Decisions about Care Priorities at the Final Stage of Life: Listening to Renal Dialysis Patients and Carers in Hong Kong

A dissertation submitted by

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Abstract

Background

Many people undergoing dialysis withdraw from dialysis for various reasons, and this withdrawal is one of the most common causes of death of dialysis patients in Hong Kong. However, care priorities and the decision-making process at end-of-life has not been emphasised. As Hong Kong is a multicultural society, culture has a role in the decision-making process of the study population. Limited studies have been conducted to explore the decision-making process of dialysis patients and their carers regarding end-of-life care, especially in the Hong Kong Chinese context; this study was performed to address this gap.

Purpose

The findings of this study may provide renal healthcare professionals with insights into the beliefs and expectations of patients and carers at the final stage of life. This study also aims to explore the effect of culture on communication about the decision-making process, to learn more about a previously hidden topic in Hong Kong.

Methods

A mixed methods sequential explanatory design was adopted and convenience sampling was used to recruit informants in a regional renal dialysis centre in Hong Kong. Quantitative descriptive data were gathered and analysed. The results were used to guide the formulation of the questions in the focus group interviews. The ethnonursing research method, based on Leininger's culture care theory, was adopted to guide the qualitative phase of the study.

Findings

Some 121 dialysis patients and 61 carers participated in this study. The dialysis patient informants considered communication barriers, Chinese cultural norms and dying in dignity the major themes in the decision-making process in their end-of-life domain; personalising care, normalising life, sharing burdens and the carer's plight were expressed as themes by the carer informants. The universalities and diversities of the findings were used to formulate a model: the overarching influence of culture in the decision-making process of dialysis patients and carers at end-of-life. This model illustrates the interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress on the core of 'dignified dying'.

Conclusions

It should be acknowledged that in the context of Hong Kong dialysis patients and carers always experience tensions and struggles in the decision-making process in shifting between Eastern and Western cultures. Decision outcomes are perceived as individualised, situational and contextual, with culture playing a central influence. Enhancing communication channels, facilitating shared decision-making and promoting advance care planning are crucial for end-of-life care. Importantly, every dialysis patient should leave the world in a dignified manner (dignified dying).

Certification of Dissertation

I certify that the ideas, experimental work, results, analyses, software and conclusions reported in this dissertation are entirely my own effort, except where otherwise acknowledged. I also certify that the work is original and has not been previously submitted for any other award, except where otherwise acknowledged.



_ _____ 30th November 2018

Signature of Candidate Date

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In memory of Tommy (replaced name), who was my patient and triggered this research idea: bless him, resting in a peaceful and painless place.

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Glossary of Terms

Term	Definition
Advance care planning	It is a process of communication between individuals, families and healthcare professionals to understand, discuss and plan future healthcare decisions in the event that an individual loses capacity
Advance directives	A legal document that states the treatment or care a person wishes to receive or not receive if he or she becomes unable to make medical decisions
Dialysis patients	People undergoing haemodialysis or peritoneal dialysis
End-of-life care	Care given to people who are near the end-of-life and have stopped treatment to cure or control their disease. End-of-life care includes physical, emotional, social, and spiritual support for patients and their families
Hé 和	Trying not to argue or quarrel in daily life
Lǐ 理	Can be seen as being polite and appropriate and conforming to society
Rén 仁	Benevolence or human-heartedness
Dào 道	Dào is the natural order of the universe whose character human intuition must discern in order to realize the potential for individual wisdom
Wǔ lún 五倫	It is the discipline in terms of self and relationship with others conducted in Confucianism. The basic societal relationships between people have been set down as: (1) father-son (2) emperor-minister; (3) husband-wife; (4) older-younger brothers; (5) friend-friend

Chapter 1: Introduction

1.1 Introduction

The National Kidney Foundation of the United States (2010) defined end-stage renal disease as progressive and irreversible kidney damage leading to loss of renal function. It is associated with patients who have a glomerular filtration rate of less than 60 ml/min/1.73 m for more than three months in the absence of known structural alterations (Kidney Disease Improving Global Outcomes [KDIGO], 2013). Only a few decades ago, end-stage renal disease was a death sentence. Up until the late 1960s, costly chronic dialysis treatment was provided for selected patients only. With the development of lower cost dialytic equipment and more equitable access to dialysis in the 1970s, the criteria for accepting patients into dialysis programmes became more open (Blagg, 2007). The principle of dialysis acceptance is based on the balance of benefits and burdens of treatment, and the best interests of each patient. Both haemodialysis and peritoneal dialysis are provided, to give patients a longer survival and better quality of life (Bristowe et al., 2015). However, older patients with end-stage renal disease, as well as patients with concurrent diseases, are now being accepted for dialytic therapy. The progression of underlying diseases, emergence of complications or gradual decline in functional status and quality of life make the caring process more complex for this group of patients as they may not obtain optimal benefit from dialysis treatment.

When end-stage renal disease is diagnosed, the majority of patients are offered dialytic therapy. Education on this therapy is provided before patients commence dialysis, however, this may not be sufficient to support informed decision-making about complicated treatment modalities, and some of these patients do not have the opportunity to attend the pre-dialysis education class as they are critically ill when they enter treatment. On receiving dialysis, patients are at risk of life-threatening complications caused by both the disease process and its treatment (Janssen et al., 2013). Dialysis patients also experience

comorbidities that further affect their quality of life, and lead to non-compliant behaviour and thoughts of withdrawal from dialysis (Germain, Cohen, & Davison, 2007; Gessert, Haller, & Johnson, 2013). In fact, communication between patients and healthcare professionals has sometimes been neglected; for example, regarding whether patients understand the treatment plan or the health professionals know patients' values, beliefs, thoughts and preferences towards certain care options when patient life is approaching the end—some dialysis patients may desire all possible therapies to sustain their lives, others may wish to give up aggressive treatment if it does not offer significant help or benefit (MacPhail, Ibrahim, Fetherstonhaugh, & Levidiotis, 2015).

An increasing number of dialysis patients are considering withdrawal from dialysis, leading to the need for end-of-life care, and in recent decades, there has been a growth in research and literature relating to end-of-life care decision-making for renal dialysis patients in Western countries; however, it is still a relatively new topic in Hong Kong (Chan, Tin, Chan, Chan, & Tang, 2010). There is a strong familial-centred approach under the influence of Confucian sociocultural attitudes towards death and end-of-life care in the Asian setting (Foo, Zheng, Kwee, Yang, & Krishna, 2012). Especially for the Chinese culture, paternalism affects the decision-making process whenever important issues need to be resolved, with the eldest son usually acting as the decision-maker. Chinese people tend to avoid talking about death in the family, to avoid attracting bad luck. As Asian culture and health practice had been influenced by the Western culture (Clark & Phillips, 2010), shared decision-making and autonomy are common topics of discussion among patients, families and healthcare professionals. In some aspects of the Western culture, death is something we prefer does not exist. People are constantly encouraged to hold onto life, even if we are with someone we know is dying (Huges, Schumacher, Jacobs-Lawson, & Arnold, 2008). The fear of death may stem from the fear of ceasing to exist, and losing one's identity and foothold in the world

(Vivat, 2008). Attachment to survivors may create an unnatural fear of death, the strong anxiety in life (Walshe, 2010). In contrast, when people live a responsible and compassionate life, they may have few regrets when death approaches—it enables them to surrender without a struggle to the inevitable, in a state of grace (Mjelde-Mossey & Chan, 2007). Therefore, when patients perceive illness and death as natural occurrences in their lives, they accept with understanding. As Cipolletta and Oprandi (2014) noted, death is not the end-of-life, it is merely the end of the body we inhabit in this life. The spirit will remain, and seek, through need of attachment, attachment to a new body and a new life.

In Chinese culture, death and dying are not openly discussed, making the end-of-life care decision-making process difficult. Being conservative, families try to protect the patient by withholding information of a poor prognosis. Sometimes, patients are excluded in the medical decision-making process. Wilkinson et al. (2014) noted that not all healthcare professionals agree on discussing end-of-life and advance care planning with patients and families. Moreover, there is a lack of specialised training in palliative care for healthcare professionals (Brown & Masterson, 2011). This leads to difficulties in initiating discussion and decision-making about end-of-life care. At present, it is unclear to healthcare professionals, especially in the Chinese context of Hong Kong, who should participate in the end-of-life discussion, what should be discussed in the decision-making process, and how decisions should be made.

1.2 The Life of Dialysis Patients

Healthcare professionals often find themselves in a dilemma when encountering seriously ill patients who have not expressed or made decisions related to withdrawal from life-sustaining therapy. Previous research has established that close relatives and carers may not know the patient’s preferences, leading to feelings of confusion, frustration and regret concerning the choices made (Davison, 2010). Patients with end-stage renal disease have a

chronic medical condition that will progress to life-threatening complications; this makes close communication with renal healthcare professionals an essential aspect of quality care (Harwood & Clark, 2014). As a patient's medical condition deteriorates, it is essential for healthcare staff to understand their beliefs, values and preferences at the final stage of life. Communication with carers is also vitally important, such that patients' preferences regarding treatment and care priorities can be ensured. Carers might ask about the patient's disease prognosis, treatment plan and lifespan during the follow-up consultation, but might not receive all information they expected because of time constraints or if doctors were not prepared to discuss end-of-life issues (Foo et al., 2012; Royak-Schaler et al., 2006).

Traditionally, Chinese patients avoid discussion of death and dying; the topic is taboo (Ho & Sanders, 2015; Sun, 2013). When the patient's condition becomes terminal and their mental capacity compromised, no one knows the will of the patient. Inevitably, family members or carers and healthcare professionals take the decision-making role. Burdens are created, whether the decision follows or deviates from the patient's own will. As Gysels et al. (2012) stated, the research priority for cultural and end-of-life care is to study the experiences of receiving and giving of end-of-life care in all conditions, and including families. In addition, Hong Kong was colonised by Britain 150 years ago that had a strong influence on Chinese culture. When combining with the globalisation, the thoughts and beliefs of the local population were affected towards the decision-making process at end-of-life (Tung, 2011). Therefore, it is necessary for healthcare professionals to identify strategies to enhance communication, as well as empower patients and carers in the decision-making process. This research aims to explore the effect of culture on communication about the decision-making process of dialysis patients and their carers regarding end-of-life care. An ethnographic methodology is used to deepen the understanding of the cultural effect and to provide insights into factors about a previously hidden topic in Hong Kong renal health care.

1.3 Background Information of People Undergoing Dialysis

In Hong Kong, in 2013 (the year in which the data were collected for this study), there were 1,115 newly diagnosed patients with end-stage renal disease accepted into renal replacement therapy programme—an incident rate of 156.96 patients per million population (pmp). The mean and median age for incident renal replacement therapy patients were 59.2 and 60.3 respectively; the social causes of death, including withdrawal from dialysis and suicide, accounted for 28.5% of the total in Hong Kong (Hong Kong Renal Registry, 2013). The reasons for withdrawal from dialysis included declining patient condition, poor quality of life and futile treatment, which led to a burden on or even acute depression in patients (Ho et al., 2010), sometimes resulting in suicide.

By comparison, in Australia, 2,544 new patients commenced renal replacement therapy for end-stage renal disease in 2013; an incidence rate of 110 per million population.[1] The median age group was 75–79 years old. The mean age of male and female patients entering the dialysis programme was 59.2 and 60.4, and median ages were 61 and 63, respectively (Australia and New Zealand Dialysis and Transplant Registry [ANZDATA], 2015a, pp. 1.2–1.6). The age figures are similar in comparison with Hong Kong. In Australia, the total number of deaths among dialysis-dependent patients was 1,518 in 2013. Of those, 557 had withdrawn from dialysis (ANZDATA, 2015b, pp. 3.6–3.8). In countries such as Australia, end-of-life discussions and decision-making with patients has occurred for decades. However, the actual cause of death following withdrawal from treatment is not known. Further, it is more common for Westerners to pursue knowledge of the disease and caring process by reading books, magazines or websites when they are diagnosed with

[1] The researcher used Australian data because he practised as a renal nurse in Sydney for four years and was studying a PhD programme offered by an Australian university.

chronic disease (de Rosenroll, Higuchi, Dutton, Murray, & Stacey, 2013; May et al., 2014). In addition, there are contrasts between Hong Kong Australia, and is combined with a comprehensive social security system and healthcare funding, which play an important role in alleviating financial and social burdens on patients. In contrast, being 'sick' attaches stigma to dialysis patients in Hong Kong (Chu et al., 2011; Mok, Ting, & Lau, 2010). They lack energy and motivation to exercise because of chronic anaemia, mood and feelings of weakness. People undergoing dialysis might not be willing to read information related to their disease and illness, leading to a knowledge deficit; this influences compliance rates for self-care activities and quality of life.

1.4 Current Care Provided to People Undergoing Dialysis

There is increasing recognition among nephrologists regarding the need to think of the efficacy and appropriateness of dialysing highly dependent and multiple comorbidity patients in Australia (Brown & Masterson, 2011)—treatment might not improve patients' survival and might in fact adversely affect quality of life. Without a comprehensive and integrated renal palliative care service, patients' symptoms are both under recognised and poorly addressed (Fassett et al., 2011). In addition, with the vast majority of nephrologists having never received palliative care training, there remains poor medical and community understanding of what constitutes palliative care, leading to renal palliative care services far behind other Western countries (Brown & Masterson, 2011).

Integrated renal palliative care should be commenced from when end-stage renal disease is diagnosed, and patients and their families may be unwilling or unable to choose dialysis or to withdraw from it. In fact, information about palliative care options is an important inclusion in pre-dialysis education (Fassett et al., 2011). Palliative care in end-stage renal disease patients is important in the contexts of conservative therapy, withdrawal of therapy and in symptom control (Greaves, Bailey, Storey, & Nicholson, 2009). Withdrawal

from dialysis is a generally accepted process, provided that there is adequate palliative care; the subsequent death can be good (Davison, 2011). However, there are cultural differences in the approach to end-of-life decisions, advanced care planning and withdrawal from dialysis. Non-Western cultures, significantly represented in the Australian population, may have very different understandings of the choices available to them through medical and health policy (Fassett et al., 2011). Therefore, cultural sensitivities need to be taken into account when discussing palliative care and end-of-life decisions. Conversely, the potential benefits of palliative care for the dialysis population are seldom mentioned to patients and carers, leading to an unwillingness or an inability to choose to withdraw from treatment. A significant barrier in promoting renal palliative care is that a majority of renal doctors and nurses have never received palliative care training, and have not been significantly exposed to this field (Davison, 2011). They are afraid of touching this tough subject.

A renal palliative care programme has been introduced recently in Hong Kong, and advance care planning is an essential component in preparing end-stage renal disease patients who chose not to enter into renal replacement therapy for their end-of-life care (Yuen, Kwok, Suen, Yong, & Tse, 2011). However, the coverage of this programme is limited; it has not been initiated comprehensively in the dialysis population. When end-stage renal disease patients are diagnosed, they tend to follow the recommendations of their nephrologist, commencing dialysis with few alternatives presented, as Hong Kong is employing a ‘peritoneal dialysis first’ scheme (Leung, 2016). The scheme is about the offer of peritoneal dialysis as the initial treatment in the government health sector when patients are diagnosed with end-stage renal disease. Patients can be exempted if they have the contraindication. In that case, the chance of discussion about their disease prognosis and treatment plan with their doctors will be less. Although they are taught to perform dialysis and self-care, they rarely think of voicing their living will to the case doctors, nurses and relatives. This means that

when their condition inevitably becomes terminal, nobody knows their preferences, leaving them open to neglect and regret. The story of a former patient of the researcher is given to illustrate; this patient was the trigger for the researcher to undertake this study.

1.5 Single Case Study

Tommy, aged 46, was an end stage renal patient I cared for early in my nursing career. His story has stayed with me and has been important in helping me to choose the topic for this research. He lived with his wife and two teenage children, and had been practicing continuous ambulatory peritoneal dialysis (CAPD) for two years before he passed away. Tommy and his family were born in Hong Kong. He received high school education locally and worked in a factory.

Being a carrier of hepatitis B complicated his condition. This situation meant that he suffered from severe peritonitis, leading to peritoneal adhesion and septicaemia. Peritoneal dialysis was not available to him at that time, and he also had no chance to receive chronic haemodialysis. As there was no chronic haemodialysis vacancy for hepatitis B surface antigen (HBsAg) carriers at that time, Tommy could only be dialysed in an acute setting. There was no future for him. Nobody talked to him about his treatment plan, opinion regarding withdrawal from treatment or end-of-life issues. He asked me what he was waiting for while he held his hand and said, ‘How come there is no long-term haemodialysis for me in the centre? No doctor tells me the treatment plan. Am I going to die? I don’t want to die, I am the bread winner of my family!’ I felt helpless. I didn’t know what to do or say. I just held Tommy’s hand and reassured him he would be all right. His eyes looked disappointed, worried, scared and regretful. He passed away, with a diagnosis of uraemia, four days later.

Apparently, his wife, children and other relatives were not prepared for Tommy’s death. Neither advance care planning nor advance directive were in practice at that

time, and it was very much up to individual doctors to talk to patients about such matters. Nurses were not permitted to respond in the way we are now.

Tommy's story embedded in my memory, and caused me to reflect on what I could have done differently. Several questions came to mind: who had the right to sentence Tommy to death? Could he have participated in his end-of-life decision-making process? Did he have care priorities? Questions like this have been explored with patients and their carers in this study.

Renal nurses have ongoing and close relationships with the end-stage renal disease patients they care for. They are usually deeply involved in the caring process, until patients die (hopefully, in a dignified manner). The purpose of end-of-life care is to maintain the comfort, choices and quality of life of a person who is recognised to be dying, to support their individuality and to care for the psychosocial and spiritual needs of them and their families (Cukor & Kimmel, 2010; Greaves et al., 2009; Hopkins et al., 2011). End-of-life care also aims to reduce inappropriate and burdensome health care interventions and to offer a choice of place of care when possible. People undergoing dialysis with severe illness end up with greater suffering and cause financial burden on the health care system. The treatment direction for those patients should change from curative or life prolonging to life maintaining and supportive (Arulkumaran, Szawarski, & Philips, 2012).

