesses. They tried to come to terms with their loss through various techniques such as rescheduling their daily activities, promoting, relaxation and doing exercises. In addition, participants sought help from their families to help them when they had physical fatigue. Thus, people with chronic illnesses seem likely
to respond to their challenges related to their health issues through a similar process, which is consistent with the current study findings.

During transitions, participants in the current study experienced various turning points such as being diagnosed with CKD, moving from a rural area to the city to access HD, changing hospitals as well as finding a job and/or becoming unemployed. Similarly, other studies found people with chronic illness such as type one diabetes and cancer experienced being diagnosed, losing a job and getting divorced as negative turning points (Kralik, Brown & Koch, 2001; Rasmussen, O’Connell, Dunning & Cox, 2007). Negative turning points for people with incurable illnesses represent life challenges. They need to overcome their challenges by using coping strategies to help them move through the transition, which enables them to adapt to life with their illnesses.

It is interesting to note that one participant in the current study got married to subsidise the cost of HD, which was a positive turning point for her in that HD represented a gain rather than loss. Thus, people with a long term illness can experience positive and negative major changes during their life transitions. If they cannot manage or cope with their major changes, they may develop anxiety and depression. Thus, coping strategies are required to help them manage their life challenges.

Current participants who were unable to adapt to CKD and HD developed emotional distress such as anxiety and stress. Periods of uncertainty required different coping techniques to manage the uncertainty, which for some people was gradual, while others made a rapid transition to the beginning phase. The current study stresses that, although transitions define a linear path, individuals adapt to CKD and HD differently depending on the cause of stress and coping strategies.
Current participants faced physical, psychological, socioeconomic and cultural effects, all of which cause stress. Lazarus and Folkman’s stress and coping theory (1984) describes the way individuals cope with stressful events. Lazarus and Folkman focused on psychological interactions people use to deal with life challenges. Participants in the current study used two main coping styles to deal with stress: health-adjustment and health-behaviours, which both encompassed four specific coping strategies: religion, spirituality, self-management and social support.

Lazarus and Folkman (1984) suggested individuals cope with environmental stressors using two main coping styles: problem-focused and emotion-focused. Participants often denied the diagnosis of CKD to come to terms with emotional distress, which is consistent with emotion-focused coping. Problem-focused coping strategies consist of maintaining self-care, seeking social support, and performing religious and spiritual practices to deal with physical fatigue, food and fluid restrictions, psychological distress and financial constraints. Thus, problem-focused coping strategies are more likely to empower people facing life challenges to move forward and have better lives.

Stress and adaptation are the basis of Roy’s Adaptation Model (RAM) (1984). Roy was concerned about how individuals deal with stress in their internal (physical and psychological symptoms) and external (changed family and social roles, financial issues and culture influences) environments. Roy (1984) outlined adaptation as an adaptive process where people deal with both the internal and external environment using coping mechanisms resulting in behavioural responses that consist of four adaptive modes: physiologic-physical, self-concept, role function and interdependence.
Interestingly, cultural influences appear to fit within contextual stimuli. Contextual stimuli such as cultural beliefs contribute to the adaptation process to help them come to terms with life challenging situations. Alternatively, cultural beliefs can act as a barrier to the adaptation process if people are not able to adapt and reconcile their cultural beliefs into their changed life circumstances. For example, participants in the current study developed emotional distress that was influenced by cultural values and beliefs related to the role of head of the family, gender and children. If Thai people with CKD no longer maintain their usual role, they may find it hard to accept their life with CKD.

Leininger’s theory (1991) focused on the relationship between the individuals’ care and culture. Both Buddhists and Muslims with CKD receiving HD participated in the current study. Religion, culture, values and beliefs helped participants to come to terms with CKD and HD. For example, Buddhist participants in the current study used religious beliefs and practices such as the Buddhist belief in karma whereas Muslims believed that God’s will was the cause of their CKD. These beliefs enabled them to live meaningfully with CKD and its treatment.

However, religion, cultural values, beliefs also acted as barriers to adaptive process because some participants were not able to integrate their beliefs system into their lives. For example, some Muslim participants were not able to participate in fasting at Ramadan resulting in emotional stress. Learning to live with CKD and HD is an ongoing adaptive process; successful adaptation to CKD and HD enable the individual grow beyond the challenge of CKD and integrate HD into their life.
Strengths, limitations and recommendations

Strengths of the study

Several strengths of the study need to be acknowledged including the fact the participants were cooperative, responsive and very willing to share their experiences in great depth. Participants were heterogeneous: a range of ages and duration of CKD and HD treatment were included, which enhances the likelihood the findings could be transferred to other Thai settings. The study also was conducted rigourously, according to qualitative methods of demonstrating rigour: credibility, transferability, dependability, confirmability, methodological integrity, transferability and data saturation as discussed in Chapter four on page 111-112.

Limitations of the study

Several limitations of the study need to be acknowledged. The sample only contained three Muslim participants; consequently, Muslim religious issues highlighted in the findings may not represent the perspective and experience of all Thai Muslim people receiving HD. The researcher was careful to preserve the real meaning of participant’s words when she translated information from the Southern Thai dialect and Thai formal language into English so her supervisors could read the transcripts. She received advice from a Thai English teacher from a Language Institute in Thailand and an English teacher in Australia to ensure the interviews were translated as accurately as possible and to preserve the integrity of the data. However, translation is a complex task as there is often no true equivalent words between two languages, thus, some distortion of the meaning could have occurred unintentionally.
Recommendations

Several recommendations can be made based on the study findings. The recommendations encompass implications for clinical practice and education for Thai people receiving HD. In addition, suggestions for further research are outlined.

Recommendations for nursing practice

The study findings have implications for nephrology generally, and renal nursing practice in particular. For example:

- Patients and their family members are often overwhelmed during the initial diagnosis and discussion about the need for dialysis and face various stressors that typically require coping strategies and support systems that people with CKD may not possess. Nephrology nurses could consider the needs of each individual person with CKD and note their changing needs during life transitions and adapt from being a well person to a person with CKD and assist individuals and their families to cope effectively.

- Nephrology nurses should be aware of and support individuals’ coping strategies to help people live with HD and develop coping strategies depending on their beliefs, values and cultural and social issues. Being willing to listen and ask about patients’ concerns and express their feelings and perform their religious and spiritual practices are an important aspect of holistic care.

- Nephrology nurses should respect people’s coping strategies and use effective verbal and non-verbal communication to enhance people’s autonomy and dignity.

- People with CKD in the current study indicated they spent a lot of unproductive time during HD treatment sessions, which caused emotional distress. Nephrology nurses could use the time people are on HD to offer activities, education, aerobic exercise
and Thai massage, based on their preferences, to help them improve muscle strength and provide emotional support. All these activities could be implemented depending on the patient’s preference, health status and cost. In addition, self-management could be incorporated into routine nephrology care to help people find meaning and purpose in having CKD.

**Recommendations for nursing education**

Several recommendations for nursing education can be inferred from the study:

- Healthcare professionals who are not nephrology specialists need information about caring for people with CKD receiving HD to protect against ineffective care by novice or untrained nursing staff.

- Information about how people with CKD adapt to CKD and HD needs to be included in undergraduate and post-graduate nursing curricula because adaptation is viewed in the literature as a broad term that is similar to coping, but not clearly defined.

- Religion, spirituality, social support and self-management are key concepts that need to be integrated in nephrology education programs to help nephrology nurses understand how individuals with CKD cope with stressful events.

**Recommendations for further research**

Several recommendations for further research emerged from the study:

- Further research is needed to examine the relationship between religion and spirituality and the way they affect Thai people receiving HD.

- Further research could explore Thai caregivers’ experience and how they adapt to the care burden and improve their quality of life.
Further research is needed to develop specific nursing interventions such as coping strategies to assist people on HD to come to terms with the stress and disruption to their life and improve their quality of life.

Interventions need to be specifically designed to reflect the role of religion and spirituality in effective coping strategies and promote physical and psychological adaption. Randomised Controlled Trial (RCT) could then be used to test the intervention.

A larger study is needed to explore how people receiving HD from other cultural settings and diverse socioeconomic groups, adapt to CKD and its treatment.

Further research could focus on the concept of adaptation and coping from the perspective of, people with stage five CKD, nephrology nurses, physicians and family members in different cultural and belief systems.

**Conclusions**

People with CKD and HD treatment went through three main transitional stages: being diagnosed with CKD, considering treatment options and accepting and living with HD. Each transitional stage was triggered by significant turning points. Thai people receiving HD reported three main coping strategies they used to manage the suffering associated with CKD and HD treatment. Religious and spiritual beliefs and practices, social support and self-management were powerful coping strategies strongly influenced by culture and belief systems.

Thus, the study elicited information that could help nephrology nurses understand how Thai people manage their life with CKD and its treatment, the importance of cultural beliefs to their CKD and HD experience and coping strategies, which could help nephrology nurses plan appropriate holistic care.
Chapter summary

Chapter six discussed the key study findings: the consequences of haemodialysis and coping strategies. Chapter six also discussed models and theories related to adaptation to CKD and HD. Chapter six also explicated the strengths and the limitations of the study, and outlined recommendations for nursing practice, education, research and made conclusions.
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Appendix A

Publications and presentations arising from the study
Publications arising from the pilot and main study


Presentations at international conferences

**Yodchai, K.**, Dunning, T., Hutchinson, A. M., Oumtanee, A., & Savage, S.


**Yodchai, K.**, Dunning, T., Savage, S., Hutchinson, A. M., & Oumtanee, A.

Poster presentation, *How do Thai patients adapt to haemodialysis?* The 41st Annual Renal Society of Australasia Conference in Tasmania, Australia (5-8 June 2013).

**Yodchai, K.**, Dunning, T., Savage, S., Hutchinson, A. M., & Oumtanee, A.

Appendix B

Critical appraisal tools
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<tr>
<th>STUDY PURPOSE: Was the purpose stated clearly?</th>
<th>Outline the purpose of the study. How does the study apply to occupational therapy and/or your research question?</th>
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Specify any biases that may have been operating and the direction of their influence on the results.
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<td>Describe ethics procedures. Was informed consent obtained?</td>
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<td>Outcome areas (e.g., self-care, productivity, leisure). List measures used.</td>
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| Were the analysis method(s) appropriate? | ○ Yes  
○ No  
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| Clinical importance was reported? | ○ Yes  
○ No  
○ Not addressed |
| Drop-outs were reported? | ○ Yes  
○ No |

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| Conclusions were appropriate given study methods and results | ○ Yes  
○ No |
Critical Review Form - Qualitative Studies (Version 2.0)
© Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M., 2007
McMaster University

CITATION:

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<td>Was relevant background literature</td>
<td></td>
</tr>
<tr>
<td>reviewed?</td>
<td></td>
</tr>
<tr>
<td>☐ yes</td>
<td></td>
</tr>
<tr>
<td>☐ no</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>STUDY DESIGN:</th>
<th>Was the design appropriate for the study question? (i.e., rationale) Explain.</th>
</tr>
</thead>
<tbody>
<tr>
<td>What was the design?</td>
<td></td>
</tr>
<tr>
<td>☐ phenomenology</td>
<td></td>
</tr>
<tr>
<td>☐ ethnography</td>
<td></td>
</tr>
<tr>
<td>☐ grounded theory</td>
<td></td>
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<tr>
<td>☐ participatory action research</td>
<td></td>
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<tr>
<td>☐ other</td>
<td></td>
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<tr>
<td>________________________________</td>
<td></td>
</tr>
</tbody>
</table>

1 When doing critical reviews, there are strategic points in the process at which you may decide the research is not applicable to your practice and question. You may decide then that it is not worthwhile to continue with the review.
<table>
<thead>
<tr>
<th>Was a theoretical perspective identified?</th>
<th>Describe the theoretical or philosophical perspective for this study e.g., researcher’s perspective.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Method(s) used:</td>
<td>Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>SAMPLING:</td>
<td>Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>Was the process of purposeful selection described?</td>
<td></td>
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<tr>
<td></td>
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<tr>
<td>Was sampling done until redundancy in data was reached?</td>
<td>Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?</td>
</tr>
<tr>
<td></td>
<td></td>
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<tr>
<td>Was informed consent obtained?</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>DATA COLLECTION:</td>
<td>Describe the context of the study. Was it sufficient for understanding of the “whole” picture?</td>
</tr>
<tr>
<td>Descriptive Clarity</td>
<td></td>
</tr>
<tr>
<td>Clear &amp; complete description of site:</td>
<td></td>
</tr>
<tr>
<td>participants:</td>
<td></td>
</tr>
<tr>
<td>Role of researcher &amp; relationship with participants:</td>
<td></td>
</tr>
<tr>
<td>Identification of assumptions and biases of researcher:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2 Throughout the form, “no” means the authors explicitly state reasons for not doing it; “not addressed” should be ticked if there is no mention of the issue.
<table>
<thead>
<tr>
<th><strong>Procedural Rigour</strong></th>
<th>Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design &amp; data collection methods.</th>
</tr>
</thead>
</table>
| Procedural rigor was used in data collection strategies? | ○ yes  
○ no  
○ not addressed |

<table>
<thead>
<tr>
<th><strong>DATA ANALYSES:</strong></th>
<th>Describe method(s) of data analysis. Were the methods appropriate? What were the findings?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Analytical Rigour</strong></td>
<td>Data analyses were inductive?</td>
</tr>
<tr>
<td>-------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| ○ yes  
○ no  
○ not addressed | Findings were consistent with & reflective of data? |
|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| ○ yes  
○ no | |

<table>
<thead>
<tr>
<th><strong>Auditability</strong></th>
<th>Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes.</th>
</tr>
</thead>
</table>
| Decision trail developed? | ○ yes  
○ no  
○ not addressed |
|-----------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Process of analyzing the data was described adequately? | ○ yes  
○ no  
○ not addressed |

<table>
<thead>
<tr>
<th><strong>Theoretical Connections</strong></th>
<th>How were concepts under study clarified &amp; refined, and relationships made clear? Describe any conceptual frameworks that emerged.</th>
</tr>
</thead>
</table>
| Did a meaningful picture of the phenomenon under study emerge? | ○ yes  
○ no |
**OVERALL RIGOUR**

<table>
<thead>
<tr>
<th>Component</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Credibility</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transferability</td>
<td></td>
<td></td>
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<tr>
<td>Dependability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Confirmability</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For each of the components of trustworthiness, identify what the researcher used to ensure each.

What meaning and relevance does this study have for your practice or research question?

---

**CONCLUSIONS & IMPLICATIONS**

<table>
<thead>
<tr>
<th>Component</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conclusions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Findings</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What did the study conclude? What were the implications of the findings for occupational therapy (practice & research)? What were the main limitations in the study?
Appendix C

Plain language statement and consent form
TO: Participant

Plain Language Statement

Date:

Full Project Title: How do Thai Patients Adapt to Haemodialysis?