Death and dying is perceived as mystery in the Chinese culture, where they define culture as the worldview, values, norms and behaviours shared by a group of individuals (Payne, Chapman, Holloway, Seymour, & Chau, 2005; Suh, Kagan, & Strumpf, 2009). Traditionally, culture is associated with specific ethnic groups, but it also can be applied to specific religious groups, specific institutions and specific interest groups (Holmes, 2014; Zhang, Chen, Gu, Liu, & Cheng, 2015).

1.6 Conclusion

People undergoing dialysis and their carers face a range of significant challenges and burdens in the treatment regimen. Unfortunately, the patients will step into their final stage of life eventually. It is an essential health decision for them to consider their care priorities and preferences at end-of-life. Few studies have explored the decision-making process of people undergoing dialysis and their carers regarding end-of-life care, especially in the Chinese context, which is the gap in the literature the researcher fills in this study. The findings of this study may inform healthcare professionals in the renal arena about the beliefs and expectations of patients and carers at the final stage of life. This study also aims to explore the effect of culture on communication about the decision-making process.

The literature review chapter (Chapter 2) presents a review of the current literature related to the study topic. Electronic databases and a manual search were employed to find the current relevant literature and identify knowledge gaps. The chapter first portrays the search process, then describes and appraises the information relating to end-of-life care decision-making, patient's rights at end-of-life, the current position of advance directives, death education and good death, the cultural impact on end-of-life issues, especially in Hong Kong, and ethnocultural effects in the health care system. This research provides the fundamental knowledge the researcher required to proceed with the research process.

As Hong Kong is a multicultural society, it is necessary to identify and adopt an appropriate theoretical framework to guide this study in relation to the cultural domain. First, ethnography was chosen as the methodology to direct research that takes account of culture. In addition, it was decided that Leininger's culture care theory was the most applicable theoretical framework to guide this study. It helped the researcher to understand the cultural context of the informants' beliefs and behaviours, and provided an avenue to encouraging informants to reveal information that they might hesitate to share in other research events.

In the methods chapter (Chapter 4), the researcher used both inductive and deductive forms of knowledge to pursue a holistic understanding of the cultural element in this study. First, by means of a mixed methods sequential explanatory study design, it aimed at collecting broader and in-depth findings from the target population. As this research study is qualitative driven, the findings of the survey were analysed and used to guide the formation of the questions for the focus group interviews. Subsequently, the features of the ethnonursing research method were utilised to identify the domain of inquiry, formulate the research questions, review the literature to identify gaps related to the domain of inquiry, develop the research plan and method of data analysis, adopt various enablers to guide the research process, and finally, synthesise themes to inform practice. The research method ensures research integrity, allowing the findings to be transformed to interventions applying to the target population and guiding the practice of renal care personnel.

The findings of the data collection phases are analysed in relation to the domain of inquiry of this study: exploring the decisions about care priorities at the final stage of life of renal dialysis patients and their carers. The characteristics of the informants and statistically significant figures and findings from the focus group interviews are summarised and described in this chapter (Chapter 5). The findings of this study answer the research questions: who should participate in end-of-life discussions? What should be discussed during the decision-making process? How should decisions be made? By applying Leininger's phases of ethnonursing data analysis enabler, in-depth knowledge from the key informants was extracted. It is believed that the findings of this chapter are capable of informing renal healthcare professionals about the decision-making process and care preferences of the informants.

In the discussion chapter (Chapter 6), key findings are described, including the interactions among communication barriers, family dynamics, sharing burdens and existential

distress contributing to the core concept: ‘dignified dying’. This chapter discusses issues affecting the viewpoints of the informants, especially culture. The universalities and diversities of the findings are compared with the current literature. Through this research study, the ideas of a good death, end-of-life care, advance care planning and advance directives were reflected in the informants. The findings substantially inform renal healthcare professionals in Hong Kong. It should be acknowledged that people undergoing dialysis and carers experience tensions shifting between Eastern and Western culture while making end-of-life decisions in the context of Hong Kong.

The final chapter discusses the limitations of the study, presents implications for nursing practice and recommends directions for future study based on the major findings. It concludes with a summary of this study.

The next chapter outlines the thesis, then reviews the literature to provide an overview of the current knowledge on decision-making processes relating to people undergoing dialysis’ end-of-life issues.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents a review of the current literature related to the decision-making processes and care priorities of renal dialysis patients and their carers at the final stage of life. This study aims to explore the effect of culture on communication about the decision-making process, to learn more about a previously hidden topic in Hong Kong. To address the research questions (Who should participate in end-of-life discussions? What should be discussed during the decision-making process? How should decisions be made?), five electronic databases and a manual search were used to find the current relevant literature and identify knowledge gaps. The literature search commenced by selecting the current broad information about decision-making, end-of-life care, care preferences of the healthy individual, residents in elderly homes and patients with chronic or terminal diseases. Subsequently, focus was concentrated to the elements of dialysis patients, carers, palliative care, culture care, advance care planning and advance directives. The layout of this chapter first describes the search process, then focuses on the description and analysis of end-stage renal disease patient care, end-of-life decision-making in practice, the legal situation and cultural beliefs about death and dying.

2.2 Literature Search Process

The literature review examines the width and depth of the current literature on the decision-making process and care preferences of renal dialysis patients with end-stage renal disease and their carers. The electronic databases used for the literature search were Medline (2006–2016), CINAHL (2006–2016), PsycINFO (2006–2016), Embase (2006–2016), and PubMed (2006–2016). Manual searches (2000–2017) were implemented for relevant articles and books found from the reference lists of the reviewed literature. The initial review of the literature was performed in April 2010 and updated until December of 2017 as new literature

was published. As the study progressed, further information and knowledge were incorporated, to support the writing of the thesis.

The initial review was a preliminarily uncovering of the knowledge on decisions about care preferences of dialysis patients at their end-of-life. Literature with keywords related to decision-making and end-of-life care, including healthy individual, residents in old-age homes, patients with chronic or terminal diseases, carer, caregiver, surrogate, conservative therapy, palliative care, supportive care, culture care, care preferences, advance care planning and advance directives, was identified, providing a global understanding and general knowledge about the topic. Further refining was based on screening the title or abstract for adult population (aged 18 or over) with a diagnosis of chronic kidney disease, end-stage renal disease, Chinese and Hong Kong was performed. Healthcare professionals (doctors, nurses and paramedics) as carers or caregivers and renal transplant patients were excluded. The remaining literature was then screened for content about patients undergoing dialysis (peritoneal dialysis or haemodialysis) or withdrawal from dialysis. Articles describing the critical care setting were excluded. The flow chart of the search process is illustrated in Figure 2. 1.

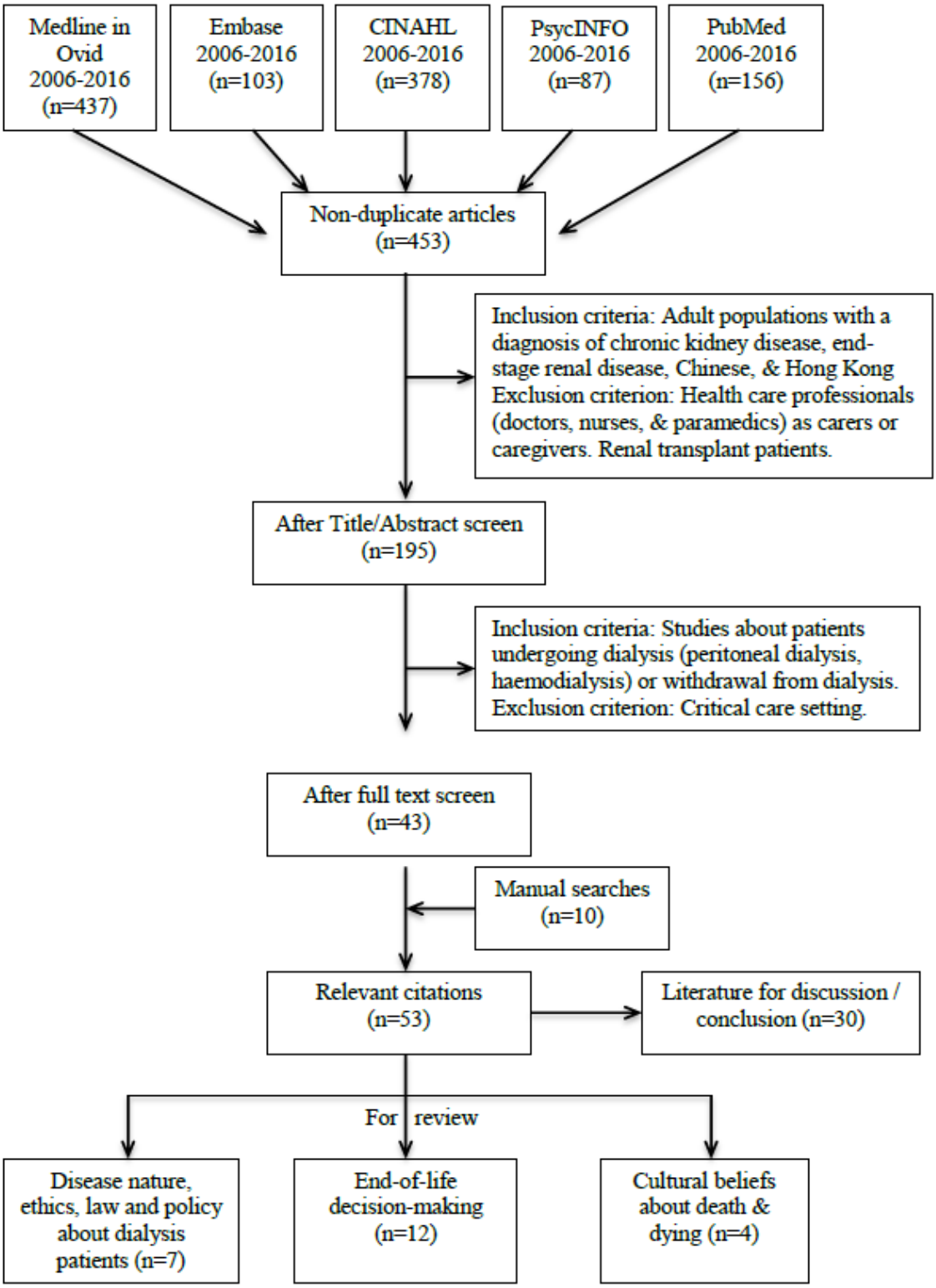


Figure 2. 1. Flow chart of the search process.

Inclusion criteria of the literature search:

- Adult populations with a diagnosis of end-stage renal disease, terminal disease or chronic disease.
- Studies describing patients undergoing dialysis (peritoneal dialysis or haemodialysis) or withdrawal from dialysis.
- Carers or caregivers caring for renal dialysis patients.
- Attitudes and cultural beliefs about death and dying of Hong Kong Chinese.
- Peer reviewed journals.

Exclusion criteria of literature search:

- Healthcare professionals including doctors, nurses and paramedics that were identified in the literature as carers, caregivers or surrogates.
- Studies carried out in critical care settings.
- Renal transplant patients.
- Papers in languages other than English.

A total of 453 non-duplicate articles were identified. The titles or abstracts were briefly read for main points and the keywords checked against the inclusion and exclusion criteria; on this basis, 258 articles were excluded. Of the 195 remaining articles, 152 were rejected via the full text screening, because the contents were not relevant to the study keywords, leaving 43 articles as the most relevant for this study. In addition, manual searches were performed based on the reference lists in the 43 articles. Some of the chosen literature was published between 2000 and 2005, as it provided knowledge on specific aspects; for example, the cultural perspective of older Chinese on end-of-life decisions. Ten books and articles were found, giving a total of 53 citations. As the coverage was relatively broad, including disease-related, psychosocial, medical-legal and behavioural-cultural aspects, it was not possible for the researcher to bring the final number down to a more manageable

number. In the end, seven articles on nature, ethics, law and policy about dialysis patients, 12 on end-of-life decision-making and four on cultural impacts on death and dying were reviewed; the other 30 were used as part of the discussion and conclusion.

As qualitative-driven mixed methods design is used in this study, a systematic approach to screening the qualitative research literature was been performed. Critical appraisal can be adopted to identify the strengths and weaknesses of a research article in order to assess the usefulness and validity of research findings. The most important components of a critical appraisal are an evaluation of the appropriateness of the study design for the research question and a careful assessment of the key methodological features of this design (Young & Solomon, 2009). Other parts should be considered include the suitability of the statistical methods used and their subsequent analysis, potential conflicts of interest and the generalisation of the research. The steps and methods of performing the critical appraisal are different in quantitative and qualitative research literatures. Most of the quantitative researches chosen were descriptive quasi-experimental design and the researcher of this study did not plan to do a systematic review, specific skills for example Critical Appraisal Skills Programme (CASP) or Scottish Intercollegiate Guidelines Network (SIGN) had not been adopted.

2.3 End-of-Life Care Decision-Making

According to the World Health Organization (WHO) (1990), palliative care is the `active total care of patients whose disease is not responsive to curative treatment and includes control of pain, other symptoms, and psychological, social, and spiritual problems.' It is asserted that palliative care should not be limited to patients at the end-of-life. Instead, it is designed to improve the quality of life of all patients suffering from chronic, life-limiting illness regardless of life expectancy. Patients with end-stage renal disease are particularly appropriate candidates for palliative care as defined by the WHO (Jablonski, 2008). Those

who opt for renal replacement therapy such as haemodialysis or peritoneal dialysis, know that their survival depends on regular dialysis or a successful kidney transplant as well as control of comorbid conditions. Patients and their families are often keenly aware that the future is uncertain and that death may not be far away (Werb, 2011). Given the uncertain but usually limited course of end-stage renal disease, psychosocial and spiritual support and assistance with end-of-life care are essential components of the care of these patients (Fassett et al., 2011). There is a recognized need for education regarding provision of palliative care in dialysis patients. However, there is no clear pathway to palliative care (Murray, Arko, Chen, Gilbertson, & Moss, 2006). The misconceptions that surround palliative care are barriers to its acceptance and incorporation as the standard of care for all patients with end-stage renal disease (Jablonski, 2008).

Shifts in the preference of terms to use in the last 30–40 years have occurred, and the specific meanings of terms have changed over time (Glare & Sinclair, 2008). Health care providers also use these terms to categorise the type of care a patient may receive during the final stage of life. Nevertheless, there is no clear clinical indicator to predict time of death; it is impossible and unreasonable to confirm a date to bind the duration as the end-of-life period. In addition, the lack of indicators for the end-of-life time frame leads to lack of what is appropriately encompassed in end-of-life care. People always assume that end-of-life care is providing comfort care holistically to the dying patients and their families at the last moment. However, without the time frame, patients would be left without receiving sufficient and appropriate end-of-life care (Izumi et al., 2012).

Patients' perspective

Withdrawal or discontinuation of dialysis therapy is challenging to patients, carers and even healthcare professionals in the renal field. Some patients feel disengaged from the clinical decision-making and discussions about their prognosis, treatment preferences and

end-of-life care (Tong et al., 2014). As dialysis patients are getting older and end-stage renal disease is becoming more complex, there is an increasing trend for patients to enter end-of-life care as a particular stage of care. Although the terms ‘end-of-life’ and ‘end-of-life care’ have been increasingly addressed in the health and nursing literature, there is no exact definition of what constitutes the time interval referred to as end-of-life (Izumi, Nagae, Sakurai, & Imamura 2012). Lorenz et al. (2008) in a systematic review shows the literature used various approaches to identify patients at the end-of-life. Some used clinician assessment of “active dying”, others used clinical characteristics, survival prediction rules, or physician judgment. However, no precise definition or characteristic has been published. Moreover, end-of-life care is often used interchangeably with comfort care, terminal care, hospice care, or palliative care. Each term represents a different level or type of care provided to patients with limited chances of recovery and medical treatment is no longer considered effective (Wong-Kim & Burke, 2013).

For patients who have serious and terminal illness, healthcare professionals should find an opportunity to discuss end-of-life care with patients while they are still cognitively intact. Moorman (2011) studied 4,500 healthy older adults in their mid-60s, and found 80% wanted to make medical decisions independently because they did not want to burden their families. They also wished to stop life-prolonging treatment if they had a terminal illness. A literature review performed by Wilson, Gott and Ingleton (2011) explored the factors that influence decision-making for individuals at end-of-life. The results were multifactorial, with contributing elements including whether the patients had carers’ support, sufficient resources from health care providers, health inequality and access, and perception of self-identity. However, the context was mainly the United Kingdom; literature reviews based on Hispanic, Latino, African and Asian populations have not been conducted.

Haras (2008) defined end-of-life decision-making as a patient's informed decision on whether to continue or withdraw from life-sustaining treatment when faced with an incurable condition. The goal of end-of-life decision-making is to meet patients' wishes and needs by choosing appropriate treatments and care. The patient with kidney disease must face the inevitable prospect of dying, and the renal nurse is often the first person who hears and responds to the patient's request to withdraw dialysis. Decisions and actions to stop treatment or withdraw from life-sustaining treatment generally occur when dialysis patients feel death is imminent. Nevertheless, Russ, Shim and Kaufman (2007) and Davison (2010) found that patients in routine dialysis sessions did not talk about or necessarily want to consider a time when they may be confronted with the decision to withdraw from dialysis. According to Russ et al. (2007), patients decided to discontinue treatment when they were in an acute episode of their chronic illness, often following a long course of physical deterioration. A decision to stop treatment involves patients giving up the life-saving treatment and facing the uncertainty of dying in pain and suffering without dialysis. The 584 dialysis patients who completed the survey in the Davison (2010) study chose family (89.2%), physicians (35.6%) and nurses (10.8%) to make the medical decision for them if they were physically or mentally incompetent. In a US study, Kwak and Haley (2005) found that Asian and Hispanic patients often consulted their family members before making health-related decisions. In fact, asking for family advice is very common in Chinese culture; decisions are then made after discussion (Bowman & Singer, 2001).