Principal Researcher: Professor Trisha Dunning

Associate Researcher(s): Dr. Sally Savage, Associate Professor Alison Hutchinson

Student Researcher: Kantaporn Yodchai

1. Your Consent

You are invited to participate in this study because you are receiving haemodialysis treatment.

This Plain Language Statement contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in the project before you decide whether or not to take part in it.

Please read the Plain Language Statement carefully. Feel free to ask questions about any information in the statement. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign a Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research.
You will be given a copy of the Plain Language Statement and Consent Form to keep as a record.

2. Purpose and Background

The number of people with kidney disease and having haemodialysis has increased worldwide. 35,112 people in Thailand have chronic kidney disease and 27,056 people needed HD treatment in 2009. Living with kidney disease means people have to make changes in their lives, especially when they need haemodialysis but there is very little information about how Thai people feel about haemodialysis.

Studies in other countries suggest people cope with the changes in their life through optimism, hope, social support, religious and spiritual coping processes. We will explore how Thai people on haemodialysis change their activities, diets, manage emotional stress, continue to work, the effect on their social relationships and income and how they feel about having haemodialysis.

Your participation in the study will supply important information that will help us design education programs for health professionals who care for people on haemodialysis to enhance their understanding of the impact haemodialysis has on people’s lives so they can help people cope with haemodialysis.

3. Who will participate?

Thai people receiving haemodialysis treatment will participate. Fifteen to 20 people from Songklanagarind and Hat Yai Hospitals will take part in the study.
4. What will I have to do if I participate?

Participation in this project will involve you participating in an interview. The interview will take approximately one hour and will be conducted when you attend the dialysis centre for treatment.

The interview will be tape recorded. You will be asked questions about your feelings, thoughts and attitudes to haemodialysis and to describe how you cope with haemodialysis in your daily life. For example, how you felt when were told you needed haemodialysis? and has your appearance changed in any way since you have been on haemodialysis?

After one or two weeks you will be given a copy of the transcript of the interview in Thai when you attend the dialysis centre for treatment, for you to check the information we collect. You will also be asked for permission for the researcher to contact you again at a later date. To make sure we understand and correctly interpret the information you supplied, a second interview might be needed to clarify some of your answers. You can choose whether to take part in the second interview or not. If you do not agree to take part in the second interview, we can still use your interview data for the study.

After the interview is completed we will transcribe and send you a copy of the transcript in Thai to verify our interpretation of the data. After confirming the transcript contents, it will be translated into English so Ms Yodchai’s Australian supervisors can read the information. At the end of the study, we will send you a summary of the findings from the study written in plain language to the address you provided when you participated in the interview. We will also send you a stamped addressed envelope for you to return any comments to us.
The information will help Ms Yodchai obtain a PhD and will be published in journals and presented at conferences. Your name will not be used in the thesis or publications.

If you agree to participate and later change your mind you can withdraw from the study at any time before the interview data is analysed. If you withdraw, any information you supply will not be used but it will be securely stored in accordance with Deakin University policy. Withdrawing will not affect your relationship with the researchers, the hospital, or your treatment in any way.

5. Possible Benefits

There may be no benefit to you from participating in this research but the study will give you the opportunity to express your opinions and describe your feelings about living with haemodialysis. In the future, the information you supply could benefit other people with haemodialysis.

6. Possible Risks

Some people may find discussing the experiences with haemodialysis and being audio-taped uncomfortable. If you feel upset about answering the questions the researcher will ask whether you want to take a break or stop the interview. If you wish to continue the interview the researcher will wait until you feel better before continuing the interview. If you would like further emotional support we will refer you to qualified counsellors who provide a free service in the hospital.

We will provide you with a summary of all the issues about living with haemodialysis that participant’s discussed in the interviews. The information will not include your name or any names that could identify participants.
7. Privacy, Confidentiality and Disclosure of Information

Any information obtained in connection with this project that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. If you give us your permission by signing the Consent Form, we plan to report the results in a doctoral thesis, in journals and at conferences but we will not use your name. The thesis, publications and conference papers will only contain group information and will not contain any information that could identify you.

All data from the study will be retained in the archives at Deakin University for six years and then it will be destroyed.

8. Results of Project

We will send you a summary of findings to the address you provided when you participated in the interview. The information will be a summary of all the issues about living with haemodialysis that participant’s discussed in the individual interviews. The information will not contain any names or information that could identify you or any other participant.

9. Further Information or Any Problems

If you require any further information or if you have any problems concerning this project, you can contact the principal researcher or any of the other researchers. The researchers responsible for this project are:

**Professor Trisha Dunning**, Ph: + 61 3 5246 5113, email:
trisha.dunning@barwonhealth.org.au

**Associate Professor Alison Hutchinson**, Ph: + 61 3 924 46446, email:
alison.hutchinson@deakin.edu.au
Dr Sally Savage, Ph + 61 3 52603249, email: sally.savage@deakin.edu.au

Assistant Professor Areewan Oumtanee, Ph: 02-218 1154, email: areeday@yahoo.com

Kantaporn Yodchai, Ph: + 613 5227 8439, email: Kyodchai@deakin.edu.au
The mailing address in Thailand is: Medical Department, Faculty of Nursing, Prince of Songkla University, 90112, Ph: 074 286520, email: kantaporn.y@psu.ac.th

The mailing address for Deakin University is: School of Nursing and Midwifery, Faculty of Health, Medicine, Nursing and Behavioural Sciences, Geelong Waterfront Campus, Victoria 3217, Australia

10. Complaints

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The Manager, Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, Facsimile: 9244 6581; research-ethics@deakin.edu.au. and quote EC00213 -2011.

Or Associate Professor Tasanee Nasae, Faculty of Nursing, Prince of Songkla University, 90112, Thailand, Telephone: 074-286401

11. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.
Before you make your decision, a member of the research team will be available so that you can ask any questions you have about the research project. You can ask for any information you wish. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers. If you decide to withdraw from this project, please notify a member of the research team before you withdraw to complete the vacation of consent form.

12. Reimbursement for your costs

You will not be paid for your participation in this project.

13. Ethical Guidelines

This project will be carried out according to the *National Statement on Ethical Conduct in Human Research* (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies. The ethical aspects of this research project have been approved by Deakin University Human Research and Ethics Committee (2011-240) and by both hospitals in Thailand.
TO: Participant

Consent Form

Date:

Site:

Full Project Title: How do Thai Patients Adapt to Haemodialysis?

I have read, or have had read to me in my first language and I understand the Plain Language Statement.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this project according to the conditions in the Plain Language Statement.

I will be given a copy of the Plain Language Statement and Consent Form to keep.

I consent to the interview being audio recorded.

I understand that the researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant’s Name (printed) ……………………………………………………

Signature                                              Date

Name of Witness to Participant’s Signature (printed)

………………………………………

Signature                                              Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher’s Name (printed) ……………………………………………………

Signature                                              Date
REVOCATION OF CONSENT FORM
(To be used for participants who wish to withdraw from the project.)
(Attach to Plain Language Statement)

DEAKIN UNIVERSITY
PLAIN LANGUAGE STATEMENT AND CONSENT FORM

TO: Participant

<table>
<thead>
<tr>
<th>Deakin University Plain Language Statement and Consent Form</th>
</tr>
</thead>
</table>

Revocation of Consent Form

**Full Project Title:** How do Thai Patients Adapt to Haemodialysis?

I hereby wish to WITHDRAW my consent to participate in the research proposal named above and understand that such withdrawal WILL NOT jeopardise any treatment [if applicable] or my relationship with *Name of Institution*.