Baharoon et al. (2010) studied 100 adult haemodialysis patients for preferences about end-of-life care. The results showed more than two-thirds of the patients were willing to make their own decisions regarding end-of-life care issues. As this was a small-scale study with a narrow scope, transferability of results is questionable. Murray et al. (2009) performed a systematic review of the decision-making needs of chronic kidney disease patients,

including barriers and facilitators to decision-making. Although 40 studies were appraised, the focus was on patients' decisions about preferences regarding dialysis modality and withdrawal from dialysis. The majority of studies reflected the healthcare professional, rather than patient, point of view. The results showed that the factors affecting chronic kidney disease patients' participation in decision-making encompassed interpersonal relationships, preservation of current wellbeing, normality and quality of life, need for control and personal importance attached to benefits and risks. It revealed that patients need more information about the disease nature, treatment modality, self-care and end-of-life issues.

Incurable, end-stage renal disease is traumatic. For some patients, being unclear on whether dialysis would extend life or bring about death complicates the decision (Cowan, 2016; Singh, Germain, Cohen, & Unruh, 2014; Song et al., 2015). Obviously, the primary goal of health and medical care is preservation of life, but when life cannot be preserved, the purpose is to provide comfort and dignity to dying patients. End-of-life care should provide the best possible treatment, accommodate comfort and dignity, and incorporate withholding or withdrawal of life-sustaining treatment in the best interests of the dying patient (Arulkumaran, Szawarski, & Philips, 2012; Haras, 2014). For most patients, reassurance on the estimated time of death provides hope. When initial anxiety is allayed, the patient's struggle is how to embrace life while preparing to die (Kuhl, Stanbrook & Hébert, 2010). Truth telling, therapeutic touch and time with loved ones are considered important for dying patients (Goodridge, 2010). They expect truth, not just reassurance and hope. Hope is not limited to escaping death, but can include savouring of final moments with the people they love and who love them and touch, both physical and emotional, that reminds patients they are still living until they are not. Patients expect time is the key need for them to come to terms with their illness, losses and unresolved issues (Hopkins et al., 2011). However, it is not a norm that patients have the right to know the truth especially in some Asian countries

(McCabe, Wood, & Goldberg, 2010). Wang, Peng, Guo, & Su (2013) revealed that 55.9% of the family members supported not to tell the truth of the cancer disease to their relative patients in mainland China. They usually act the decisional role in disclosing their relatives' bad news rather than the physicians as the medical professionals are obligated to try to avoid adverse effects on cancer patients while notifying them about the disease. Li, Yuan, Gao, Yang, Jing, & Yu (2011) indicated that nondisclosure is the common practice while families are legally recipients of vital medical news and decision-maker in mainland China.

Carers' perspective

As carers play an important role in the decision-making process, Tong et al. (2014) performed a thematic synthesis to demonstrate in-depth knowledge extracted via various qualitative methods on dialysis patient and carer perspectives of end-of-life care. Of the 948 articles screened, 711 involved patients and 178 carers. Most studies had focused on the decision-making of patients on dialysis therapy, not on palliative or supportive care. Reasons for withdrawal from dialysis treatment had not been identified either. Five themes emerged from thematic synthesis: invasive suffering, personal vulnerability, relational responsibility, negotiating existential tensions and preparedness. Various sub-themes related to end-of-life care and decision-making included body deterioration, loss of freedom, burden and harm, imminence of death, autonomy and dignity, trust and safety, accepting the natural course of life, respecting sanctity of life, informational power and preparedness. The findings showed the participants felt ambivalent towards prolonging life. The patients and carers also experienced pressure and disempowerment by the load involved with making end-of-life decisions, leading to decreased capacity for treatment goal setting and coping with uncertainties. Ultimately, patients had not prepared well for death, and carers felt guilty and frustrated. The study recommended promoting the trust and rapport between patients, carers and healthcare professionals, so that misunderstandings and feelings of abandonment could

be alleviated. The involvement of carers in the end-of-life or palliative care setting should be advocated to facilitate transparent decision-making (Fassett et al., 2011; Jassal & Watson, 2009). Counselling and provision of detailed information to carers could help to develop coping strategies and with managing the lifestyle changes associated with the patient's illness and treatment. Hence, advance care planning should be implemented to empower patients, carers and families in articulating the care preferences and goals at the final stage of life (Crail, Walker, & Brown, 2013). A clear decision can then be made. As the cultural domain plays a role in end-of-life care, but most of the researches studied the white population. Further knowledge about other ethnic groups, such as Africans and Asians, is required.

Song et al. (2015) presented a randomised controlled trial to study advance care planning and end-of-life decision-making in dialysis patients and surrogates. The study was conducted with 210 eligible patients–surrogate dyads who were randomly assigned to an interventional or a control group. The dyads were measured for preparedness for end-of-life care and surrogate bereavement outcomes at regular intervals. The authors applied the Sharing Patient's Illness Representations to Increase Trust (SPIRIT) as the advance care planning interventional tool, based on the representational approach to patient education, to reflect the theories of illness cognition and conceptual change (Donovan et al., 2007). The results of the SPIRIT interventional group showed enhancement of dyad congruence under goals of care, surrogate decision-making confidence and a composite outcome combining the two. However, these effects decreased as time went by: only half of the interventional group retained this effect at 12 months. In contrast, the surrogates were helped by SPIRIT to recover from bereavement distress, expressing that knowing their loved sick relatives' wishes had reduced their bereavement distress (Detering, Hancock, Reade, & Silvester, 2010). SPIRIT, as a tool of advance care planning, assisted patients and surrogates to think about and discuss end-of-life decision-making, and to further explore their feelings on care options

at end-of-life. However, the results of this study cannot be generalised to Asian or Chinese populations, since it was conducted only in one US region. As the participants were either African-American or white, future study should be implemented to include other ethnic groups, such as Chinese, to test the effectiveness of this advance care planning tool.

Sandman and Munthe (2010) noted that when patients are unable to make their own medical decisions, healthcare professionals routinely rely on next of kin and significant others to guide the decision-making process. The responsibility of surrogate decision making usually falls to the family because of their intimate and longstanding knowledge of the patient's goals, values, preferences and best interests. Surrogates face special challenges and enormous pressure, especially when patients' wishes are unknown. In a Canadian study, it was concluded that among carers who had taken care of relatives during the end-of-life period, 92% did not want futile life-sustaining treatments to extend their own life (Biola, Sloane, Williams, Daaleman, & Zimmerman, 2010). In previous studies, when the spouse acts as surrogate, the participation in end-of-life decisions may contribute to psychiatric illness, as they experience anxiety and depression once they know the patient's status (Grande et al., 2009; Ward-Griffin, McWilliam, & Oudshoorn, 2012). Thus, this decision-making requires flexibility and patient centeredness, and nurses are in an ideal position to help patients and families through the process of making health care decisions near the end-of-life. They must be willing to engage patients and families in the process, leading to enhanced shared decision-making (Barry, 2012; Brunori, Viola, Maiorca, & Cancarini, 2008).

Barriers to end-of-life decision-making

Barriers to dialysis patients' end-of-life decision-making include knowledge deficits, misconceptions and beliefs about end-of-life (Baharoon et al., 2010). Healthcare professionals may worry that such discussions will upset patients or rob them of hope, though

studies demonstrate that patients welcome these discussions (Beernaert et al., 2014; Pantilat & Isaac, 2008). Notwithstanding, such discussions can be difficult because they involve emotionally laden issues, confront death explicitly and may convey bad news (Foo et al., 2012). Further, physicians often dominate in the discussion, use jargon, fail to elicit patient values and goals of care, and miss opportunities for empathic connection (Ngo-Metzger, August, Srinivasan, Liao, & Meyskens Jr, 2008; Russ & Kaufman, 2012).

In Hong Kong, where this study was conducted, paternalism has occurred locally for a long time, with physicians making decisions based on what they think best for the patient (Wong et al., 2012). Germain, Davison and Moss (2011) also found that physicians might be an obstacle to a good death, because of their own beliefs regarding preservation of hope and life, and an inadequate educational preparation to deal with end-of-life issues. In contrast, respect for patient autonomy dominates decision-making in North America, and is promoted, empowering patients to choose among treatment options (Sudore & Fried, 2010). Respect for autonomy is in line with the principles of informed decision-making, under which patients must understand their condition and receive adequate information to consider the advantages and disadvantages of treatment options. End-of-life decisions should not be constrained by resource limitations; patient preferences and practice standards are the key elements to be considered.

Although death is the natural path for every human being, only a minority of people in Chinese culture would choose to talk about death with others, or even think about it. Fung, Lam and Lui (2010) found that Chinese people avoid talking about end-of-life, because of fear, the unknown, suffering, pain and separation from loved ones, and further, they think it will cause bad luck to themselves or their families. Some patients believe that discussing death could make physicians uneasy (Chan & Pang, 2011). Those issues might interfere with and become barriers to the final decision, and make it harder to plan as the patient wishes.

Deciding how to spend the final days is not easy nor simple. The kind of treatment, the sort of care and whether die at home or in an institution are common questions patients have to ask themselves. End-stage renal disease patients express concerns about the disease process, treatment-related complications and alterations of lifestyle related to dialysis that would not only burden themselves, but their family members and carers. Patients fear leaving family members behind, and not being able to follow the growth of their children was recognised as the key regret at the end-of-life (Hsin & Macer, 2006).

2.4 Patient Rights at End-of-life

When patients or carers have to make medical decisions, they have the right to receive sufficient knowledge and information about the care they are eligible to receive. The more knowledge they have, the greater their participation in the disease management process. Since Hong Kong is a multicultural society, the ethical and legal considerations from the local and the Western worlds may influence the care received by patients. Because the decision to discontinue dialysis is an important life choice, patients and carers cannot be excluded from this process.

According to the World Health Organisation (WHO) (2011), human beings should have freedom of choice, including in the health care system. This assertion is based on the concept of the person, the fundamental dignity and equality of all human beings and the notion of patient rights. Patient rights vary across countries and jurisdictions, often depending on prevailing cultural and social norms. In Australia, the Patient's Rights Charter is based on the understanding of the different roles and responsibilities of patients and healthcare professionals. The charter applies to all parties in the health care system, including patients, families, carers and providers of health care (Australian Commission on Safety and Quality in Health Care [ACSQHC], 2008). In the US, there are eight key areas of the Patient's Bill of Rights, adopted by the US Advisory Commission on Consumer Protection and Quality in the

Health Care Industry in 1998 (American Cancer Society, 2011), one of which stresses the importance of taking part in treatment decisions, states that patients have the right to know their treatment options and take part in decisions about their care. Parents, guardians, family members or others that patients choose can speak for them if they cannot make their own decisions. A number of cases (Cukor & Kimmel, 2010; Luckett et al., 2014; Murray et al., 2009; Song et al., 2015) have addressed the right to refuse life-sustaining medical treatment. Broadly speaking, under certain circumstances, a person may have a right to refuse life-sustaining medical treatment or to have life-sustaining treatment withdrawn. One consideration in these cases is the patient's interests regarding autonomy, privacy and bodily integrity. This must be balanced against the particular country's cultural and traditional attitudes towards preservation of life, prevention of suicide, protection of dependents and the protection of the integrity of the medical profession.

The Australian Patient's Right Charter (ACSQHC, 2008) acknowledges social and cultural diversity, situating it within a broader framework of human rights and basic right to health care, as set out in the United Nations Universal Declaration of Human Rights (ACSQHC, 2008). The charter also consists of eight key points, two of which are specifically related to end-of-life care issues. The first is 'respect', incorporating mutual respect, dignity and consideration between patient and health care provider during the provision of care, being respectful of culture, beliefs and values. The second is 'participation': patients are always involved in decision-making about their care. An important aspect of participation is informed consent, which must be obtained before any procedure or treatment.

In the Hong Kong context, there are five rights in the patients' charter in the Hospital Authority (2014) of Hong Kong. This charter has been established in the belief that the community and hospitals work as partners in a positive and open relationship to enhance the effectiveness of the health care process. Among the five rights, three are significant for this

study topic. First, patients have the right to choice: they can accept or refuse any medication, investigation or treatment, and must be informed of the likely consequences of doing so. Second, the right of information regarding which health care services are available and the charges involved. Third, patients have rights to medical treatment: medical advice and treatment that meets the currently accepted standards of care and quality. Obviously, the present policy and regulations on the rights of patients to choose their treatment already in existence, especially in the Western world. Therefore, patients do have the right to self-determination regarding their treatment plan, even if this results in death (Hofmann, 2007; White & Fitzpatrick, 2006). Various guidelines have been published to bind the practice of renal physicians to promote patient rights and shared decision-making when patients are at the comatose stage (Moss, 2011). Davison (2012) and Del Vecchio and Locatelli (2009) expressed that there were not many end-stage renal disease patients executing their rights to select their care priorities at end-of-life and adopting advance directives. In comparison with Western society, the protection and usage of the policy of patient rights is more limited in Hong Kong, since the citizen of Hong Kong do not have legitimate support for performing advance directives. Helping dialysis patients or carers to make medical decisions not only relies on established legal and ethical policy, but on discovering the underlying rationale regarding why they are reluctant to participate in the decision-making process.

2.5 The Present Position of Advance Directives

Preparation for death is one of the most important tasks in end-of-life care, and may enhance the sense of control patients have in ensuring their preferences be respected (Chan et al., 2010; Cukor & Kimmel, 2010). Discussing advance directives for health care in Hong Kong, Chiu and Li (2000) defined an advance directive as a written statement by a person when he or she is mentally competent to decide the form of health care he or she would like to receive in future, when he or she is no longer competent. Although legislation of advance

directives has been promoted for years, the Government of Hong Kong currently has no formal policy or legislation related to advance directives; it has been claimed by the government that the people of Hong Kong are not yet familiar with the concept of advance directives. However, there are efforts to engage the community in discussion; for example, in December 2009, the Food and Health Bureau (2009) issued a Consultation Paper titled 'Introduction of the Concept of Advance Directives in Hong Kong'. Through the consultation, the government prepared (1) to produce an information package on advance directives for the public, (2) to develop any supporting necessary guidelines and procedures for making and executing advance directives following consultation with the public, medical and legal professionals, (3) to consult the public about the acceptance of advance care planning and the appropriate way to promote this concept in Hong Kong (Hui, 2010; Tse, 2010). When a patient is terminally ill, in a state of irreversible coma or in a persistent vegetative state, the healthcare professionals and family members caring for the patient often encounter the problem of providing the patient with appropriate forms of health care or medical treatment. To temporarily fill the service gap, the Code of Professional Conduct of the Medical Council of Hong Kong contributed to the advance directives issue by providing guidelines on care for the terminally ill. The Working Group on Advance Directives of HA Clinical Ethics Committee firstly issued guidance for Hospital Authority (HA) staff on advance directives for adults in 2010, then the HA Clinical Ethics Committee (2016) has reviewed and updated the guidance. An advance directive form has been developed (see Appendix A). It appears this is the current standard for healthcare professionals to decide and discuss the issue with patients and carers. Nevertheless, it is the responsibility of clinicians caring for dying patients to maintain dignity and limit suffering (Chan et al., 2010).

The United States has a long history of legislative support for advanced care directives. For example, in 1991, the Congress passed the Patient Self-Determination Act,

which specifies that hospitals be reimbursed by Medicare should they have a policy on living wills. All hospitals, nursing homes and home health agencies should advise patients of their rights to medical care and to execute an advance directive (Chiu & Li, 2000). The legislation for advance directives has been taken place in the US since the enactment of the California Natural Death Act 1976 (Chiu & Li, 2000). The UK government response was different. In the past 15 years, they have had many discussions and debates related to advance directives or advance care planning, stating that the current UK law adequately covers the situation, and that these documents do have legal status when properly enacted. The Enduring Powers of Attorney Act (1985) allowed a person to delegate financial decisions if he or she becomes mentally incapacitated (Johnston & Liddle, 2007). The British Law Commission recommended the development of Continuing Powers of Attorney that allow a person to delegate decision-making powers not only vis-à-vis finance, but health care and personal welfare. It was not until 2010 that the people of England and Wales were able to make an advance directive or appoint a proxy, under the Mental Capacity Act 2005 (Chu et al., 2011), but only pertains to an advanced refusal of treatment when the person lacks mental capacity, and must be considered valid and applicable by the medical staff concerned.

According to the British government, every adult with mental capacity has the right to agree to or refuse medical treatment. To make their advance wishes clear, people can use a living will, which can include general statements about wishes, but is not legally binding, and specific refusals of treatment called ‘advanced decisions’ or ‘advanced directives’ (NHS, 2010). Though a former British colony, Hong Kong is slowly progressing in philosophies on caring for terminally ill patients. With support from the law, healthcare professionals in Hong Kong can provide ethical and moral treatment and care to improve end-of-life care for patients who need it.

2.6 Death Education and Good Death

Healthcare professionals should work from the perspective of the patient. However, culture needs to be considered when applying this universal statement about person centred care from the World Health Organisation (2011) that has been widely adopted around the world, including Hong Kong. The preferences and needs of patients should be considered the priority and starting point for the care offered (Goldsteen et al., 2006). By providing information, knowledge and support to end-of-life patients to make relevant and crucial medical decisions can be empowering. Empowerment of dying patients can be achieved by providing them with knowledge and support relevant to making crucial medical decisions. Moreover, clinicians, patients and carers should change their normative belief that talking about death is taboo in ordinary communication about health and illness care (Cipolletta & Oprandi, 2014). Instead, informing dying patients about their prognosis, condition and shortened life expectancy means they can prepare for the coming death and talk freely with others about their dying (Goldsteen et al., 2006). Therefore, death education is important, to provide patients with their disease and illness status and a clear view of their final stage of life; this facilitates patients and carers making medical decisions at end-of-life.

As early as the 1960s, researchers were discussing death education (Mjelde-Mossey & Chan, 2007). Death-related research has developed extensively, with different interpretations and definitions of death education. Although the importance of death education has long been overlooked in Hong Kong it has recently been seen been more interest and attention by health professionals (Chan & Pang, 2010; Chan et al., 2010; Chu et al., 2011; Law, 2009). Death education for health professionals is still limited, and frequently fails to help them consider planning for end-of-life care as a process in which patients may experience different needs in different phases. Since the advent of life-sustaining treatments such as dialysis and transplants, the question has arisen for, patients, carers and healthcare

professionals, of whether allowing a person to discontinue treatment is the same as allowing the patient to commit suicide (Bostwick & Cohen, 2009). However, this view is beginning to change.

In the context of end-stage renal disease, where patients are dialysis dependent, they will die within a month if dialysis is discontinued (Rabetoy, 2006). If the patient has been informed of this, and decides to withdraw from dialysis therapy knowing that doing so will cause death, it is controversial to name it suicide (Chochinov et al., 2006; Mjelde-Mossey & Chan, 2007). Likewise, the central tenet of advance directives concerns the principle of patient autonomy, which allows him or her to decide, when conscious, the form of health care he would like to receive when he is no longer mentally competent (Hui, 2010; Mok et al., 2010; Tse, 2010). In that case, it is the responsibility of healthcare professionals to assess whether dialysis patients and carers have sufficient knowledge about advance directives such that patients are able to adopt it when it has been legitimised.

In the modern secular view, people prefer to end their lives with ease of body, mind and spirit (Green, 2008). The main point is to avoid suffering. In the East and West context, patients with terminal illnesses have expressed the following ideas as contributing to the quality of good death: dying while asleep, achieving a sense of control, awareness of dying, free from discomfort, dying peacefully, dying quickly, prepared for death, giving up roles, no more burden, saying goodbye, and surrounded by family (Hsu, O'Connor, & Lee, 2009; Huges et al., 2008; Kehl, 2006; Kendall et al., 2007; Mjelde-Mossey & Chan, 2007; Vig & Pearlman, 2004; Vogel, 2011; Wiegand & Petri, 2010). In a more recent study, Molzahn et al. (2012) stated control of symptoms, preparation for death, opportunity for closure or sense of completion of life, and good relationships with healthcare professionals were the factors important for a good death. In the local context, The Society for the Promotion of Hospice Care in Hong Kong performed a study on 719 people on the topic 'what is meant by good

death and death perception' in 2004: the top three scores were no pain, saying goodbye to survivors and dying peacefully. It seems the concept of good death is almost universal (Chan & Pang, 2011; Haras, 2008). Thus, what constitutes a good death is a personal preference, even when individuals in a family may not have the same view. Wiegand and Petri (2010) reported that family members described a good death as comfortable, quick, lacking burdensome symptoms and in a peaceful environment. In contrast, a bad death was expressed as dying in pain and with the presence of unrelenting and unrelieved symptoms. Achieving a good death requires collaboration among patients, carers and healthcare professionals. As there is no definite categorisation of the end-of-life period, the planning of the care should commence from when the patient has been diagnosed with the chronic and untreatable illness. Good death is a major attribute of end-of-life care (Guo & Jacelon, 2014). In all likelihood, patients and carers optimal preferences for care will coincide with a good death.

When people talk about dying well or a good death, they are thinking of the dying process; death is perceived as the event that concludes the process (Hsu et al., 2009). In America, the concept of good death provides a script for playing one's last scene with dignity (Chochinov, 2006). There is a strong correlation between good death and dignity, as the qualities of both are similar (Ho et al., 2013). In fact, while dignity differs between individuals, people often fear they will lose it as they near the end-of-life (Wiegand & Petri, 2010). Dignity emphasises the need for patients to retain in control of their environment and destiny (Cipolletta & Oprandi, 2014; Haras, 2008). The purpose of end-of-life care is to relieve suffering through comprehensive physical, psycho-spiritual care. Understandably, dignity is perceived as a basic requirement that must be met in caring for dying patients. The concept of dignity affects a patient's understanding, attitudes and behaviours in a health care situation. Generally, patients' preferences are considered an essential component of dying in dignity (Pleschberger, 2007), but sometimes this preference contradicts the collective

decision-making format of Chinese culture, in which the predominant emphasis is on familial harmony (Guo & Jacelon, 2014). Lloyd, White and Sutton (2010) argued that the constitution of good death depends on social and cultural norms, and should have variations in a multicultural society like Hong Kong. Therefore, transcultural comparisons are particular useful in identifying the meaning of good death, given that different cultural norms and values concerning death and dying are not always easily distinguished (Lloyd et al., 2010).

2.7 Cultural Influences on Decision-Making

Culture plays an essential role in the way we perceive life and death; it is also reflected in the behaviour of a person towards illness. Commonly, people define culture as a set of beliefs, attitudes, values and behaviours shared by a group of people, and transferred from one generation to the next (Thomas, Wilson, Justice, Birch & Sheps, 2008). Giger, Davidhizar and Fordham (2006) defined culture as the values, norms, beliefs and practices a group of people learn, share and use to guide thinking, decisions and actions in a structural way. Culture is multifaceted, always changing and sometimes contradictory (Holmes, 2014). There is no doubt about the importance of culture in the decision-making process of end-of-life care. It is not entirely based on an individual's ethnicity, but also on spirituality/religion, economic status, level of education and acculturation, age, gender, sexual orientation, country of origin and migration status (Mitchell & Mitchell, 2009). Moreover, culture can affect patient and provider understanding of health, illness, death, dying, grief and bereavement (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009). It also influences communication patterns, decision-making styles, responses to symptoms, treatment choices and emotional expression at end-of-life (Napier et al., 2014). When cultural differences are overlooked or inadequately addressed in health care contexts, lower levels of care occur (Bosma, Apland & Kazanjian, 2010). Therefore, a patient's cultural background is essential to consider when

providing health care, because it defines the proper way to behave in a given situation to maintain integrity and self-respect (Zhang et al., 2015).

Although Hong Kong is culturally Chinese, it has a unique history and a mixed culture, gained while under the influence of Britain. Along with globalisation, healthcare professionals including doctors and nurses arriving from mainland China mixing with the original Western-style doctors in Hong Kong means ethical attitudes and behaviours might differ substantially. Failure to identify suitable moral and ethical expectations in the mixed culture of healthcare professionals may lead to conflicts and miscommunication of care offered to patients at end-of-life (Blank, 2011).

Since dialysis patients and carers in Hong Kong are the target population to be studied, understanding their culture would provide more knowledge to consolidate the study findings. Chinese comprise 91.8% of the population, with other floating groups comprising around 8.2% (Hong Kong Census and Statistics Department, 2012), Han Chinese constitute about 95% of the Chinese population in Hong Kong, often referred to as Hong Kong Chinese (or Honkers, Honkies and Hongkonger) (Leung, 2010). Chinese culture dates back thousands of years; some Han Chinese believe they share common ancestors, originating from the patriarchs Yellow Emperor and Yan Emperor (Leung, 2010). It is well known that Chinese culture gives a basic identity to Chinese people, embedded with core values that are unique and consistent. Chinese culture covers diverse school of thoughts, including Confucianism, Taoism and Buddhism (Blank, 2011).

2.7.1 Confucian ethics

The moral and ethical culture of Hong Kong originated at about 500 BC from Confucianism, which has been the backbone of the official philosophy and Chinese value system. In Confucianism, rules cover many aspects of social behaviour of individuals, and thus, the entire range of Chinese human interactions in society (Blank, 2011). It is a set of

guidelines for living that provides an overarching foundation for the values and beliefs of Chinese. The central ethical principle of Confucianism is benevolence (*Rén* 仁), which constitutes the foundation of all social relations. Apart from core benevolence—to love all humanity—it also refers to a set of moral values, for example, kindness, deference, loyalty and forgiveness (Cheng, Lo, & Chio, 2010). It can be applied to decision making via the Confucian saying, 'Do not do to others what you would not like them to do to you' (己所不欲，勿施於人) (Leung, 2010). The idea of compassion and avoidance of undue suffering are embedded in Chinese culture, stemming from *Ren*, with older patients potentially deciding to forgo life-sustaining treatment so as not to bother their family members (Bowman & Singer, 2001). Also, many older Chinese on the mainland are refusing treatment because medical bills would increase the financial burden on the whole family.

Two other important traditional Chinese beliefs are the Confucian ideal of propriety, *Lǐ* (*理*), reasoning, and the Taoist belief of *Dào* (*道*), the way of life. These are reflected in physician paternalism, a phenomenon in Chinese culture. *Lǐ* can be seen as being polite and appropriate and conforming to society. Practicing *Taoism* is to exercise discipline and emotional control in all circumstances (Cheng et al., 2010).

2.7.2 Collectivism

Chinese culture is one of the most collectivistic among Asian countries, and encourages Chinese people to feel more responsible to their families and society than to themselves (Oyserman, Coon, & Kemmelmeier, 2002). Collectivism affects how medical decisions are made and who makes them. Contrary to the individualism of Western culture, interdependent relationships take precedence over the values of self-reliance and independence (Cheng et al., 2010). Since the autonomy of patients is not crucially valued in a collectivistic culture, patients generally do not expect to make medical decision themselves; they usually consult the opinion of their family members. Healthcare professionals in Hong

Kong, usually trained in the domain of Western medicine, might experience ethical dilemmas when trying to incorporate patient autonomy in their daily practice. In comparison, in the Euro-American studies, patients were keen on making medical decisions and desired autonomy and self-efficacy in their treatment plans (Chambaere et al., 2011; Colclough & Brown, 2014; Ditto, Hawkins, & Pizarro, 2006; Harwood & Clark, 2014; Koncicki & Swidler, 2013; Kurella Tamura, Goldstein, & Perez-Stable, 2009; Mazanec, Daly, & Townsend, 2010; Song, Ward, & Lin, 2012; Wilson-Genderson, Cartwright, & Pruchno, 2009). Even Chinese immigrants have been found to have less belief in personal control over preferences for care—they prefer to let families or physicians make medical decisions rather than being personally involved (Ho, Radha Krishna, & Yee, 2010).

2.7.3 Filial piety

Under the guidance of Confucianism, filial piety also plays a role in the decision-making process of Chinese patients. Filial piety is defined as the optimistic and ideal father–son relationship, which means children, especially eldest sons, have a great obligation to protect, care for and respect their parents (Sun, 2013; Zhang et al., 2015). Filial piety encompasses a broad range of beliefs, attitudes and behaviours, captured in a Confucian concept consisting of two common Chinese terms: *xiao shun (孝順)*, actions performed in admiring parents or seniors in the family, and *xiao jin (孝敬)*, a kind of belief and attitude showing respect to the seniors in the family (Sun, 2013). The uniqueness of filial piety to the Chinese population can be expressed in various aspects. First, it is the most important ethical value of the Chinese and regarded as the root of all virtues (Zhang et al., 2015). Second, filial piety can be applied to define the inter-generation relationships of Chinese culture, which are characterised by respect for authority and obedience in young towards the old (Ho, 1996; Hsu et al., 2009; Isay, 2005). Further, filial piety provides a sense of bonding for people sharing the same ancestry, which is seen as a biological linkage allowing people to communicate

across time and space. It helps to bind the family together in a stable and harmonic state. Members in the family are defined according to their positions on the hierarchical ladder, and the authority of elders is never challenged (Sun, 2013). It works as an essential transmitter of culture in the Chinese population (Isay, 2005; Yip, 2004).

Although taking care of the older or infirm seems universal to all cultural groups, fulfilling filial duty has unique cultural meanings that may influence end-of-life decision-making. Chan et al. (2010) stated that sick parents in Chinese culture are often considered incompetent to make medical decisions; adult children or eldest sons, for the sake of fulfilling filial obligations, may override the parents' wishes for executing advance directives. Frequently, adult children wish healthcare professionals to conceal emotional-triggered information from their terminally ill parents, to protect the sick parents from stress or worry (Ji, Lee, & Guo, 2010). In such cases, the implementation of advance care planning becomes difficult, as full disclosure of the terminal illness contradicts filial piety.

2.7.4 Paternalism

Unlike in Western culture, individuals in a Confucian society are deemed unequal based on their social characteristics such as gender, age and occupation (Tang, Chua, & O, 2010). In Confucian teaching, males, including the grandfather, father and eldest son in the family, have absolute authority and are the essential decision-makers (Sun, 2013). Sometimes, adult sons may be given a higher priority than the wife of the patient to act as the surrogate for end-of-life decisions (Kwak & Haley, 2005; Wong, McCarthy, Howse, & Williams, 2007). Wives, daughters and daughters-in-law do not usually assume the role of medical decision-maker, even though they generally provide care to the patients (Calvin, Engebretson, & Sardual, 2014).

Paternalism has been one of the traditional characteristics of the therapeutic relationship in medicine worldwide, and it stands on the opposite side of autonomy (Barnes et

al., 2012; Ko & Lee, 2009). In Hong Kong, the social status of physicians is very high and they are seen as knowledgeable. Physician paternalism has been practised in Hong Kong since the colonial period (Ting & Mok, 2011). Physicians make decisions based on what they discern to be in the patient's best interests, even for those patients who could make the decisions for themselves (Sandman & Munthe, 2010). Under this definition, it is assumed that physicians always know better than the patient what is good for the patient. This representation of the physician–patient relationship has been criticised by patients and families (Bernal, Marco, Parkins, Buderer, & Thum, 2007). The central debate about paternalism is whether physicians really know what is the best treatment for patients without properly informing them, and also, whether they are justified in carrying this treatment out if they believe it is in the patient's long-term interests and that, eventually, the patient would agree that the doctor's action had been correct. If everyone accepts the premise that each individual is of equal value, then everyone's rights should be equally respected (Feely, Albright, Thorsteinsdottir, Moss, & Swetz, 2014). The patient's interests are served by giving them the right to choose or refuse treatment plans, as equal beings; paternalism, therefore, is essentially dehumanising (Davison, 2012). Physician paternalism adds conflict to patient autonomy in end-of-life treatment decision-making when physicians who feel obliged to intervene override patients' will.

Chinese culture has long regarded certain behaviours in a negative light, with personal openness, confronting authority and standing out considered culturally impolite and offensive (Ji et al., 2010). Patients may think it inappropriate to reveal what they truly think about their treatment preferences, and ultimately, defer end-of-life care decisions to their case doctors.

2.8 The Mixed Culture of Hong Kong

Studying Chinese philosophies always starts with the thinking style that people use intuitively to make sense of their social world (Ji et al., 2010). Chinese people tend to favour

a holistic framework in processing information, instead of the analytical style of the Europeans and Americans. In holistic thinking, things are interconnected; that is, the dynamics among the elements rather than the elements themselves are of interest (Ji, Zhang, & Nisbett, 2004). Chinese culture is full of rich and complex traditions that guide the beliefs of people when they encounter various situations. Confucianism is considered by most Chinese people to present the core values of Chinese culture. The classical understanding of death and dying in Confucianism can be illustrated by the study of the meaning of life lying in this present life (Chen, 2012).

The history of Hong Kong must be considered. Hong Kong was managed by the British government from 1841 until it re-joined China on 30 June 1997. During these 156 years, Hong Kong emerged as a blend of East and West, and old and new cultures (Soontiens, 2007). Abbas (1997) noted that Hong Kong benefited from this unique situation, but at the same time, it impeded the region from developing an identity and culture. Although Hong Kong was a colony of the British government, it was firmly rooted in traditional Chinese beliefs, region and culture, and the impact of British rule on cultural values is expected to be limited.

There are considerable numbers of Filipinos, Indonesians and Thais in Hong Kong, and this may influence perceptions of health, dying and death. Filipinos, Indonesians and Thais comprised 112,453 (1.6%), 87,840 (1.3%) and 11,900 (0.2%) of the total Hong Kong population of 6,864,346 (Hong Kong Census and Statistics Department, 2012), with the majority working as domestic helpers, who might take care of older and sick people for much of the time in their daily work activities. In fact, as some end-stage renal disease patients live alone, with employed domestic helpers acting as their main carers, it is postulated in the current study that the cultures of the carers might influence the end-of-life care decision-making for dialysis patients.

Chinese philosophies emphasise harmony, respect, self-control, yin–yang balance, interdependency, community and collectivism (Leung, 2010). These subcultural values are the mixture of East and West that guide parent–child interactions, social relationships, individual and group aspirations (Sun, 2013). Moreover, culture can influence the perceptions of health, illness, death, grief and bereavement held by patients, carers and health care service providers (Gysels et al., 2012). Froggatt and Payne (2006) and Waldrop and Kirkendall (2010) found that culture influences the definitions of what end-of-life is, and also influences patient and carer understanding of the appropriate components of end-of-life care (Seymour, Payne, Chapman, & Holloway, 2007). Simply, there are differences between Eastern and Western cultures. Up close, the perceptions of the people of Hong Kong towards end-of-life issues may be different from those in Macau or the southern provinces of mainland China, which is mere hours travel from Hong Kong.

2.9 Ethnocultural Effects in the Health Care System

Patient perceptions of health and their expectations for care, treatment choices and advanced care planning are influenced by culture (Duffy, Jackson, Schim, Ronis, & Fowler, 2006). Cultural belief is that families should spare patients the suffering that accompanies the responsibility of decision-making (Giger, Davidhizar, & Fordham, 2006). Apart from patients having their own desires regarding end-of-life decisions, families, carers and culture also play an important role. The role of family members is essential when a loved one is dying. Healthcare professionals recognise the cultural context of patients as fundamental to a successful therapeutic relationship. Further, the impact of culture affects communication among healthcare professionals, patients and carers, and these differences must be addressed to develop a care plan that meets the needs of the patient in a meaningful and beneficial way (Brown, Chambers, & Eggeling, 2008; Brown, & Masterson, 2011). For example, both African-American and Latino groups have a strong tradition of sacrificing personal needs to

serve dying members, in particular, spouses and children become the primary caretakers of ill and dying patients (Born, Greiner, Sylvia, Butler, & Ahluwalia, 2004). Even though they want to care for their families, they do not want their families to care for them. In East Asian cultures, family sovereignty works in accepting treatment; however, it is another matter entirely for the family to withhold or withdraw treatment on behalf of the patient (Fan, 1997). Many Asia–Pacific people hold filial piety or duty to parents paramount; children, particularly the eldest son, must preserve their parents' lives at all costs (Payne et al., 2005; Searight, & Gafford, 2005).