Participant’s Name (printed) ..............................................................

Signature                     Date

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1. ค่าใช้จ่ายของท่าน

ท่านได้รับชัยให้เข้าร่วมโครงการวิจัยนี้ เนื่องจากท่านได้รับการรักษาโดยการพักโรคด้วยเครื่องได้แก่เกิด

เอกสารบีบนี้ระบุและเอื้อที่เกี่ยวข้องกับโครงการวิจัยนี้ โดยจะเข้ามาให้ท่านได้เข้าใจถึงกระบวนการ และขั้นตอนในการวิจัยทั้งหมดอย่างเป็นที่ และข้อเสนอเกี่ยวกับสุดท้ายที่จะเป็นไปได้เพื่อที่ท่านจะได้มีข้อมูล ประกอบการตัดสินใจว่าจะเข้าร่วมในโครงการวิจัยนี้หรือไม่

กรุณาอ่านเอกสารบีบนี้โดยละเอียด หากท่านมีข้อสงสัยประการใดที่เกี่ยวข้องกับเอกสารบีบี้ ท่านมีสิทธิที่ จะข้อความได้ และหากท่านต้องการปรึกษาการเข้าร่วมงานวิจัยครั้งนี้กับยุทธิ สำหรับบุคลากรทางการแพทย์ ท่านมีสิทธิที่จะกระทาได้

เมื่อท่านเข้ารายงานและเข้มงวดของโครงการวิจัยและผลของที่จะเข้าร่วมโครงการวิจัยในครั้งนี้ ท่านจะต้องมีข้อใน แบบฟอร์มยินยอมเข้าร่วมวิจัย การตอบคำถามของท่านจะยืนยันว่าท่านได้รับทราบและเข้าใจรายงานและเนื้อหาของ โครงการวิจัยแล้วและยินยอมที่จะเข้าร่วมในงานวิจัย

ท่านจะได้รับตัวแพร่ชื่องบบีบี้และแบบฟอร์มยินยอมเข้าร่วมวิจัยเพื่อกู้ไว้เป็นหลักฐาน

2. วัตถุประสงค์งานวิจัยและที่มาของปัญหา

จำนวนผู้ป่วยโรคไตเรื้อรังที่ต้องรับการรักษาด้วยการพักโรคด้วยเครื่องได้แก่เพิ่มสูงขึ้นทั่วโลก ประเทศไทยมีจำนวนผู้ป่วยไตเรื้อรัง 35,112 ราย และการทำการรักษาด้วยเครื่องได้แก่เพิ่มจำนวน 27,056 ราย ใน พ.ศ. 2009
การเข้าประชุมปีการเรียนรวมนั้นทำให้ผู้ป่วยต้องปรับตัวโดยเฉพาะอย่างยิ่งเมื่อผู้ป่วยต้องรับการรักษาโดยการพักเกลือด้วยเครื่องใด้เทียม แม้ว่าจะมีป่วยโรคใดที่รับการรักษาด้วยเครื่องใด้เทียมจำเป็นจะต้องในขั้น แต่เราเกี่ยวของความรู้สึกผู้ป่วยโดยที่อย่างไรก่อการรักษาพอกเกลือด้วยเครื่องใด้เทียม

งานวิจัยต่างประเทศกล่าวหนานี้เพราะผู้ป่วยรับการรักษาด้วยเครื่องใด้เทียม ให้ใช้วิธีการปรับตัวที่เกิดจากการเปลี่ยนแปลงที่เกิดจากการพอกเกลือด้วยเครื่องใด้เทียม เช่น การติดยา ความระหว่างการสมัครหนังสือผลตามการใช้หลักการทางกายภาพและข้อบัญญัติ ในกรณีงานวิจัยเรื่องนี้จะทำให้ศึกษาผู้ป่วยไทยที่รับการรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียมมีการเปลี่ยนแปลง กิจกรรมประจำวัน อาหาร อาหาร การงาน ความสัมพันธ์ของสังคมและรายได้อย่างไรที่ศึกษาผู้ป่วยรู้สึกอย่างไรในการรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียม

การเข้าร่วมงานวิจัยของท่านจะให้ข้อมูลสำคัญที่จะเป็นประโยชน์ต่อพยาบาลที่สูญและผู้ป่วยโรคความเรื้อง ระยะสูงทำให้เข้ารับการรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียม นอกจากนี้ ข้อมูลที่ได้จากท่านจะช่วยพยาบาลในการพัฒนาหลักสูตรอบรมให้ความรู้สิ่งผลกระทบของโรคความเรื้องระยะสูงทำให้การรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียมเพื่อช่วยให้ผู้ป่วยปรับตัวเข้ากับการรักษาด้วยเครื่องใด้เทียมได้ดีขึ้น ข้อมูลดังกล่าวยังจะใช้ในการอบรมพยาบาลที่สูญและผู้ป่วยโรคความเรื้องที่เข้ารับการรักษาด้วยการพอกเกลือด้วยเครื่องใด้เทียม

3. ใครจะเป็นผู้เข้าร่วมวิจัย?

ผู้ป่วย 20 ราย ที่ทำการรักษาวัคซีนพอกเกลือด้วยเครื่องใด้เทียม จากโรงพยาบาลสงขลานครินทร์ และโรงพยาบาลที่อยู่จะเข้าร่วมในการวิจัยครั้งนี้

4. อะไรที่คุณจะต้องร่วมด้านนี้การจ้างทำเลขาเข้าร่วมวิจัย?

หากท่านเข้าร่วมงานวิจัย ท่านจะมีสิทธิ์ดังนี้

- การสมัครงานจะใช้เวลาประมาณ 1 ชั่วโมง
- การสมัครงานจะถูกอัปทะบันทึกไว้ ท่านจะถูกถามคำถามที่เกี่ยวกับความรู้สึก ความคิดและทัศนคติที่ทำให้มีต่อการรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียม นอกจากนี้ท่านจะต้องอธิบายว่าท่านมีวิธีรับรู้ที่เข้ากับการรักษาโดยการพอกเกลือด้วยเครื่องใด้เทียมอย่างไร ตัวอย่างคำถาม เช่น ท่านรู้สึกอย่างไรเมื่อท่านต้องได้รับการพอกเกลือด้วยเครื่องใด้เทียม และข้อมูลทางกายของท่านที่เปลี่ยนไปอย่างไร ระหว่างการรักษาด้วยวิธีการพอกเกลือด้วยเครื่องใด้เทียม
- หลังจากที่พอกเกลือดไปแล้วท่านจะได้รับข้อมูลจากบ้านเทียมเมื่อท่านเข้ารับบริการพอกเกลือด้วยเครื่องใด้เทียม เพื่อตรวจสอบข้อมูลเพื่อความถูกต้อง และทุกวิจัยจะขออนุญาติต่อท่านหากทุกวิจัยต้องการสมัครงานท่านอีกครั้งในภายหลัง ผู้วิจัยอาจเป็นต้องมีท่านสมัครสมาชิกใหม่
เพื่อให้ทำาอธิบายคำสำคัญของคำานวนเดิมเพื่อให้แน่ใจว่าผู้รับข้อมูลเข้าใจที่มีความสำคัญของการดำเนินการของคำานวนได้ถูกต้อง ทำาสามารถเลือกว่าต้องการหรือไม่ต้องการเข้าร่วมการสัมภาษณ์ครั้งที่สอง และถ้าทำาปฏิเสธการสัมภาษณ์ครั้งที่สองทางผู้วิจัยจะยังคงใช้ผลสัมภาษณ์ในการวิเคราะห์ข้อมูลในงานวิจัยครั้นนี้