Studies have been conducted on Caucasians, South Asians, Chinese and Filipinos in relation to patient and carer attitudes to and decisions on end-of-life care. It is widely regarded as inappropriate and 'wrong' to talk about diagnoses of terminal diseases for Chinese people (Johnstone & Kanitsaki, 2009). Medical decisions are shared among family members, rather than an individual making a decision as an expression of personal autonomy (Chan, 2004). However, patients and family members often have difficulty communicating with each other, and the patient might hesitate to express views or preferences that are different from others, just as older patients often rely on their children to act for them. At the same time, carers fear that making a decision to withdraw from dialysis means they are making a decision to hasten the patient's death (Tse, 2009). Bowman and Singer (2001) and Kwak and Haley (2005) reported that older Chinese did not personally want life support, and thought terminal illness was hopeless and that use of life support or prolonging life indefinitely would burden and bring suffering to the individual, family and society.

In many cultural groups, it is viewed as inappropriate for any human to have the power to end life (Candib, 2002). Filipino patients may not want to discuss end-of-life care because these exchanges demonstrate a lack of respect for the belief that individual life is determined by God (Searight & Gafford, 2005). Conversely, Filipino patients and families

defer end-of-life decisions to physicians, with a long tradition of physician-centred and paternalistic decision-making (Giger, Davidhizar & Fordham, 2006).

Families also feel that it is a burden to share ideas and opinions about end-of-life care with patients that might not tolerate it well (Cohen, Germain & Poppel, 2003). Therefore, recently, family-directed care has been defined as the preference for family members to reach consensus and direct care together (Marks & Arkes, 2008). Healthcare professionals should have the responsibility to proactively inform families of what they can expect both from the disease process and the health care system, to gain cooperation and coordination. A patient's background may provide healthcare professionals with useful clues about their beliefs. Each individual should be assessed in the context of his or her family and culture. Lack of open and culturally sensitive discussion among patients, carers and healthcare professionals might mean patient choice is ignored. With awareness of cultural influences, healthcare professionals can ensure dying patients have quality end-of-life care.

2.10 Summary

This literature review chapter reviews and integrates different evidence and knowledge relevant to end-of-life care decision-making. As Hong Kong is a multicultural society, based on traditional Confucianism, but with the addition of the colonisation effect of the British system, the mixed culture may influence ethical and legal considerations in caring for patients. Patients, carers and healthcare professionals may experience difficulty in communicating with each other in a society such as Hong Kong. Because the decision to discontinue dialysis and care preferences at end-of-life are crucial for dialysis patients and carers, changing normative beliefs regarding the taboo nature of communication for end-of-life care should be a priority. The literature shows that every patient expects to have a good death to be part of end-of-life care. The present review supports the proposition that existing knowledge is insufficient to inform renal healthcare professionals to provide optimal care to

their patients, nor is it sufficient to support patients and their carers to openly discuss these matters with their family or their health care providers.

In the next chapter, the theoretical framework is illustrated and discussed, to assist the researcher to understand the cultural context for the informants' beliefs and behaviours, and allowed the researcher to gain access to information that informants might hesitate to share in other research events.

Chapter 3: Theoretical Framework

3.1 Introduction

The literature review in the previous chapter shows that culture is an essential component of the decision-making process of chronic illness patients and their carers in patients' final stage of life (Bosma et al., 2010; Werth, Blevins, Toussaint, & Durham, 2002). Moreover, as Hong Kong is a multicultural society with a mix of Eastern and Western cultures, it is crucial to identify and adopt an appropriate theory framework to guide this study in relation to the cultural domain.

Among different methods of inquiry, ethnography is the most appropriate to direct research that takes account of culture (Atkinson, Delamont, Coffey, Lofland, & Lofland, 2007). Ethnography originated from anthropology, and makes use of inductive logic to reveal the meaning and understanding of the target group (Robinson, 2013). The target group in this study is Hong Kong Chinese renal dialysis patients and their carers. The history and development of ethnography and its major philosophical foundations are discussed in this chapter.

It was decided that the theoretical framework to guide this study should be derived from the nursing profession. Leininger's (1988, 1997) culture care theory is the core theory in a field of practice termed ethnonursing. The theory is specifically useful when nurse researchers study how culture affects the decisions people make about health care and the sorts of culture-related care practices nurses provide when caring for clients from a different culture. It is adopted as the theoretical framework to guide the qualitative aspect of this study although nursing scholars and scientists have critiqued the concept of transcultural nursing in recent decades. Still, culture care model is merely vehicle among others that enable nurses to deliver effective transcultural nursing care (Higginbottom at el, 2011). With the help of the ethnonursing research method, the researcher was able to understand the cultural context of

informants' beliefs and behaviours, as well as establish trustful relationships that enabled the revealing of information informants might hesitate to share in other research events.

3.2 Ethnography

Ethnography is commonly used to study cultures and cultural contexts, enabling researchers to gain an understanding of interactions among individuals, others and the culture of the society (Cruz & Higginbottom, 2013). Ethnography can be traced back to the late nineteenth century, when anthropologists commenced applying participant observations in studies, based on the foundation of epistemology (Atkinson et al., 2007). It is one of the oldest forms of qualitative research methods, in which anthropologists immerse themselves into the study life, writing field notes and conducting interviews (Hoare, Buetow, Mills, & Francis, 2012). As anthropologists apply ethnography as a research process and write findings as an ethnographic product, the term ethnography is applied as a methodology (process) and a method (product) (Savage, 2006; Walter, 2010). Therefore, ethnography is viewed as both contextual and reflexive, emphasising the significance of context in understanding situations and meanings as the researcher uses various strategies to collect findings (Savage, 2000).

Sociologists use ethnography to study small communities to portray cultural features. There are many approaches associated with ethnography, including autoethnography, critical ethnography, feminist ethnography, focused ethnography and life history, but they all mostly focus on describing human society and culture (Atkinson et al., 2007; Reeves, Kuper, & Hodges, 2008; Savage, 2000). Although originating in anthropology, ethnography is part of the cultural research of social psychology, sociology, political science, education and nursing. Researchers in the health care industry have utilised ethnography to explore the perspective of patients' health beliefs and identify the cultural components of the health and illness domains (Morse, 2007; Robinson, 2013).

The main aim of ethnography is to provide in-depth and global insights into people's views and actions, as well as their nature, through observations and interviews (Reeves et al., 2008; Savage, 2006). Fetterman (2010) noted that ethnography gives an interpretation of people's stories in their own words and local context. As ethnography is not only a methodology but also a method, its advantages have tended to be underestimated. It is an adaptable method that can change direction and allow the researcher to follow leads and hunches, or even change focus (Hunt & Symonds, 1995). Ethnography can be referred to as a way of collecting data, as guidance for data production, as the product of data collection, as a composite of theoretical principles, and as a method and written account (Savage, 2000; Savage, 2006). It employs basic skills, for example, listening, watching and asking questions, and the skills of probing to assist the researcher exploring the studied issues. Through direct and sustained social contact with participants, the researcher discovers what is going on, and then systematically records experiences and thoughts (Streubert Speziale & Carpenter, 2003; Willis & Trondman, 2002).

When adopting ethnography, the researcher should be aware of the diverse epistemological positions. Epistemological diversity is a term used to alert the researcher to be open minded while performing the study, and to tolerate various unfamiliar practices and views concerning knowledge and inquiry (Siegel, 2006). In line with the research topic, the researcher should pay attention to the diversities on beliefs and belief systems, research methodologies and methods of inquiry, cultures and cultural epistemologies. Throughout the study process, the researcher should participate, rather than just observe while collecting experiential data in the settings. Moreover, diverse epistemological views may stimulate questions about the evaluation of ethnographic study and the relevance and validity of criteria used, which can enhance the trustworthiness of the findings (Savage, 2000).

Ethnographic research can be problematic, owing to the relatively long periods of time researchers spend in talking to informants and observing actions; it may be difficult to secure repeated access, impeding successful, thorough data collection (Reeves et al., 2008).

In this research, a focused ethnographic approach was chosen to specifically consider the decision-making process at end-of-life in the context of Chinese culture for dialysis patients and their carers living in Hong Kong. It helped to identify the features of informants for common or diverse behaviours and experiences (Knoblauch, 2005; Morse, 2007). Based on the specific nature of the approach, the researcher might gain a better understanding of the complexities of the study issues from the 'emic' and 'etic' views (discussed further in 3.4 Emic and Etic; Atkinson et al., 2007; Robinson, 2013; Savage, 2006). The ethnographic approach can incorporate a range of quantitative and qualitative methods in the progress of the study (Savage, 2000). In this research, it helped in accessing beliefs and practices, to promote the understanding of patients' and carers' behaviour surrounding care preferences at the end-of-life. The descriptions, general ideas and beliefs of the informants were developed through surveys, focus group interviews and field notes, which created a triangulation of information relating to specific phenomena, and established rigour (Robinson, 2013). The survey data were the general life experiences of informants, subsequently clarified by the key informants in the ethnographic focus group interviews, with the aim of eliciting meaning.

Ethnography has been used by many researchers for the past few decades, their experiences could be learnt and adopted by the researcher of this study. Davis (1963, cited in Bloor, 2010) conducted an early ethnographic study of chronic illness (of child polio victims and their families). Various researchers have since studied pain and suffering, experience of illness, attitudes towards illness, communication and information management in the health care system (Savage, 2006; Savage, 2000; Streubert Speziale & Carpenter, 2003; Wilson et

al., 2009). It was valuable to look into dialysis patients' and carers' views on the experience of illness, decision-making process and health care delivery.

3.3 Culture Care Theory

The theory of culture care serves as the theoretical framework of the qualitative part of this study. Its founder, Madeleine Leininger, a nurse and anthropologist, began to develop an interest in studying culture and care in nursing when she encountered challenges in the care of mildly disturbed children from diverse cultural backgrounds in the US in the early 1950s. There was little published data relating to this issue at that time. She was the first nurse to recognise that nurses and other healthcare professionals failed to appreciate the role of culture in the healing process (McFarland & Wehbe-Alamah, 2015). Leininger (1988) identified culture and care as major dimensions missing in nursing and health care services. She applied knowledge of anthropology to enrich her experience of different cultures relating to caring (Chiu, 2000). Culture care theory was developed focusing specifically on nursing care and health. With further worldwide and in-depth study, Leininger proposed that such knowledge could greatly transform nursing and health care, in both education and practice, and serve as a sound basis for the new discipline of transcultural nursing (McFarland & Wehbe-Alamah, 2015). Through six decades of continual study and research, culture care theory has been established as a major nursing theory, providing transcultural care to people of diverse cultures (Farren, 2014; McFarland, Mixer, Wehbe-Alamah, & Burk, 2012).

In culture care theory, cultural-based factors are recognised as influences on human care expressions, beliefs and practices related to health, illness and wellbeing and nurses' thought, practice and research. Leininger (2006) postulated that human care is what makes people human, gives dignity to humans and inspires people to recover and help others. Further, while there could be no curing with caring, caring could exist with curing. Care has come to be viewed as meaningful, explicit and beneficial. It is a powerful and dynamic force

in understanding the completeness of human behaviour in the context of health and illness worldwide. Culture was viewed as the broadest, holistic and universal feature of human beings, and care was predicted to be embedded in culture, which might have to be teased out.

Leininger conceptualised and formulated four tenets in the development of the theory (McFarland & Wehbe-Alamah, 2015). The first major and central theoretical tenet was that care diversities (differences) and universalities (commonalities) existed in transcultural nursing knowledge (Leininger, 1997; Leininger & McFarland, 2002). These diversities and universalities of thoughts, opinions, attitudes and ways of spending life could be collected as well as analysed. The second major theoretical tenet was that worldview and social structure factors, such as religion, economics, education, technology, politics, kinship (social), ethnohistory, environment context, language and generic and professional care factors, would greatly influence cultural care meanings, expressions and patterns in different cultures (Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015). Cultural conflicts and gaps between professional renal and generic renal care were predicted to be a major concern for therapeutic culturally congruent care. The third major tenet is that both generic emic (folk) and etic (professional) health factors may affect health and illness outcomes. These three theoretical practice modes give rise to three major actions and decision guides for providing culturally congruent, safe and meaningful health care (McFarland & Wehbe-Alamah, 2015): culture care presentation and maintenance, culture care accommodation and negotiation and culture care restructuring and patterning (Leininger, 1988, 1995, 1997; McFarland & Wehbe-Alamah, 2015).

Culley (1996) states that cultural difference has been conceptualised in nursing dialogue using cultural framework tends to ignore some parts of the issues of race, ethnicity and health. She criticises knowledge of different cultures will improve the assumption of Leininger's model of care and services. It is necessary to recognise the ways where race,

socio-economic status, gender and age may overlap. There also has inequality in the structural and political aspects of the ethnic minority groups that are not given dominance in this culturalist approach. Instead, the approach negatively promotes the culture with the hazard of stereotype the minority (Salway, Higginbottom, & Miller, 2009). Even if healthcare professionals overcome stereotyping of the patients in cultural beliefs and practice, it may not change the racism and discrimination of the ethnic minority groups in the society (Josipovic, 2000). Mitchell, Gale, Matzo, McDonald, & Gadmer (2002) critiques on the 'magical use of culture' in the culture care theory leads the researchers having unintentional cultural essentialism or even stereotyping the beliefs and practices of cultural groups by focusing on differences among cultures. The generalisation may affect nurses paying adequate attention to the individual patient's value which may not correspond to the individual's cultural group (Rajan, 1995). Nurses should be aware of the potential limitations of the transcultural theory while applying in education and clinical practice. Some criticisms state transcultural nursing theory may impede nurses' ability to use their tenets to clinical practice (Mitchell et al., 2002).

In applying culture care theory, nurses benefit from broad and holistic dimensions, such as social structure factors, ethnohistory, genetics and religion. It understands that culture care is the synthesis of two major constructs, emic and etic, that guide the researcher to discover, explain and account for health, wellbeing, care expressions and other human conditions.

3.4 Emic and Etic

In ethnography, the distinction between emic and etic perspectives is similar to the intrinsic and extrinsic features of the particular culture of the study population (Hoare et al., 2012). Atkinson et al. (2007) stated:

> Emic is the ultimate goal of the identification of codes that are meaningful to members of the community. The etic perspective, codes meaningful to the analyst, is considered useful for initial data gathering as well as for cross-cultural comparison. (p. 288)

The emic approach is described as the 'insider' or 'inductive' perspectives and words of research informants that illustrate the particular features of culture from inside the group; the etic approach is portrayed as 'outsider' or 'deductive'—observing and reporting behaviour without the viewpoint of those being studied (Hoare et al., 2012; Morris, Leung, Ames, & Lickel, 1999; Olive, 2014).

During ethnographic interviews, the meanings or wordings of the informants might be discounted on the basis of inconsistency across various life experiences, beliefs and inherited misconceptions from cultural insiders. Sometimes, in this study, the researcher could not avoid his research lens in decoding reality, and measures were taken to prevent the researcher from inadvertently imposing his (etic) interpretation onto informant's (emic) interpretation (Yin, 2010).

Conversely, etic accounts based on survey data might be dismissed because the researcher remained at a distance from informants, potentially insensitive to how informants were affected by the questions (Morris et al., 1999). The differences between emic and etic perspectives are always present because of the researcher's value system, which ultimately guides the design, execution and reporting of a study (Yin, 2010). Therefore, the researcher should have sufficient self-awareness to guard against using the emic sense of self, so as to become a participant observer in his practice. In ethnographic research, the divergence between emic and etic perspectives is perceived to be an opportunity rather than a limitation (Olive, 2014). Agar (2011) stated emic and etic are not separate kinds of understandings; they are both parts of any understanding.

In this study, the balance of emic and etic was ensured using reflexive processes after each interview, with the field-note taker providing insights and clues for remodelling of research questions or applying more specialised research tools. Nevertheless, the final yield of the focus group interviews should be a comprehensive cultural portrait of the target population that incorporates the ideas or thoughts from the informants (emic) and the views of the researcher (etic) (Creswell, 2007). To achieve this, the researcher has to be cognisant that he is part of the social world under study. Reflexivity is an important issue that the researcher must bear in mind when enquiring, listening and recording during the study (Pereira de Melo, Sevilha Stofel, Gualda, & Antunes de Campos, 2014).

In addition, culture care theory describes care that has cultural and symbolic meaning, such as care as protection, care as respect and care as presence (McFarland & Wehbe-Alamah, 2015). These care linkages are essential to provide culture-specific care, and are often gender-linked. Similar to the definition of the emic and the etic in the ethnographic point of view, emic and etic care in culture care theory are specifically defined as follows. Generic (emic) care refers to the learned and transmitted way indigenous, traditional or local folk (emic) knowledge and practices provide assistive, supportive, enabling and facilitative acts for or towards others with evident or anticipated health needs to improve wellbeing or help with dying or other human conditions (Leininger, 1997; Leininger & McFarland, 2006: McFarland & Wehbe-Alamah, 2015). Professional (etic) nursing care refers to formal and explicit cognitively learned professional care knowledge and practices obtained through educational institutions (usually non-generic). They are taught to nurses and others to provide assistive, supportive or group acts, to improve health, prevent illness or help with dying or other human conditions (Leininger & McFarland, 2006).

The constructs emic and etic care are the major components of culture care theory. While researching, Leininger wanted to identify differences and similarities among and

between cultures and to differentiate the client's insider knowledge in contrast with the researcher's outsider or professional knowledge (Leininger, 1997; McFarland & Wehbe-Alamah, 2015). It was believed desirable to know what is universal (or common) and what is different (or diverse) among cultures with respect to care. Coincidently, the purpose of this study is to explore the decision-making process of dialysis patients and carers at the final stage of life, including commonality or diversity in views, ideas and thoughts, which could inform healthcare professionals regarding approaches to establishing care priorities. Further, findings can provide and balance the emic and etic views of professional knowledge. Consequently, it can help to alleviate the difficulties in initiating discussion and decision-making about the end-of-life process of dialysis patients and carers.

To offer a broader and deeper paradigm, ethnonursing research methods based on the theory of culture care diversity and universality were adopted to guide the study and collect in-depth ideas and needs of informants in the transcultural nursing phenomenon domain.

3.5 Ethnonursing Research Methods

The term ethnonursing derives from the Greek word ethos, which describes people or culture in the context of life history, and the word nursing, which reflects the current state of research focusing on nursing phenomena. Ethnonursing has evolved with the scientific and humanistic aspects of human care in the cultural context (Leininger & MacFarland, 2006; Lee, 2012), and helps to address informant needs and offers a culture-centred approach to discovering transcultural nursing phenomena from a qualitative perspective (Shapiro, Miller, & White, 2006).

The ethnonursing research method is a rigorous, systematic and in-depth method for studying multiple cultures and care factors in familiar environments (Farren, 2014; Hubbert, 2005; McFarland & Wehbe-Alamah, 2015). It focuses on the inter-relationships of care and culture to arrive at the goal of providing culturally congruent care services (Mixer,

McFarland, Andrews, & Strang, 2013). The ethnonursing method aids in addressing a gap in the literature between care and wellbeing (Farren, 2014). It was formulated to provide researchers investigating both macro and micro phenomena related to the researcher's stated domain of inquiry, with direct observation, participation, reflection and rechecking the informants used to understand the researcher's experience (Burkett & Morris, 2015). Further discussion and application of the ethnonursing research method is provided in the methodology and methods chapter.

3.6 Summary

In summary, the researcher adopted an ethnographic approach as the fundamental basis to guide this study. Amidst different approaches, focused ethnography, together with ethnonursing as the research method, were chosen to investigate fields specific to dialysis patients and carers, which might be socially and culturally differentiated and fragmented. In addition, Leininger's culture care theory, derived from ethnonursing, was used as the theoretical framework. Through the application of the theory, nurses benefit from the broad and holistic dimension. The two major ethnographic constructs—emic and etic—helped to guide the researcher to discover, explain and account for the illness and care priorities of dialysis patients at end-of-life. It also assisted to identify commonalities or diversity in their views, ideas and thoughts that could inform healthcare professionals regarding the approaches to establishing care priorities. Likewise, the ethnonursing research method is a naturalistic, inductive and qualitative research process mostly designed to guide the study of culture care meanings. With the groundwork of the culture care theory as the theoretical framework, the researcher was able to explore the decision-making process of the studied population holistically, and importantly, taking into account cultural aspects.

Chapter 4: Methods

4.1 Introduction

The primary aim of this study is to explore the decision-making process of dialysis patients and their carers regarding end-of-life care. This study also aims to explore the effects of culture on communication about the decision-making process, to learn more about a previously hidden topic in Hong Kong. Knowledge about the decision-making process was acquired through ethnographic methods. First, the mixed methods sequential explanatory study design, aimed at collecting broader and in-depth findings from the target population, is discussed. In the quantitative phase, a survey with close-ended questions was conducted with both the dialysis patient and carer groups. The findings were then analysed and used to guide the qualitative component of the study; specifically, the questions to be asked during the focus group interviews.

The second part of the chapter details the methods selected to conduct this study. The features of the ethnonursing research method are outlined. As this study uses qualitative-driven mixed methods design, ethnonursing research methods helped to identify the domain of inquiry, formulate the research questions, review the literature to identify gaps related to the domain of inquiry, develop the research plan and method of data analysis, adopt various enablers to guide the research process, and finally, synthesise themes to inform practice. Further, research integrity, including validity, generalisability and trustworthiness, are discussed, so that such findings can be transformed to interventions applying to the target population, guiding the practice of healthcare professionals in the renal domain.

4.2 Mixed Methods Sequential Explanatory Design

A good study design not only assists the researcher to set out the flow of the study but directs readers as they progress through, and increases understanding of the topic (Fetters, Curry, & Creswell, 2013). A mixed methods sequential explanatory design was used to guide

the quantitative and qualitative phases of this study, to provide a better illustration of the domain of inquiry.

The mixed methods sequential explanatory design is characterised by an initial quantitative phase, followed by a qualitative phase (Creswell & Plano-Clark, 2011; Ivankova, 2006). The two phases are connected in the intermediate stage of the study (Andrew & Halcomb, 2009; Doyle, Brady, & Byrne, 2009). The design starts with the collection and analysis of the quantitative data that addresses the research questions. The content of questions in the subsequent qualitative phase of the study is derived from the findings of the quantitative phase (Creswell & Plano-Clark, 2011; Creswell, Plano-Clark, Gutmann, & Hanson, 2003; Fetters, Curry, & Creswell, 2013; Ivankova, 2006). The purpose of this design is that the quantitative data and findings provide a general understanding of the research question, while the qualitative data and analysis refine and explain the quantitative findings, exploring informants' views at a deeper level (Creswell & Plano-Clark, 2011; Creswell et al., 2003). Fetters et al. (2013) argued that the sequential explanatory design is the most straightforward of the mixed methods designs.

Mixed methods design is used to explore the complexity of the phenomena observed and experienced during the research. Mixed methods research involves the integration of quantitative and qualitative approaches to generate new knowledge in a single study or a multi-phased study (Creswell & Plano-Clark, 2011; Tashakkori & Teddlie, 1998). It has become increasingly popular over the last 25 years, as some social scientists recognised difficulties with linking worldview or epistemology to a specific quantitative or qualitative method. Mixed methods has been formulated to develop valid research by combining different methods to collect and analyse a mix of quantitative and qualitative data in the same study. Methodologists such as Creswell (2007) argue that combining the two approaches can provide a better understanding of research problems than a single approach. Further, the

research questions can be broad and complex, with multiple aspects explored (Creswell, 2007; Tariq & Woodman, 2013). Mixed methods design has the potential to balance the strengths and weaknesses in the quantitative and qualitative approaches while addressing multifaceted issues, especially in patients living with chronic illness (Stange, Crabtree, & Miller, 2006; Tariq & Woodman, 2013). While quantitative research data include closed-ended results that show in attitudes, behaviours or performance instruments, qualitative research data consist of open-ended information gathered from participants during interviews that allows participants to express their ideas, opinions or feelings in their own words. In addition, qualitative data can also be collected by participant observation or gathering documents from various sources (Andrew & Halcomb, 2009; Meetoo & Temple, 2003).

Phase A of the study was conducted using a quantitative survey including closed-ended information. From the researcher's practice experience, the phrase 'care priorities at final stage of life' was quite strange and scary to most of the Chinese patients and carers he encountered in the dialysis population. The survey provided an opportunity to orient informants to the focus of the study while providing necessary information. They could complete the survey in their own time and with privacy to allay tension, and consider if they wanted to accept the invitation to participate in a more in-depth exploration of end-of-life care preferences in a focus group with other patients and carers. Throughout the focus group interviews, a set of open-ended questions was established, based on the findings from the survey and guided by Leininger's semi-structured inquiry guide enabler. Informants in the focus groups responded to open-ended questions and raised quite different issues to those provided during the survey. The qualitative data from focus groups generated different information, reflecting common versus diverse views that prepared people to deal with more sensitive issues during the interviews (Archibald, Radil, Zhang, & Hanson, 2015; Buber, Gadner, & Richards, 2004). In summary, to attain the benefits of collecting the quantitative

attitudes, thoughts and behaviours of the informants together with the emic ideas, opinions and feeling, the mixed methods design was adopted to enrich the findings of the study.

4.3 Applying the Ethnonursing Research Method

Ethnonursing developed as a qualitative nursing research method, focused on naturalistic, encountering and largely inductive (emic) modes and processes with diverse strategies, techniques and enabling guides to document, describe, explain and interpret informants' worldview, meanings, experiences, symbols, life experiences and other related aspects (Lee, 2012; Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015).

Ethnonursing research methods are popular among transcultural nurse researchers (Burkett & Morris, 2015; Honda & Hohashi, 2015; Hubbert, 2005). The findings were in line with the assertions of Leininger's (1997) culture care theory, by sustaining a body of knowledge regarding cultural perspectives to clarify etic and emic phenomena in the context of health and illness. Hubbert (2005) applied the ethnonursing method to explore the subculture of adults residing in a Christian, midwestern urban homeless shelter. Two types of informants—key (nine shelter residents) and general (20 shelter staff and volunteers)—were recruited to the study. Enablers such as observation-participation-reflection and stranger-trusted-friend were utilised to collect relevant data based on the rationale of convenience sampling. The researcher made use of the enablers to reach beyond the protective shield of the shelter residents, as they tended to hide their beliefs and be reluctant to share with the stranger. However, on becoming a trusted friend, the researcher was able to obtain authentic, credible and dependable data from the informants. This is an effective way for the researcher to expand the usability of findings. As the study population might not be Christian, it could incorporate knowledge of the religions applying to a similar population.

Tasci-Duran and Sevil (2013) used the ethnonursing method to uncover women's health behaviours during the prenatal period in Bornova District, Izmir. Eighteen informants

were recruited via the convenience sampling method. The data collection strategy consisted of an information form and a semi-structured interview. Leininger's six steps of thematic and category analysis was adopted, to illustrate the concept of family power and patriarchal effect in the medical decision-making process. The findings were similar to those of the Chinese culture domain. Burkett and Morris (2015) illustrated the use of the ethnonursing method to enable trust in research with culturally diverse informants. Several common enablers were adopted, for example, the sunrise enabler, the study gatekeeper enabler, and the observation-participation-reflection and stranger-trusted-friend enablers, which enriched the trustful relationships between the researchers and urban African-American families. Reliability of the findings was ensured by the rigour employed in data collection and analysis.

Honda and Hohashi (2015) performed a cultural phenomenon study on the internal and external familial environment and support needs of Japanese families on temporary work assignments in the US using mixed methods with an ethnonursing approach. The researcher discovered that there was a tendency for most data to be collected from just one member of the family, the eldest male or breadwinner, which, although a common cultural practice, made it difficult for the researchers to evaluate the family as a system. Lee and Hohashi used the observation-participation-reflection enabler and ethnographic interviews to collect qualitative data. Validity and reliability were checked by re-interviewing 10 families. The participants of this study had experiences in living abroad and were receptive to foreign culture—findings may have been different if the participants had been new immigrants.

The above examples demonstrate the benefit of using the ethnonursing qualitative method with the theoretical framework of the culture care model. With guidance from the enablers, emic knowledge and information was obtained from the cultural domain in each of the studies. However, not many researchers described how they managed their pre-assumptions and interpretations during the data collection process—the reports did not

provide all the processes involved in ethnonursing methods clearly, and novice researchers might find it difficult to follow when conducting similar studies. Hubbert (2005), Tasci-Duran and Sevil (2013) and Honda & Hohashi (2015) did not explicitly state what prevented the researchers from using the emic sense of self while acting as participant observers in the data collection process. When these processes are not reported, it is difficult to know if and how reflexivity and credibility are affected. Based on the experiences of the above studies, this study attempted to implement the major steps of and draw guidance from the ethnonursing research method.

Hong Kong's population is comprised of people from Eastern and Western cultures. The researcher should be alert to the high level of internal diversity, which may influence end-of-life care decision-making among subcultures in Chinese people living in Hong Kong. Particularly, the attitudes and beliefs related to death and dying are often culturally based (Wilson et al., 2009). The researcher adopted Leininger's (2006) five steps in the research method for this study, to ensure that possible diversities were identified in the study participants.

The first step is to identify the domain of inquiry as the major focus of this study and formulate research questions. As stated in culture care theory, the domain of inquiry should be a clear and concise statement reflecting the nursing care phenomena to be studied (Imes, 2005). The research focus statement was set as follows:

> *To explore the decisions about care priorities at the final stage of life of renal dialysis patients and their carers in Hong Kong.*

As the purpose of this research is to identify and understand the central influences on the decision-making process, including the role of culture, the research questions derived from the domain of inquiry were:

1. Who should participate in the end-of-life discussion?

2. What should be discussed during the decision-making process?
3. How should decisions be made?

The second step is reviewing the literature to identify gaps related to the domain of inquiry. The third is to develop the research plan and method of data analysis, and the fourth is to choose and adopt enablers—here, the stranger-trust-friend, Leininger's semi-structured inquiry guide and phases of ethnonursing data analysis enablers—to assist and guide the research processes regarding the domain of inquiry.

Finally, deep analysis over the synthesis and interpretations was performed. Interview and field data were collected and described, categorised and then analysed for care categories and contexts, leading to the development of major care themes (McFarland & Wehbe-Alamah, 2015; Mixer et al., 2013).

Leininger's ethnonursing methods provide researchers with a number of guides termed enablers (McFarland & Wehbe-Alamah, 2015). The guides most useful in this study were the stranger-trust-friend, Leininger's semi-structured inquiry guide and the phases of ethnonursing qualitative data analysis enabler; the next section addresses each in turn. These enablers assist the researcher to identify emic findings and deliver culturally congruent, sensitive, meaningful care to dialysis patients and carers (McFarland & Wehbe-Alamah, 2015). Enablers provide a good foundation and guide for the culture care experiences of culturally diverse (or similar) cultures, subcultures and groups (Burkett & Morris, 2015; Hubbert, 2005). They provide strategies to support the researcher to gain access to and learn from informants, and about their perceptions and expectations of care at the final stage of life (Leininger & McFarland, 2002).

4.3.1 Stranger-trust-friend enabler (stranger-friend enabler)

The stranger-trust-friend enabler is one of the earliest enablers developed by Leininger and has been used often during data collection. It helps the researcher to move

from a stranger to a friend role. The enabler also assists in gaining trust from informants and moving forward to in-depth interviews for the discovering of nursing phenomena (Burkett & Morris, 2015; Leininger, 1997; Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015). The stranger-trust-friend enabler is used as an assessment or reflection guide for the researcher, so that the researcher is aware of informants' behaviour, feelings and responses during the data collection process (Burkett & Morris, 2015). When applying the stranger-trust-friend enabler in both hospital settings and the community context, it can serve as a powerful means of self-disclosure, self-reflection and assessment, so as to provide high reliability and confirmability with informants. The entrusted researcher, using the ethnonursing research process, is able to obtain truthful, sensitive, meaningful and credible data (McFarland & Wehbe-Alamah, 2015). For studies with a special interest in cultural impacts (such as this study), informants typically regard the researcher as an etic stranger (outsider) until proven otherwise, and are often reluctant to express their ideas to the researcher; consequently, the data collected are superficial, inaccurate and incomplete (Burkett & Morris, 2015; Leininger & McFarland, 2006).

When the researcher used the stranger-trust-friend enabler in this study, he engaged and participated in activities with potential participants to build up trust; for example, paying visits to the haemodialysis dialysis centre, attending a sport day activity, joining the self-help group annual dinner and taking part in outings. At those activities, sharing of ideas and viewpoints assisted in showing the researcher's sincere interest in their specific group and expressing a respectful presence. Some of the potential informants were inactive because of the nature of their disease, physical immobility or deteriorating health, and did not attend these activities, except for treatment at the dialysis centre. With this group of potential informants, the researcher did not have the opportunity to share informal time. As a

recruitment strategy, gatekeepers were invited to promote the study, substantiate the trustworthiness of the researcher and invite participation.

A study gatekeeper, in the ethnonursing research method context, is a person well known to study informants; often, a key person who understands the common language, patterns of behaviour and attitudes of the cultural group (Burkett & Morris, 2015; Leininger & McFarland, 2002). The president of the renal patient self-help group and the nurse consultant working in the dialysis centre were invited to be the gatekeepers of this study. They played an important role by providing information about the study and the researcher to potential participants who were unable to join other information opportunities. They also aided the researcher to gain trust and entrance into the target recruitment group.

4.3.2 Leininger's semi-structured inquiry guide enabler

The purpose of the Leininger's semi-structured inquiry guide enabler is to assist the researcher to enter in the world of the informants and find information to provide holistic, culture-specific care. First, the researcher should use broad and open inquiry instead of direct confrontation, to help the informant feel comfortable in answering in a natural manner. This kind of guide focuses on the individual rather than the community. Open-ended questions were developed for the domain of inquiry while using this enabler. The semi-structured, open-ended questions in the interview guides for both dialysis patients (Appendix B) and carers (Appendix C) were designed to elicit more information than closed-ended questions during interviews. When asking questions based on the domain of inquiry, informants are encouraged to share stories and life experiences which not only enabled the status of the researcher to move from stranger to trusted friend (Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015), but collected relevant data in an effective and systematic way.

4.3.3 Leininger's phases of ethnonursing data analysis enabler

The Leininger's phases of ethnonursing data analysis enabler (Appendix D) was developed and modified to facilitate the research process in providing rigorous, in-depth and systematic analysis of qualitative data; it is particularly helpful for findings derived from the ethnonursing research method (Leininger, 1995). The phases of ethnonursing data analysis enabler has four phases of analysis. It begins with the researcher commencing analysis of the data on the first day and continuing to do so until data saturation is reached. In the first phase, raw data are collected, described and documented by the researcher, based on the domain of inquiry and research questions asked in the study (Morris, 2012). The researcher interprets the focus group interview data from key informants. In the second phase, while the researcher is listening to the audio recordings, relevant data are identified and coded, with reference to the purpose of carrying out the study and the research questions. Emic and etic descriptors (codes) are separated into the components of similarities and differences from the dialysis patient and carer viewpoint. The third phase describes the categories and contextual analysis. The findings from the focus group interviews are assessed and analysed for saturation or recurrent categories of similar or different expressions, meanings and interpretation related to the domain of inquiry. This process enhances meaning-in-context, credibility and confirmability of the findings. In phase four, the highest level of data analysis, themes are developed to reflect the findings relating to contextual factors and cultural interpretations originating from the informants. Finally, interpretations from the key informants towards the diverse themes and universalities are identified. Importantly, each phase of Leininger's phases of ethnonursing data analysis builds on and supports the previous phases, to establish accurate, fruitful and meaningful findings.

In this present study, both quantitative and qualitative data were collected independently in sequence and analysed to answer the research questions. This design offers

a unique opportunity to support the qualitative data from the informants' emic view that was partly derived from the quantitative data.

4.4 Setting

Preparatory meetings were held twice: once for the renal staff, including physicians, nurses and the medical social worker, and once for the nursing staff at the dialysis clinic. Ethics approvals from the University of New England (approval number: HE12-085, see Appendix E) and the ethics committee of the study hospital (approval number: HKEC-2012-048, see Appendix F) were granted prior to data collection. During the meetings, the purposes and procedures of the research study were explained. The logistics of the data collection process were shared and discussed with the dialysis centre and clinic staff. Not only was cooperation gained, but suggestions were taken from clinic staff about the flow of recruiting informants smoothly in the clinic.