• หลังจากการสัมภาษณ์เสร็จสิ้น ทางผู้วิจัยจะส่งตอบกลับสัมภาษณ์ แล้วจะส่งไปให้ทางตรวจสอบความ ถูกต้องในการแปลความหมาย และหลังจากทำาได้เห็นได้ว่าเป็นผลลัพธ์ที่เป็นผลสัมภาษณ์ได้ดังหลัก บทสัมภาษณ์ เพื่อหามีถูกต้องเป็นภาษาอังกฤษ เพื่ออาจที่ปีกานงานวิจัยชาว后续หรือสามารถเข้าใจ

• หลังจากงานวิจัยเสร็จสิ้น ทำาจะได้รับสรุปผลงานวิจัยที่ได้เขียนเป็นภาษาไทยที่เข้าใจง่าย โดยจะ ส่งไปยังที่อยู่ของทำาที่ทำาได้ให้ไว้ในระหว่างการเข้าร่วมการสัมภาษณ์ หากทำามีข้อเสนอแนะ เพิ่มเติมในแบบสรุปผลงานวิจัย ทำาสามารถแสดงข้อดีและบัตรปันที่ทำาผู้วิจัยได้เรียนไว้ให้แล้วนั้น

• บทสัมภาษณ์ดังกล่าวจะถูกนำไปใช้ในบทบาทพื้นฐานของผู้วิจัยและนำไปดีพิพพ์ อัลตราสุมบุคคลของ ทำาจะถูกเปิดเผยด้วยการใช้แบบแผนและทรัพยากรที่ต้องการทำา

• หากทำาแสดงสิ่งที่เข้าร่วมงานวิจัยแล้วเกิดเปลี่ยนใจในภายหลัง ทำาผลที่ดีที่จะตอบต่อถัดจากงานวิจัยเมื่อได้ก็ได้ก่อนที่ข้อมูลจะถูกวิเคราะห์ การตอบต่อของทำาจะไม่ส่งผลความไม่พอใจใด ๆ แก่ ผู้วิจัยหรือโรงพยาบาลที่ทำารับบริการอยู่

5. สิทธิประโยชน์ที่ทำาอาจได้รับ

ทำาอาจไม่ได้รับสิทธิประโยชน์ใด ๆ จากการเข้าร่วมวิจัย อย่างไรก็ตาม ทำาจะได้โอกาสในการแสดงความ คิดเห็น และรับทราบความสุขที่เกิดขึ้นกับประสบการณ์ในการปรับตัวและการเรียนรู้ที่จะอยู่ร่วมกับโรคใด ระยะสูงทางและการรักษาโดยการพัฒนาด้วยเครื่องมือที่ทำาได้รับ

6. ความเสี่ยง

งานวิจัยครั้นนี้มีความเสี่ยงสำหรับการใช้ในการ nauyaตามที่จะมีการเปลี่ยนแปลงที่ทำาทราบระบบการ วินิจฉัยโรค ดังนั้นหากทำาผู้สัมพันธ์ที่ทำาไปเป็นประโยชน์และต้องการการรักษาด้วยเครื่องมือเพิ่ม และ เรียนรู้สิทธิโภชนาการวัิตสุขหรือสิ่งที่ผู้วิจัยจะทำาผ่านการทำาต้องการพิจารณารายละเอียดหรือไม่ หากทำาไม่ยินยอม ยกเลิกที่จะให้ผลสัมภาษณ์ไม่ไป ผู้วิจัยจะรอจนกระทั่งทำาผู้สัมพันธ์ที่จะให้ข้อมูลขั้นตอน หากทำาต้องการการสนับสนุนทางด้าน อาการผู้วิจัยจะให้บริการทำาโดยหากทำาเข้าพยาบาลจิตเวชยา หรือผู้ให้คำปรึกษาในโรงพยาบาลที่ทำารับ บริการ
หากทำาการแสดง เช่น หอยปูติดข้าม เหนืออย่าง ครึ่งใส่ อาเจียน และทำาใจติ่งผัดจังหวะในระหว่างที่มีการสัมภาษณ์ ผู้วิจัยจะหยุดการสัมภาษณ์ และจะเริ่มรายงานแพทย์ที่หน่วยบริการการรักษาโดยการพอกเสื้อด้วยเครื่องที่เหมาะสมอย่างช้า

ผู้วิจัยจะส่งข้อมูลผลสรุปงานวิจัยเกี่ยวกับประเด็นของการดำเนินชีวิตด้วยเครื่อง bitmask ที่ทำาได้รวมถึงการขอความร่วมมือในระหว่างการสัมภาษณ์ โดยผลสรุปงานวิจัยดังกล่าวจะไม่ใช่ข้อของทำา หรือข้อใด ๆ ที่จะทำาให้สามารถระบุถึงทำาได้

7. ความเป็นส่วนตัว การเก็บข้อมูลเป็นความส่วนและการเปิดเผยข้อมูล

ข้อมูลใดๆ ที่ผู้วิจัยได้รับในการวิจัยตั้งแต่ที่มีความสามารถในการรับรู้ได้จะถูกเก็บเป็นความส่วน

ข้อมูลส่วนตัวจะถูกเปิดเผยในกรณีที่ได้รับอนุญาตจากทำาทำา หรือเดินทางแล้วมีข้อบังคับทางกฎหมาย แล้วทำาแสดงข้อมูลในแบบฟอร์มเรียนรู้วิทยาที่แน่นอนดังนี้

ผู้วิจัยจะรายงานผลการวิจัยในวิทยานิพนธ์วิทยฐานะโดยไม่ยอมถึงซึ่งข้อของทำา ในกรณีที่เป็นงานที่มีประโยชน์ ผู้วิจัยจะให้ข้อมูลที่มีความสามารถในการรับรู้จากทำาเรียนรู้วิทยาที่แน่นอนดังนี้ ก็ตามจะมีเฉพาะข้อมูลกลุ่มทำา ขณะเช่นไม่มีข้อมูลที่ซีรีส์ถูกต้องทำา จงไม่มีการอ้างถึงข้อมูลของทำาอย่างเป็นจุด

ข้อมูลทั้งหมดที่ได้จากงานวิจัยนั้นจะถูกเก็บไว้ที่มหาวิทยาลัยแลกิน เป็นระยะเวลายี่ปีก่อนจะถูกทำาลาย

8. ผลวิจัย

ทำาจะได้รับสรุปงานวิจัย ส่งไปยังที่อยู่ของทำา ที่ทำาได้ให้ไว้ในระหว่างเขาร่วมสัมภาษณ์แล้วนั้น บทสรุปผลงานวิจัยหลักกล่าว จะสรุปประเด็นต่างๆ เกี่ยวกับการดำเนินชีวิตด้วยเครื่อง bitmask ที่ทำาได้รับการขอรับการสัมภาษณ์ บทสรุปงานวิจัยดังกล่าวจะไม่ใช่ข้อของทำา หรือข้อมูลใด ๆ ที่สามารถระบุถึงทำาได้

เหตุผลของการส่งข้อมูลไปยังที่อยู่ของทำา เพื่อเป็นการแจ้งให้ทำาทราบเกี่ยวกับผลสรุปงานวิจัย และทำาจะได้ถึงโอกาสที่จะเสนอแนวความคิดเห็นของทำาในประเด็นต่าง ๆ ที่ทางผู้วิจัยได้สรุปไว้แล้วนั้น ทำาสามารถส่งข้อเสนอแก่ผู้ดำเนินงานวิจัย ที่ทางเราได้แนบไว้ที่พร้อมที่จะแสดงไปให้เรียบร้อยแล้ว การส่งผลสรุปงานวิจัยไปยังทำา นั้นเป็นส่วนสำคัญของงานวิจัยที่ทำาให้ไม่ถูกถือความถูกต้องของการแสดง หรือผิดเกี่ยวกับการขออนุญาตของทำา