In practicing renal nursing for more than a decade in Hong Kong and Australia, the researcher observed ethnographically significant cultural behaviour and interactions from dialysis patients and carers when they encountered life and death issues. The researcher experienced the regular categories and routines of the target population in responding to these difficult physical, psychological, social and spiritual situations. In this study, the researcher played the role of a learner to collect in-depth data from the informants' perspective. In fact, the biggest challenge was that the researcher had to balance between getting too close to the informants and maintaining a suitable distance. This goes to the core of balancing emic and etic approaches in studying human beings from the ethnographic aspect (McFarland & Wehbe-Alamah, 2015).

This study was conducted in the dialysis clinic, renal ward and renal dialysis centre of a regional hospital in Hong Kong. The hospital is situated in a densely populated area, serving low to middle-high socioeconomic class residents. Comprehensive medical service

coverage offered residents convenient consultations when needed. The dialysis clinic was in a separate block from the main hospital compound, while the renal ward and dialysis centre were in the same block. The majority of the medical and nursing staff working in the ward and dialysis centre were renal trained. All were born in Hong Kong, and had received medical or nursing training locally. When patients were diagnosed with end-stage renal disease, they were admitted through the emergency department or dialysis clinic for continuation of care. A pre-dialysis education programme was offered and they could choose to accept renal replacement therapy, such as peritoneal dialysis or haemodialysis, and wait for renal transplantation if their general health status was suitable. There was a group of patients who had not yet accepted their diagnosis of end-stage disease and were not willing to attend the pre-dialysis education session. Other patients declined renal replacement therapy and chose instead to join renal palliative care. In such cases, the lifespan of the patients is limited and this period provided an opportunity for healthcare professionals to introduce end-of-life care discussions. For patients who adopted dialysis therapy, arrangements were made for them to attend follow-up sessions every Tuesday for in-centre haemodialysis and Wednesday for ambulatory peritoneal dialysis on discharge. They were either advised to attend the nurse clinic or follow up in the ordinary clinic, depending on the specific services they required. Patients were seen at 4–8-week intervals for normative follow ups.

4.5 Sampling

Sampling is an important element in research design, especially in the context of culturally sensitive topics (George, 2002). Convenience sampling is adopted in this study. It is a nonprobability or nonrandom sampling where members of the target population that meet specific practical criteria, such as easy accessibility, affordable, geographical proximity, availability at a given time, or the willingness to participate are included for the study (Polit & Beck, 2012). Convenience sampling methods emphasise on the generalizability to ensure

that the knowledge gained is representative of the population from which the sample was drawn (Etikan, Musa, & Alkassim, 2016). Upon using the sampling method, Leiner (2014) stated that it is essential for the researcher to describe how the sample would differ from the one that was randomly selected. It is also necessary to explain the subjects who might be excluded during the selection process or the subjects who are overrepresented in the sample. The primary assumption associated with convenience sampling is that the members of the target population are homogeneous, that is, there would be no difference in the research results obtained from a random sample, a nearby sample, or a co-operative sample (Etikan, Musa, & Alkassim, 2016). Convenience sampling technique applies to both qualitative and quantitative studies although it is most frequently used in quantitative studies while purposive sampling is typically used in qualitative studies (Haslam & McGarty, 2014; Polit & Beck, 2012). Therefore, it is more appropriate to apply the convenience sampling in this mixed methods design research.

Haslam & McGarty (2014) expressed that the convenience sampling should not be taken to be representative of the population; the problem of outliers is also the disadvantage of it which are cases who consider as not belonging to the data. The effect of outliers can be more devastating in convenience sampling subject selection. The researcher does not know how well a convenience sample will represent the population regarding the traits or mechanism under research. In convenience sampling, the informants selected by the researcher may not apply to the research problem. Hence, there is a risk of collecting poor quality data due to poor research outcomes and as such, difficult to convince others to accept the findings of research based on poor foundation (Oppong, 2013; Tashakkori & Teddlie, 2003).

As the ethnonursing approach aims to provide in-depth and global insights into informants' views and actions through observations and interviews, a broad background in

informants can enhance the knowledge and understanding of the cultural context of the study (Haslam & McGarty, 2014; Lee, 2012; Polit & Beck, 2012). Therefore, the researcher adopted convenience sampling of homogenous informants for both the quantitative (Phase A) and qualitative (Phase B) phases. Since this sampling method let the researcher choose informants within the same disease group and similar treatment modality, it was required that the researcher consider critically the parameters of the target population and choose sample informants on this basis (Silverman, 2011).

4.5.1 Selection of informants

A population of 381 dialysis patients was registered for dialysis care at the regional dialysis centre. The renal physician in charge of the dialysis centre and his delegates helped to screen the potential informants according to the inclusion and exclusion criteria of the study. Based on their clinical judgment, 43 patients were excluded from the study because of cognitive issues, severe stroke and depression. Using the information provided by the renal physicians, the researcher briefed potential informants at clinics, the dialysis centre and the renal ward. The researcher gave a five-minute presentation to patients and their families and carers, describing the research and outlining what would be expected of people who chose to participate. Information sheets in both English and Chinese (see Appendices G and H) with details of the research and the researcher's contact details were provided before signing the consent forms (English version: Appendix I; Chinese version: Appendix J). The selection of informants was based on the inclusion and exclusion criteria.

The inclusion criteria included the following factors:

1. Renal dialysis patients and their carers who were willing to participate in the study.
2. Dialysis patients who were cognitively intact and mentally competent to participate, as assessed by the physician in charge of the dialysis centre.

3. Dialysis patients who were physically well enough to participate, as assessed by the physician in charge of the dialysis centre.
4. Dialysis patients and their carers who were fluent in speaking and listening in Cantonese or English and who were able to read and write in Chinese or English.

The exclusion criteria included the following factors:

1. Dialysis patients and their carers who had impaired eyesight, and/or listening and speaking difficulties.
2. Dialysis patients and their carers under 18 years of age.

Throughout the preparatory meetings with the ward and clinic staff, it became clear that the majority of informant recruitments could be carried out at the dialysis clinic. This area was staffed by general nurses and other supporting staff who had no or limited knowledge about the special characteristics and behaviour of the dialysis patients frequenting the clinic. The ward and clinic staff had their own responsibilities and duties, and therefore, the researcher could not rely on them for the recruitment procedure. As it was normal for patients to wait hours to see doctors for very short consults (rarely more than several minutes), the researcher made use of this waiting time to recruit informants. With an assistant, the researcher visited the dialysis clinic during clinic days every Tuesday and Wednesday from December 2013 to April 2014. Renal physicians made notes in the patients' folder if they were not suitable for the study based on the inclusion and exclusion criteria. All potential informants, both dialysis patients and carers, received a five-minute introduction about the study before information sheets were given and consent forms signed.

In addition to recruiting informants in the dialysis clinic, the researcher visited the haemodialysis centre and dialysis ward to introduce the study. There were two sessions (morning and afternoon) of in-centre haemodialysis each day, from Monday to Saturday (no service on Sunday). Some 16–18 patients were dialysed in the morning and 10–12 in the

afternoon. During the dialysis centre visits, the researcher identified that most patients dialysed in the afternoon belonged to the critically ill category. They were excluded from the potential informant list. Patients usually had dialysis two or three times a week; therefore, the researcher visited the dialysis centre from Monday to Wednesday, all day, implying all in-centre haemodialysis patients would be visited and invited to participate in the research. When dialysis patients suffered from any dialysis-related complication or other comorbid disease, they were admitted to the renal ward for speciality care, since the majority of the physicians and nurses there were renal trained. However, not many patients could be recruited from this unit because of the severity of their illness.

To increase the recruitment rate, the researcher invited the president of the renal patient self-help group to be the gatekeeper. This helped significantly, since patients and carers could be introduced to the nature of the study while they were attending activities organised by the self-help group, for example the workshop ‘Working with dialysis’, the annual picnic and the end-of-year dinner. If there were any potential informants, the researcher took follow-up actions. To start the recruitment process, the researcher would approach whoever showed interest. Informants from the carer group were mostly recruited from the social activities and at the clinic where they accompanied the patients for the follow up.

As noted in the consent form, the patient and carer informants were asked whether they would like to join the focus group interviews (Phase B study). In addition, the researcher invited the potential key informants to participate in the focus group interviews when they returned the survey questionnaires. As the initial response rate to the Phase B study was low, further measures were employed to recruit more key informants. First, the researcher took the renal ward and haemodialysis centre rounds for a week. During this time, he talked with potential recruits about the study and answered questions they had about participating in a

focus group interview. Second, the researcher invited key carer informants when they were in the wards and dialysis centre. Third, the president of the renal patient self-help group, who served as a gatekeeper for the study, was contacted and willingly agreed to promote the study, in particular, Phase B, to potential informants. She was able to address questions and offer assurances of the researcher's integrity.

4.5.2 Sample size

During the recruitment phase, a target sample of 338 dialysis patients was identified and approached in the recruitment areas of the health service. Some 121 dialysis patients and 61 carers agreed to participate in the quantitative survey (Phase A) study and were asked to complete a self-administered questionnaire after signing the consent form. The response rate of the patient group was 35.8%; the non-responsive sample was affected by the controversial and, for many Chinese, culturally taboo nature of the study topic. In contrast, the response rate of the carers could not be calculated since there was no data on their population size in the centre. Estimation of the sample size was difficult and unfeasible to ascertain with the resources available to the researcher.

Following completion of the quantitative survey, patient and carer informants who were willing to participate in Phase B of the study were invited to join a 60–90-minute focus group interview. Normally, samples for qualitative studies are much smaller than those used in quantitative studies; frequencies are rarely important in qualitative research, as one occurrence of the data is potentially as useful as many in understanding the process behind a topic. This is because qualitative research is concerned with meaning and not generalised hypothesis statements (Crouch & McKenzie, 2006). A subsample of 24 patients in four focus groups and 14 carers in three focus groups who were categorised as key informants agreed to participate in focus group interviews (Phase B). One carer group comprised maid-carers. In addition, as stated by Cooksey and McDonald (2011), Francis et al. (2010) and Mason

(2010), sample size in the majority of qualitative studies should generally follow the concept of saturation, one of the principles of qualitative research. Morse (2000) suggested 30–50 interviews for ethnographic studies as guidance. In contrast, Atran, Medin and Ross (2005) suggested that in studies involving cultural context, especially when sensitive topics were investigated, as few as 10 informants were sufficient to achieve reliability and consensus. There are other factors that affect sample size in qualitative studies, and researchers generally use saturation as a guiding principle during data collection. Lee, Woo & MacKenzie (2002) suggested that studies using more than one method require fewer participants, as do studies that use multiple in-depth interviews with the same participant. Although the idea of saturation was helpful at the conceptual level, it provided little practical guidance for estimating sample size for strengthening the research prior to data collection.

4.6 Data Collection

The research was divided into two stages. Phase A of the study used a survey questionnaire with the majority of the questions being derived from a study by Davison (2010); with permission from Dr. Davison (Appendix S). Its use in this study dialysis patient could either choose English or Chinese version (Appendix K & Appendix L) and carers (Appendix M & Appendix N), including demographic questions, followed by structured questions on knowledge pursue and decision-making regarding care priorities at final stage of life. Some of the questions allowed informants to choose multiple answers. Carers were encouraged to call on their experience of caring and also to try to empathise with the patients' position while completing the survey. They were able to select all responses that applied to multiple choice questions. The presentation of results shows this to be the case. A preliminary understanding of the viewpoints of informants was noted through the analysis of the survey data. Commonalities and differences from informants were illustrated and assisted the researcher to set the questions in the focus group interviews. Focus group interviews

based on the ethnonursing method were performed in Phase B, to explore emic data from key informants related to the study topic.

4.6.1 Phase A: Development of the survey questionnaire

Survey development was based on the Davison (2010) design, with further adoption of the elements from Bowman and Singer (2001) and Chan and Pang (2007). Examples of Davison's (2010) self-reported knowledge questions include 'How informed are you in regards to your medical condition and how your medical condition will change over time?', 'How do you see your health in the next 12 months?' and 'Do you know what palliative care is?'

The following questions were asked regarding end-of-life care preferences (Davison, 2010):

- If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions about your medical care for you? (Multiple choice)
- How do you normally get information that will help you make a personal decision regarding your health/wellbeing? (Multiple choice)
- How comfortable are you in discussing end-of-life issues with family members? (Scored on a 5-point Likert scale, very uncomfortable to very comfortable)
- Has your doctor talked to you about how much time you have to live? (Yes/No)
- During the past 12 months, have you had a discussion with any of the following people about your choices concerning end of your life care? (Multiple choice)

'How would the end-of-life decisions be made?' and 'Who should be involved in this decision?' were selected from Bowman and Singer (2001). Other survey questions were added from Chan and Pang (2007). The English version of the survey was given to two renal physicians and three senior renal nurses to assess for face validity. It was then translated into Chinese. The content validity of the survey was assessed by two people: a senior renal nurse

and a secondary school teacher who was teaching English and whose first language was Chinese.

4.6.2 Phase B: Development of focus group interview schedule

Since this research study uses a qualitative-driven mixed methods design, a set of open-ended questions was derived from the findings of the survey, under the guidance of Leininger's semi-structured inquiry guide enabler, informed by Leininger's culture care theory. Starting from inquiring about the worldview towards the study topic, questions related to kinship, cultural values and beliefs, educational factors, communication factors and specific nursing care factors were included. In-depth questions were based on the findings of self-reported knowledge and end-of-life care preferences, with reference to Chan and Pang (2007). Examples of questions asked in the focus group interviews include the following:

- Could you please tell us about your feelings coming back to discuss this topic?
- How do you feel when you discuss end-of-life issues with somebody?
- If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your behalf? Why?
- Who should initiate the discussion on end-of-life care?
- Who should participate in the discussion?
- What should be discussed in the decision-making process?
- Would you like to make an advance directive if it is available?

Emic data and additional insights of dialysis patients and carers on the decision-making process about end-of-life care priorities were collected.

Renal dialysis patients and their carers who were willing to join the focus groups after completing the Phase A survey were invited to participate in 60–90-minute focus group interviews. These interviews were performed in a separate area in the patient resource centre in the hospital. It was a quieter space, away from the busyness of the renal ward, dialysis

centre and clinic. Informants felt familiar with the venue since they received pre-dialysis education and ongoing education activities there. To end each interview session, debriefing was provided to informants regarding any query or follow-up question; for example, informants asked why they had the disease, what diet they should adhere to and what exercises they should or should not do. Key to this research was their request for more knowledge about advanced directives.

4.6.2.1 Advantages of focus group interviews

Focus groups have been widely used, especially in examining experiences of diseases and health services. These groups exploit group interaction and allows informants to ask each other questions, exchange anecdotes and comment on ideas and perspectives (Curtis & Redmond, 2007; Tong et al., 2009). Krueger (1994) argued that focus group interviews look into human being's attitudes, concepts and perceptions through interaction with other people towards the developed services or programmes. The interaction within a group provokes rich experiential data (Asbury, 1995). Focus groups are well suited for qualitative studies, including grounded theory, ethnography and phenomenology (Webb & Doman, 2008). They provide an environment in which informants are encouraged to reflect on and express their views, yet maintain distance from considering the issues in relation to their own events, if necessary, which can particularly be the case with topics of a sensitive and complex nature (Barnes, Jones, Tookman & King, 2007). In addition, it is appropriate to use focus groups with Chinese populations because it is a useful way to support people to manage cultural reluctance or hesitancy to share attitudes, opinions and perceptions on, for example, end-of-life issues.

The focus group interview approach is commonly used to learn about cultures and cultural contexts, and to study the social interactions, behaviours and perceptions that occur within groups, organisations and communities (Leininger & McFarland, 2002). It often

provides theoretical insights into the cultural variables of the target population, and generates rich data, in this case, to reflect broadly the perspectives of the dialysis patient and carer population (Lane, McKenna, Ryan, & Fleming, 2001). The size of focus groups is generally between four and 12 participants, with between five and 10 participants considered optimal (Curtis & Redman, 2007; Kroll, Barbour & Harris, 2007; Shaha, Wenzel, & Hill, 2011). Data obtained from repeating focus group interviews with a range of participants can provide more useful information, enriching the quality of the data. The focus group approach generates common and diverse information, reflecting public versus private views, and better deals with sensitive issues (Archibald et al., 2015; Buber et al., 2004).

The interview guide was based on the semi-structured inquiry guide enabler of the ethnonursing approach, including leading of the interviews, decisions on the follow-up questions, allocation of time to asking and responding to questions, and the impact of the experience (Curtis & Redmond, 2007; Packer-Muti, 2010). Focus group interviews were repeated with a range of informants to provide a richer quality of data. Data saturation was used as a guide for the appropriate focus group sample sizes (Cooksey & McDonald, 2011).

4.6.2.2 Disadvantages of focus group interviews

There is a potential for focus groups to be dominated by a small number of (or even a single) vocal or dominant informants, which might hinder the outcomes of the study (Webb & Doman, 2008). For a focus group interview to be a disclosing of belief, the conversation must flow naturally, to reveal what the informants are thinking. Individuals have different characters, including being active or passive, and inevitable, some informants will be more dominant in the focus groups. Outspoken informants might skew the results, or a single persuasive participant might cause other participants to change their original opinions. In this study, two patients and one carer expressed their psycho-emotional concern about the nature of the end-stage renal disease and dialysis life. While this is an important issue, it was not a

focus for this study. Their conversations distracted and diverted the flow of the interviews. To avoid these problems, the researcher re-directed the flow back to the theme of the focus groups and tried to involve everyone, to ensure all informants had equal time and that all points of view were heard. The psycho-emotional issues were dealt with in the debriefing period. Technically, recording data could present difficulties. It was sometimes not possible to record when many informants were speaking at the same time; only those closest to the digital recorder were recorded. Moreover, little attention has been paid to factors, for example, power differentials between informants or the sensitive nature of the issue under investigation, that might limit the extent to which informants are prepared to disclose information (Happell, 2007).