9. ข้อมูลเพิ่มเติมและปัญหา

หากทำาต้องการข้อมูลเพิ่มเติมหรือมีปัญหาการกระทำที่เกี่ยวกับกับงานวิจัยครั้งนี้ ทำาสามารถติดต่อผู้วิจัยหลักหรือผู้วิจัยทำาอีก ๆ ของโครงการวิจัยนี้ได้ตามระยะเวลาที่กำหนด
• ผู้ช่วยศาสตราจารย์ อาร์วาร์รน์ อัมบาร์นี, หมายเลขโทรศัพท์: 02-218 1154, email: areeday@yahoo.com

• กลั่นพร ยอดไชย หมายเลขโทรศัพท์: +61 3 5227 8439 อีเมลล์ Kyodchai@deakin.edu.au ที่อยู่ประเทศไทย: ภาควิชาการพยาบาลอาหรับศาสตร์ มหาวิทยาลัยสงขลากรีนฟิลด์ 90112 หมายเลขโทรศัพท์ 074 286520 อีเมลล์: kantaporn.y@psu.ac.th

• ศาสตราจารย์ หวั่น ตันมิง (Professor Trisha Dunning) หมายเลขโทรศัพท์: +61 3 5246 5113 อีเมลล์ trisha.dunning@barwonhealth.org.au

• รองศาสตราจารย์ ยอสิชัน อัลลิซัน (Assoc. Prof. Alison Hutchinson) หมายเลขโทรศัพท์: +61 3 924 46446 อีเมลล์ alison.hutchinson@deakin.edu.au

• ดร. Sally Savage หมายเลขโทรศัพท์: +61 3 52603249 อีเมลล์ sally.savage@deakin.edu.au

ที่อยู่ มหาวิทยาลัยเด็กนิ้ว: School of Nursing and Midwifery, Faculty of Health, Medicine, Nursing and Behavioural Sciences, Geelong Waterfront Campus, Victoria 3217, Australia

10. ค่าร้องเรียน

หากท่านมีข้อร้องเรียนประการใดที่เกี่ยวข้องกับการวิจัย กรุณาติดต่อไปยัง The Manager, Office of Research Integrity, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, โทรศัพท์: 9251 7129, โทรสาร: 9244 6581; research-ethics@deakin.edu.au และ quote EC00213-2011

หรือ ที่อยู่ มหาวิทยาลัยสงขลากรีนฟิลด์: ผศ. ทับศิริ ฉัตรเสถียร คณะพยาบาลศาสตร์ มหาวิทยาลัยสงขลากรีนฟิลด์ 90112 หมายเลขโทรศัพท์074-286401

11. การมีส่วนร่วมตัวอย่างตามผลการใช้

การเข้าร่วมในงานวิจัยดังกล่าว จะต้องเป็นไปตามความสมัครใจ หากท่านไม่ต้องการที่จะเข้าร่วมวิจัย ท่านมีสิทธิที่จะปฏิเสธไม่เข้าร่วม ท่านมีสิทธิที่จะถอนตัวไม่เข้าร่วม เมื่อใดก็ได้
ก่อนการตัดสินใจ ทำสำมะโนภาพคณะผู้บีบจน์เข้าสังกัดที่เกี่ยวข้องกับงานวิจัยนี้ ทำสำมะโนภาพข้อมูลใดก็ได้ ทำคำเรื่องของย้ายมอบเข้ารวมงานวิจัยก่อนต่อเนื่องทำได้มีโอกาสชักภาพและได้รับคำตอบที่ทำพึงพอใจ

ถ้าทำสำมะโนภาพที่จะถอนตัวออกจากโครงการวิจัยนี้  กรุณาแจ้งคณะผู้วิจัยก่อนการถอนตัว การแจ้งถอนตัวของทำเรื่องจะช่วยให้บุคคลที่ทำแผนถอนตัวด้วยหรือที่ปรึกษาด้านวิจัยสามารถประเมินความเสี่ยงด้านสุขภาพจากการถอนตัวหรือสิ้นที่ทำพึงกระทำก่อนการถอนตัวได้

12. คำตอบแทน

ทำจะไม่ได้รับเงินตอบแทนใดๆ จากการเข้าร่วมวิจัยครั้งนี้

13. จริยธรรมงานวิจัย

โครงการวิจัยนี้ได้ทำตาม คำแนะนำแห่งชาติว่าด้วยจริยธรรมการปฏิบัติงานในการวิจัยที่เกี่ยวข้องกับมนุษย์ (มิบ.2538) โดยสถิติการจัดการแพทย์และสุขภาพแห่งชาติ คำแนะนำแห่งชาติจะช่วยเพื่อพิทักษ์สิทธิของบุคคลที่เข้าร่วมงานวิจัยที่เกี่ยวข้องกับมนุษย์ โครงการวิจัยนี้ได้ผ่านการตรวจสอบและรับรองโดยคณะกรรมการจริยธรรมงานวิจัยมนุษย์แห่งมหาวิทยาลัยเด็กนี้แล้ว
เด็กนักเรียนและแบบฟอร์มยินยอมเข้าร่วมวิจัย

ถึง ผู้เข้าร่วมวิจัย

แบบฟอร์มยินยอมเข้าร่วมวิจัย

วันที่........................................

สถานที่........................................

ชื่อโครงการวิจัย: การปรับตัวของผู้ป่วยชาวไทยต่อการพอกเลือดด้วยเครื่องทำไส้ถ่านอย่างไร?

ข้าพเจ้าได้ทราบหรือมีบุคคลอื่นอ่านให้ข้าพเจ้าฟังโดยใช้ภาษาไทย และข้าพเจ้าเข้าใจว่าจะแจ้งแล้ว

ข้าพเจ้ามีโอกาสที่จะขอความช่วยเหลือจากข้าพเจ้าไม่กับค่าตอบที่ข้าพเจ้าได้รับ

ข้าพเจ้ายินยอมเข้าร่วมโครงการวิจัยในครั้งนี้โดยประกาศการบังคับตามเงื่อนไขที่ปรากฏในค่าชิ้น

ข้าพเจ้าจะได้รับค่าชิ้นและแบบฟอร์มยินยอมเข้าร่วมวิจัยเพื่อเก็บไว้

ข้าพเจ้ายินยอมมันที่ทำในขณะที่ทำการสัมภาษณ์ข้อมูล

ข้าพเจ้าเข้าใจว่าผู้วิจัยจะไม่เปิดเผยข้อมูลส่วนบุคคลและข้อมูลส่วนตัวของข้าพเจ้าหากข้อมูลที่เก็บข้อมูลกับ

งานโครงการวิจัยมีได้รับการดิสก์พื้นหรือเผยแพร่ต่อสาธารณะไม่ว่าในรูปแบบใดก็ตาม

ชื่อของผู้เข้าร่วมวิจัย............................................

ลายมือชื่อ...................................................... วันที่........................................

ชื่อของพยาบาล ..............................................

ลายมือชื่อ...................................................... วันที่........................................

ประเภทของผู้วิจัย: ข้าพเจ้าได้เข้าร่วมโครงการวิจัย วิชาระบบและความเสี่ยงต่อการปฏิบัติผู้เข้าร่วมวิจัย

แล้วและข้าพเจ้าเชื่อว่าผู้เข้าร่วมวิจัยเข้าใจคำอธิบายของข้าพเจ้า

ชื่อผู้วิจัย..............................................

ลายมือชื่อ...................................................... วันที่........................................
แบบฟอร์มการพิทักษ์การยืนยันเข้าวิจัย
(ใช้ในกรณีที่ผู้เข้าวิจัยต้องการจะสอนตัวออกจากระบบการวิจัย)
(แบบแบบฟอร์มเนื้อหาพร้อมกับคำชี้แจง)

มหาวิทยาลัยเด็กกิจ

คำชี้แจงและแบบฟอร์มยืนยันเข้าวิจัย

ถึง ผู้เข้าวิจัย

คำชี้แจงและแบบฟอร์มยืนยันเข้าวิจัย มหาวิทยาลัยเด็กกิจ

การพิทักษ์การยืนยันเข้าวิจัย

ขออนุญาต: ผู้ป่วยโรคไม่ทราบสาเหตุทารกไทยปรับตัวให้เข้ากับการรักษาโดยการฟอกเลือดด้วยเครื่องได้ที่บ่อยได้อย่างไร

ข้าพเจ้าประสงค์ที่จะพิทักษ์การยืนยันเข้าวิจัยข้างต้นและเข้าใจว่าการออกตัวของข้าพเจ้าจะไม่กระทบต่อการรับการรักษาของข้าพเจ้า (หากมี) หรือความเสี่ยงพนันกับสถานบันทึกช่องด้าน

ข้อผูกพันวิจัย.................................................................

ลายมือชื่อ.................................................... วันที่.....................................................
Appendix D

Questionnaire and interview guide
Demographic data

The researcher will ask the participant the demographic questions.

1. General demographic data

1.1 Age…………….years…………months

1.2 Gender

☐ Male    ☐ Female

1.3(a) Marital status

☐ Single    ☐ Married    ☐ Other (please state)…………

(b) If married, how long have you been married?..........years

(c) How many children do you have?..................... Male........ Female........

(d) How old is your eldest child now?..................years old

1.4 (a) How many family members do you live with?..........people

(b) Would you describe your family relationship as?

☐ Good    ☐ Fair    ☐ Poor

Explain…………………………………………………

1.5 Are you still working? ☐ No    ☐ Yes

(a) If yes, do you work full time or part time?

☐ Full time

☐ Part time

(b) What is your occupation?

☐ Farmer    ☐ Homemaker

☐ Government employee    ☐ Business person

☐ Private employee    ☐ Other (please state)…………
1.6 Religion

☐ Buddhist  ☐ Muslim  ☐ Christian

☐ Other (please state)…………..

1.7 Education

☐ Primary School  ☐ High school

☐ College/University  ☐ Other (please identify)……………

1.8 Socioeconomic status

☐ No income  ☐ < 5,000 baht/month

☐ 5,000-10,000 baht/month  ☐ 10,000-20,000 baht/month

☐ >20,000 baht/month

1.9 Do you think your income is sufficient for your needs?

☐ Yes  ☐ No  ☐ Not sure

1.10 How will you pay for your treatment?

☐ Totally reimbursed or insurance

☐ Partially reimbursed

☐ Totally self-paid
2. **Health information**

2.1 Do you have any illnesses besides renal disease?

☐ No  ☐ Yes (please specify) ..............................................

2.2 Do you have complications associated with your haemodialysis treatment?

☐ No  ☐ Yes (please describe) ..............................

2.3 How long have you had chronic kidney disease? ............ years ........ months

2.4 How long have you been receiving haemodialysis? ......years ............months

2.5 How often do you have haemodialysis treatment? ..........times/week

2.6 Current treatment

☐ Haemodialysis only

☐ Haemodialysis and western medicines

(Please name the medicines you use) ............................

☐ Haemodialysis and traditional medicines

(Please name the medical you use) ............................
Interview guide

The researcher will use unstructured questions and use prompts and probes in response the individual’s answers to elicit further information.

Please tell me:

1. How you felt when were told you needed haemodialysis?
2. Has your appearance changed in any way since you have been on haemodialysis?
3. Can you tell me how [change in appearance] made you feel?
4. Have you experienced any difficulty in your daily life since you started haemodialysis?
5. Can you tell me about [difficulties mentioned]?
6. Has haemodialysis affected your family relationships? If so, how?
7. What did that mean to you?
8. How do you feel about being dependent on haemodialysis?
9. Can you describe or tell me more about…?
10. Is there anything else that you would like to share with me?

Thank you very much for participating in this study
แบบบันทึกข้อมูลด้านประชากร

แบบบันทึกข้อมูลด้านประชากรและข้อมูลด้านสุขภาพจ่าทำการสอบถามโดยผู้วิจัย

1. ส่วนที่ 1 ข้อมูลด้านประชากรทั่วไป

1.1 อายุ.................ปี................เดือน

1.2 เพศ

☐ ชาย ☐ หญิง

1.3 (a) สถานภาพสมรส

☐ โสด ☐ สมรส ☐ อื่นๆ ระบุ..................

(b) ถ้าสมรส ท่านแต่งงานกับภรรยาหรือสามีของท่านนานกี่ปีแล้ว ...................... ปี

(c) ท่านมีบุตรกี่คน...............คน ผู้ชาย.............คน ผู้หญิง.............คน

(d) ลูกคนใดของท่านมีอายุกี่ปี ..................ปี

1.4 (a) ท่านอยู่กับสมาชิกครอบครัวกี่คน .................................................คน

(b) โปรดอธิบายความสัมพันธ์ที่ท่านมีกับบุคคลในครอบครัวว่าอย่างไร

☐ ตี ☐ ปากกลาง ☐ แย่

(โปรดอธิบาย)...........................................................................................................

1.5 (a) ปัญจามนูญยังคงทำงานอยู่หรือไม ☐ ไม่ ☐ ท่า

(b) ถ้าท่านใช้ คุณท่านในเวลาหรือนอกเวลา

☐ ในเวลา ☐ นอกเวลา
(c) คุณทำทําอาชีพใด

- ขาวสําน
- แม่บ้าน
- รับราชการ
- พนักงานบริษัท
- รับจ้างทั่วไป
- อื่นๆ ระบุ........................................

1.6 ศาสนา

- พุทธ
- อิสลาม
- คริสต์
- อื่นๆ ระบุ........................................

1.7 ระดับการศึกษาสูงสุด

- ประถมศึกษา
- มัธยม
- อนุปริญญาหรือเทียบเท่า
- อื่นๆ ระบุ........................................

1.8 รายได้เฉลี่ยต่อเดือน

- ไม่มีรายได้
- น้อยกว่า 5,000
- 5,000-10,000
- 10,000-20,000
- มากกว่า 20,000

1.9 ท่านเคยรับรายได้ของท่านเพียงพอทับรายจ่ายหรือไม

- เพียง
- ไม่พอ
- ไม่แน่ใจ

1.10 ดิทริการเบิกค่ารักษาพยาบาล

- ชําระค่ารักษาประกันสังคม
- จ่ายบางส่วน
- เป็นไม่ได้
ส่วนที่ 2 ข้อมูลด้านสุขภาพ

2.1 ท่านมีโรคประจำตัวอื่นนอกจากโรคติดเชื้อหรือไม่
   □ ไม่ □ ใช้ (โปรดระบุ) ...................................................

2.2 ท่านมีภาวะแทรกซ้อนที่เกี่ยวข้องกับการรักษาโดยการผูกเลือดด้วยการใช้เครื่องโลหะเทียมหรือไม่
   □ ไม่ □ ใช้ (โปรดระบุ) ...................................................

2.3 ท่านป่วยเป็นโรคใดเฉพาะเจาะจงนานแค่ไหน ............ ปี ............ เดือน

2.4 ท่านได้รับการรักษาโดยการผูกเลือดด้วยเครื่องล้างใดนานแค่ไหน ........ ปี ............ เดือน

2.5 ท่านได้รับการรักษาโดยการผูกเลือดด้วยเครื่องล้างใดบ่อยแค่ไหน .................... ครั้ง/อาทิตย์

2.6 การรักษาในปัจจุบัน
   □ ท่านรับการรักษาด้วยการผูกเลือดด้วยเครื่องล้างโดยอย่างเดียว
   □ ท่านรับการรักษาด้วยการผูกเลือดด้วยเครื่องล้างโดยใช้ยาแพร่กระจาย
     (กรุณาระบุชื่อยาที่ท่านใช้) ...................................................
     ...................................................................................

   □ ท่านรับการรักษาด้วยการผูกเลือดด้วยเครื่องล้าง โดยใช้ยาแพร่กระจายพร้อมที่ย่าพื้นเบียน
     (กรุณาระบุชื่อยาที่ท่านใช้) ...................................................
คำถามสัมภาษณ์

กรุณาตอบคำถามต่อไปนี้

1. ทำไมเมื่อเรียนรู้ว่า_tasks ทำเรื่องต่อไปให้รับการรักษาโดยวิธีพอกเลือดด้วยเครื่องไฮเทียม

2. อาการของทางกายของผู้ป่วยเปลี่ยนแปลงไปอย่างไรบ้าง ระหว่างการรักษาด้วยวิธีการพอกเลือดด้วยเครื่องไฮเทียม

3. ผู้ป่วยที่มีผลิตภัณฑ์เปลี่ยนแปลงนี้ทำให้ผู้ป่วยอย่างไร

4. อะไรคือผลที่ดีที่สุดในการคุ้มครองในขณะที่รับรักษาโดยการพอกเลือดด้วยการใช้เครื่องไฮเทียม

5. การรักษาโดยการพอกเลือดด้วยการใช้เครื่องไฮเทียมมีผลกระทบต่อความสัมพันธ์ในครอบครัวของผู้ป่วยหรือไม่ ถ้ามี มีอย่างไร

6. ในความหมายนี้ผู้ป่วยอย่างไร

7. ทำไม

8. ทำไม

9. ระบุ

10. ระบุ

ขอบคุณที่ให้ความร่วมมือ
Appendix E

Ethics approval
Memorandum

To: Prof Trisha Dunning
School of Nursing & Midwifery
B

c: Ms Kantaporn Yodchai

From: Deakin University Human Research Ethics Committee (DUHREC)

Date: 13 December, 2011

Subject: 2011-240
How do Thai Patients Adapt to Haemodialysis?

Please quote this project number in all future communications.

The application for this project was considered at the DUHREC meeting held on 12/12/2011.

Approval has been given for Ms Kantaporn Yodchai, under the supervision of Prof Trisha Dunning, School of Nursing & Midwifery, to undertake this project from 12/12/2011 to 12/12/2015.

The approval given by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the approval. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time,
- Any events which might affect the continuing ethical acceptability of the project
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HREC's.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit
research-ethics@deakin.edu.au
Telephone: 03 9251 7123
EC: 54-338-19-2-3

Documentary Proof of Ethical Clearance
The Ethics Committee, Faculty of Medicine, Prince of Songkla University

The Project Entitled : How do Thai Patients Adapt to Haemodialysis?
Principal Investigator: Asst. Prof. Kantaporn Yodchok
Name of Department : Faculty of Nursing, Prince of Songkla University

has been reviewed and approved by The Ethics Committee, Faculty of Medicine, Prince of Songkla University.

Date of Approval : October 26, 2011

Signature Redacted by Library

(Assoc.Prof. Verapol Chandeying, M.D.)
Associate Dean for Research Affairs
Memo

Government Section: Hat Yai Hospital  Nursing Group  Operation Unit  Telephone No. 1772
At Songkhla 0027.103 (Special)  Date: October 21, 2011
Topic: Report the consideration of the research ethics  No. 2/2011

Dear Head of Nursing, Hat Yai Hospital,

The committee of research ethics for Nursing Group, Hat Yai Hospital, assigned to evaluate the research ethics of the study to consider whether to allow the researcher to collect data from the patients or officials of Hat Yai Hospital, would like to report the result of the research proposal, entitled “How do Thai Patients Adapt to Haemodialysis?” by Miss Kantaporn Yodchai as follows:

1. Patient right protection is provided for data collection.
2. The information is written and letters of consent for participants are provided.
3. Officials in Dialysis Unit and doctors are willing to participate in this research.

So, the committee agrees to ☐ allow the researcher to collect the data.
☐ not to allow the researcher to collect the data because........

Your kind consideration is highly appreciated.

.....signed.....  .....signed.....
(Miss Thanthip Kitpaiboonchai)  (Mrs. Chitchanok Anuchan)
Committee of Research Ethics  Chair of Research Ethics Committee

The researcher is required to make an agreement with Nursing Group, Hat Yai Hospital as follows:

1. The research agrees to give the Nursing Group a complete research. ☑ Yes  ☐ No
2. The researcher is willing to be a consultant of this subject for the Nursing Group.
   ☑ Yes  ☐ No.
3. The research will strictly follow the permission steps, explanation, and right protection.
   ☑ Yes  ☐ No.
บัตรที่เกี่ยวข้อง

สำรับชายา โรงพยาบาลหาดใหญ่ กลุ่มการพยาบาล งานพยาบาลผู้ป่วย โทร ๑๗๓
ที่ ๓ ๐๑๖ ๐๑๐/พิเศษ วันที่……เดือน……ปี……พ.ศ.……
เรื่อง รายงานผลการพิจารณาการให้บริการด้านบริการรักษา ครั้งที่……/๒๕๕๙

เรียน หัวหน้าโรงพยาบาลหาดใหญ่

ตามที่ คณะกรรมการประเมินงานวิจัยด้านบริการรักษา กลุ่มการพยาบาล โรงพยาบาลหาดใหญ่
ได้รับมอบหมายให้ดำเนินการประเมินงานวิจัยด้านบริการรักษา เพื่อประกอบการพิจารณาอนุมัติให้ผู้จับกัน
ข้อมูล จากประชุมวิจัยด้านบริการรักษาของโรงพยาบาลหาดใหญ่ ในกรณีเรื่องการพิจารณาโครงการวิจัยของ
ครู… นักศึกษา… (ที่มา) จาก… แผนก… สถาบัน… คณะ… มหาวิทยาลัย…
เรื่อง…..

มีดังต่อไปนี้

1. ศูนย์วิจัย ลำดับ…
วิจัย… ผลการวิจัย…

2. ศูนย์วิจัย ลำดับ…
วิจัย… ผลการวิจัย…

3. ศูนย์วิจัย ลำดับ…
วิจัย… ผลการวิจัย…

สุขภูมิ อนุญาตให้เก็บข้อมูลเพื่อการวิจัยได้
[ ] อนุญาตให้เก็บข้อมูลเพื่อการวิจัย
[ ] ไม่อนุญาตให้เก็บข้อมูลเพื่อการวิจัย

จึงเรียนมาเพื่อโปรดพิจารณา

[Signature Redacted by Library]
[Signature Redacted by Library]