4.6.3 The reflective journal in data collection

Although the researcher had previously worked in the dialysis clinic, renal ward and haemodialysis centre, the familiarity gained through that experience was not sufficient to manage the recruitment process or to conduct the survey data collection smoothly. Events did not unfold as the researcher expected. Several modifications and refinements were made while recruiting informants and collecting data. Reflections were recorded on these experiences, across three areas: the waiting hall of the dialysis clinic, the renal ward and the haemodialysis centre.

4.6.3.1 Waiting hall of the dialysis clinic

The recruitment of informants and collection of survey data commenced in the waiting hall on the scheduled Tuesday and Wednesday mornings. The researcher called for the attention of the patients and carers every half hour, before explaining the details of the research study. There were not many attractions on offer for the public in the waiting hall. Alternatively, the researcher approached individual patients or carers for recruitment after the five-minute presentation. Reactions from potential informants were often quite extreme, from

no response, to hesitation, and at times, even agitation. It was discouraging, and suggested that the researcher should modify the skills and technique of recruitment. Nevertheless, there could be many factors affecting the reactions from patients and carers after finishing a session of data collection. The disease contributed to the overall weakness and malaise of the patient informants, leading to no response. As the Chinese tend to be preservative, individuals tend not to express their mindsets, ideas and beliefs to strangers or in public. They hesitate to talk or communicate until they become familiar with the environment and personnel. As the data collection period fell on the weeks before and after Lunar New Year, patients and carers showed more hesitation about participating in the study because of the sensitive, taboo topic: potential informants might think they would attract bad luck if they joined the study at this special time of year.

The environment of the waiting hall was crowded, noisy and distracting. Announcements from the microphone and chats among the attendants drew the attention of potential informants. The researcher was unable to do anything, and the situation worsened, which affected his confidence level and made him question the value of continuing the recruitment and data collection process. After consulting with supervisors, literature was found relating to obstacles in data collection. It seems this researcher was not alone. He discovered that the greater the understanding of the study topic and the goal of the data collection, the greater the chance of improving recruitment. With an understanding of the reasons for the confusion and the taboo nature of the study topic, strategies were initiated to facilitate the recruitment process. These are discussed in the following paragraphs.

4.6.3.2 Haemodialysis centre

The researcher realised that the timing of recruitment was very important in the haemodialysis centre. It was worse when stepping into the environment, especially when patients had just returned for dialysis, were in their first hour of haemodialysis, and one hour

prior to finishing dialysis. Nurses were rushing to connect patients to the haemodialysis machine, patients were anxious about their pre-dialysis figures and health conditions and machine alarms were sounding, making the environment tense. A dialysis session usually lasts 4–6 hours, during which there are opportunities to interact with patients. However, this did not mean that the patients would listen to explanations and information about the study. They usually fell asleep after connecting to the haemodialysis machine within half an hour, as they felt relaxed under the care of the renal nurses and always fatigued, given the nature of their disease. Nevertheless, the researcher could approach carers about participating in the study at this moment. Once the patients woke, they were more rested and able to consider the invitation to participate in the study as key informants.

4.6.3.3 Renal ward

The researcher also performed renal ward rounds during the study period. The ward environment was crowded with sick patients. They yelled, faces showing despair and pain. This level of expressed distress among the patients was not conducive for considering whether or not to participate in a research study. Some of the dialysis patients did not match the inclusion criteria—they were not cognitively intact or mentally competent, or they were not physically well enough. Surprisingly, two patients were recruited from the ward to join the focus group interviews.

4.6.3.4 Issues in focus group interviews

The focus group interviews were performed in the activity room of the resource centre of the regional hospital. Both dialysis patients and carers were familiar with the environment, since most of the activities offered by the dialysis centre were held there. It offered a quiet and undisturbed environment for the focus group interviews. Although the literature indicates that talking about death is taboo for the Chinese, this was not overly apparent in the groups, except in the last group, in which the informants were older (more than 70). As the thoughts

and attitudes of the informants joining the interviews might be more positive towards life and treatment, this group might be a little different from the mainstream. The informants tended to express their unhappiness about long-term dialytic therapy and quality-of-life issues in the interviews. The researcher could see the group dynamic, and to an extent, some informants were easily influenced by peers. Repeated questions were asked to clarify each individual's thoughts and beliefs (Kulavuz-Onal, 2011). During the discussion, informants aligned themselves with or rejected previous members' statements. Some might exaggerate their experiences or opinions to create symbolic effects on group members. The researcher used comforting statements to end the topic when the normal flow of interview questions was interrupted (Lehoux, Poland, & Daudelin, 2006). Concerning the passive and quiet informants, it was believed that they would give clues when they wanted to talk, and were provided with sufficient time and opportunities to express their ideas.

4.6.3.5 Strategies to overcome the issues with recruiting informants

When a person is healthy, or the disease is under control, he or she seldom thinks about dying, which may attract taboos. Some people believe talking about something can make it more likely to happen. Initially, group description and explanation of the study information were performed at 30-minute intervals at the clinic, with face-to-face contact for dialysis patients and carers who indicated an interest in participating in the study. Because of the low response rate, the researcher tried to explain more detail about the nature of the study and its aims and processes, to alleviate worry and uneasiness in potential informants. In addition, the president of the renal patient self-help group and the nurse consultant in the dialysis centre were invited to be gatekeepers. When the renal physicians and the nurse consultant were informed about the poor recruitment numbers, they invited potential informants during consultations, which boosted numbers. They played an important role by providing information and aiding the researcher to gain trust and entrance into the target

group. These strategies reflected the stranger-trust-friend enabler in Leininger's ethnonursing methods (McFarland & Wehbe-Alamah, 2015).

4.6.4 Enhancing minority group participation

Some people live only with the maids in Hong Kong. Either their families live out or have migrated overseas; the issue exaggerates when people suffer from chronic illness such as the dialysis patients. The population of foreign domestic helpers at 31 December 2011 was 299,961, of which 49% were from Indonesia and 48% from the Philippines (Immigration Department, 2011). These maids were categorised as an ethnic minority group, since they comprised about 4% of the population of Hong Kong. Some of the patients may rely on the maids to perform the peritoneal dialysis regularly for them. The patients and maid-carers live together and interact each other in the daily life which prompted the researcher to think about whether there was any influence on the decision-making process of dialysis patient at end-of-life. Therefore, the maid-carers as the ethnic minority groups were included in the study sample. However, one of the obstacles encountered while performing data collection was a lack of participation of carers who were foreign domestic helpers (maids) of the dialysis patients. Difficulty was encountered in that the maids were not keen on participating in either the survey or the focus group interviews. Reasons varied, including lack of rapport with the researcher, language barrier, cultural differences and lack of incentive. Therefore, measures had to be taken to enhance the participation of those ethnic minority groups, to enrich the data from a cultural perspective. Two Filipina maid-carers completed the survey, but did not want to participate in the focus group.

In the United States, it is widely believed that ethnic minority groups are less willing to participate in health research, because of lack of trust in the research and health researchers (Wendler et al., 2006). Sue and Dhindsa (2006) noted difficulties in conducting research for ethnic minority groups because populations are small in number and knowledge and theory

are frequently lacking. In an attempt to overcome the sample size problem, some researchers aggregate different focus groups into one, use convenience samples or oversample ethnic groups when possible. Difficulties are also found regarding data validity, since there might have been misunderstandings regarding the measures or questionnaire items and cultural response sets and limitations in language proficiency (U.S. Surgeon General, 2001).

In an ethnography study, the researcher sometimes has to access informants because of a 'gatekeeper'—a person who is a member of or has insider status with a cultural group (Creswell, 2007). This gatekeeper might be the initial contact for the researcher and guides the researcher to other informants (Atkinson, Delamont, Coffey, Lofland, & Lofland, 2007). It is wise that the researcher (stranger) of the cultural group approach a gatekeeper to facilitate contact with other informants. The maid-carers refused the researcher before he had a chance to begin to explain the research study in the waiting hall of clinic; identifying gatekeeper informants provided a way to invite maid-carers to participate in the study (Tashakkori & Teddlie, 2003). This strategy can be viewed as a response to overcoming the problems associated with sampling concealed or marginalised populations, such as cultural minority groups. This process is based on the assumption that a 'bond' or 'link' exists between the initial sample and others in the same target population (Dusek, Yurova, & Ruppel, 2015).

The president of the dialysis patient group was contacted with a request to assist in identifying a gatekeeper for the maid-carers. An Indonesian maid-carer was introduced in the dialysis centre. Her employer was an in-centre haemodialysis patient receiving three dialysis sessions per week. The maid helped to recruit two Indonesian maid-carers as informants. Despite the difficulties recruiting ethnic minority maid-carers, three Indonesian maid-carers including the gatekeeper did volunteer to complete the survey after the gatekeeper explained the study to them. They also volunteered to participate in the focus groups. Apparently, the

maid-carers could talk freely in a non-threatening environment, and the group dynamic under the same cultural background offered assurance during the group interview; subsequently, fruitful data could be attained. Their perspectives on end-of-life care in Hong Kong were quite limited, but they expressed that the medical services were better than in their home country. Their health beliefs were similar to those of the Chinese community. They used familial-centred approaches to make medical decisions when family members had severe illnesses. As Islamic Indonesians, they believed that any disease or illness was a gift from Allāh, a kind of life test.

4.6.5 Limitations in the process of data collection

A number of issues hindered the data collection process. Since the approval granted from the hospital ethics committee was very close to Christmas and Lunar New Year, potential informants were hesitant to participate in the study as Chinese usually have superstition to avoid talking about ominous things at traditional Chinese festivals. Don't talk about ghosts, death, zombies or anything related to the dead on New Year days – it's unlucky (Leung, 2010). During the New Year's holidays, everyone should refrain from using foul language and bad or unlucky words. Death and dying are not mentioned. Ghost stories are also taboo. Participants did not want to stir up or catch bad luck by participating at that time. In addition, the information session and invitation to participate in the research were performed in the waiting hall of the specialist clinic. This was a less-than-ideal environment. It was difficult for the researcher to adjust the tone so that the patients and carers could hear the study information and at the same time not interfere with the normal environment of the clinic. As a stranger from the patients' and carers' viewpoint, sometimes special techniques had to be utilised to open up dialogue. The data collection period lasted from December 2013 to July 2014.

4.7 Reflexivity

The researcher's familiarity with the beliefs, values and attitudes of the target population caused him to be very aware of the potential to make assumptions about the informants' mindset and viewpoints during the data collection period. This phenomenon triggered concern for reflexivity.

Reflexivity refers to the struggle between the role as a researcher and becoming one of the members of the study culture (Streubert Speziale & Carpenter, 2003). It entails the exploration of a researcher's own interpretation and theories in use, which involve habitual ways of seeing and acting in the study domain, making sense of actions and events or resolving problems (Liberati et al., 2015). When a researcher is engaged in an ethnographic study, the complex experiences in reflexivity with texturing or layering of the shared different thoughts from informants and the researcher might stimulate future interests and ideas in the study paradigm (Berry & Clair, 2011). It is important for the researcher to remain objective and stay focused on the research; the researcher must guard against altering the meanings, reflections and culture identified by the informants (Streubert Speziale & Carpenter, 2003). How then can the researcher discover the emic without becoming a part of the culture during data collection and analysis? It rests on the quality and empirical knowledge of the researcher.

As a practicing specialist renal nurse for more than a decade, the researcher encountered various situations when dealing with conversations among dialysis patients and carers related to care to be provided at final stage of life, and care expected to be received at that moment. Decisions on withdrawal from dialysis were always difficult for carers when the patients' health condition suddenly deteriorated or there was a loss of mental competence. Mostly, the preference of the patient was not known and sometimes neglected. With ongoing observations, interpretations and communication in the renal speciality, the researcher had

reflected on his past experiences and encounters by isolating personal understanding and assumptions before commencing the thematic data analysis process. Statements were set to remind him of reflexivity; for example, ‘I am a data collector in this study. I should consciously think about how the information is used. I retrieved the viewpoints of the dialysis patients and carers towards care priority at end-of-life’. Ethnographic reflexivity assisted to create open-ended and undecided texts to collect data in a clear and powerful way (Berry & Clair, 2011). Based on clinical experience, Chinese dialysis patients perceived discussing death and dying as taboo. They would not share their ideas and thoughts about what sorts of care they wanted to receive when they were unconscious. In regard to the researcher’s personal assumptions, dialysis patients and carers would not touch this sensitive, ‘burning’ issue. The researcher was conscious about this assumption during the focus group interviews, and listening to the informants in an open-minded manner found that some of the informants from both the patient and carer groups did express in a way that dying and end-of-life were not forbidden to talk about. They had communicated with their relatives what to do when they were unconscious. By accepting the disease trajectory, the informants were positively facing their final stage of life. This was an example of deep listening and understanding without adding the personal perceptions of the researcher to the emic information of the informants.

Field notes and a reflective diary were used to record observations and impressions of each interview. This enabled the researcher to remain reflexive throughout the interviews. During the data analysis process, the researcher kept in mind and was alert to his personal assumptions and embedded perceptions towards patients’ view of end-of-life care and care priorities. By concentrating on the emic narrative expressions from the informants, true understandings could be noted from the focus group interviews.

It is recommended that reflexivity be involved in the research design when conducting an ethnographic study. It allows the researcher to explore cultures in the context of dialysis patients and carers, leading to greater understanding of the dynamics of the decision-making process on care priorities at final stage of life, which enriches the affective and subjective humanistic nature of practice (Lichterman, 2015; Streubert Speziale & Carpenter, 2003). The researcher was conscious of the personal perceptions and assumptions during data collection and writing up of the findings. By frequently reflecting on new understandings, the emerged vision and the findings from the narratives of the informants were periodically compared, to restrain the researcher's personal understanding from contaminating the clarity of the findings. Ultimately, those findings could be shared among the healthcare professionals practicing in the renal field, as well as the patient and carer groups.

4.8 Data management

4.8.1 Instrumentation and enablers

The content of the survey was adopted from Bowman and Singer (2001), Chan and Chui (2011), Chan and Pang (2011) and Davison (2010), and modified for the local context. Two surveys of 23 closed-ended questions and demographic data were developed, for patient and carer informants. Two of the 23 questions belonged to the category of patient self-reported knowledge and the other 21 concerned patient end-of-life care preferences.

The questions and interview guides for both dialysis patients (Appendix B) and carers (Appendix C) for the focus group interviews were derived from the results of the survey data. The purpose of the interview guides was to enter the world of the informants and determine what, how and why they thought or perceived and their attitude towards the domain of inquiry. Subsequently semi-structured questions were prepared according to the domain of inquiry. All interviews were audio-recorded and transcribed verbatim. The ethnographic

record was processed immediately after each focus group interview, to allow an ongoing review of data and assist the researcher to formulate and modify questions for subsequent interviews. Leininger's phases of ethnonursing data analysis enabler for qualitative data was applied to collect, interpret and analyse the records from the focus group interviews. Open coding was used initially to provide unrestricted coding of data so as to the inquiry by closely examining, comparing and categorising the data. The codes were categorised, and various codes were grouped to categories. Categories of similar meaning were articulated to themes. Three themes from patient groups and four themes from carer groups were identified for discussion.

4.8.2 Data analysis

The quantitative data in Phase A were initially analysed using descriptive statistical methods. Associations of characteristics of dialysis patients and carers with variables of care as well as advance directives of decision-making were examined by applying chi-square, Mann-Whitney U, and Kruskal-Wallis H tests. Findings from dialysis patients and carers were separated initially, then compared for commonalities and diversities. The survey data provide the elementary ideas and records of how the informants perceived the research topic. Moreover, the survey findings were used to assist in setting the questions in the interview guides for the focus group interviews.

The demographic and survey data were analysed using descriptive statistical methods. The Statistical Package for the Social Science (SPSS) version 20.0 was used for data entry and analysis. The survey data consist of nominal, ordinal, interval and ratio data, which were sub-categorised for non-parametric data analysis as they were not normally distributed. Frequency, percentage, median and mean were used to describe the central measure of data. Non-parametric techniques were used to explore the relationships among ethnicity, gender, place of birth, working status, educational status, dialysis treatment and months on dialysis,

with the self-report knowledge questions and end-of-life care preferences. Chi-square test for independence was used to explore the relationship between two categorical variables. Mann-Whitney U test was applied to assess for the significant difference in the ordinal dependent variable, for example comfortability in discussing end-of-life issues with relatives, renal doctor, and renal nurse, by a single dichotomous independent variable. The Kruskal-Wallis H test, a rank-based non-parametric test, was used to determine if there was any statistical significance between three or more groups of an independent variable on an ordinal dependent variable (Gravetter & Wallnau, 2007; Kellar & Kelvin, 2013; Polit & Beck, 2012).

Qualitative data were analysed following Leininger's phases of ethnonursing data analysis enabler (McFarland & Wehbe-Alamah, 2015), as it is the most rigorous and time-intensive of the choices (Curtis & Redman, 2007). In the first phase, the researcher collected, recorded and analysed the focus group data related to the domain of inquiry and purpose of the research. The recorded interviews were initially interpreted with the assistance of the field notes to modify the subsequent interviews. The researcher noted not only the emic data from the key informants, but attended to the etic ideas. The transcribed conversations and categories of experiences were listed, whether they were direct quotes or paraphrased. All transcribed data were stored in a computer based on the guidelines to maintain privacy and confidentiality. In the second phase, a professional translator translated the transcribed data from Chinese to English. It was coded and classified as related to the domain of inquiry. The commonalities and diversities of the emic and etic findings were studied for meaning. During the third phase, the researcher examined and categorised the coded data with respect to meanings-in-context, so as to strengthen the credibility and confirmability of the findings. This phase was commenced at the data collection period, since recurrent categories of common or diverse meanings, wordings, expressions and interpretations were scrutinised to note for saturation of ideas. In the fourth phase, emic data were characterised according to the

recurrent categories from the informants. At the highest level of data analysis in the enabler, diverse and universal themes among dialysis patient and carer informants were identified. Finally, findings were identified to inform the relevant parties, such as the dialysis patients, their carers and healthcare professionals working in the renal field.

4.9 Protection of Human Rights

Ethics approval was granted from the Human Research Ethics Committee of the University of New England (HE12-085, see Appendix E) and further approval was obtained from the ethics committee of the studied hospital (HKEC-2012-048, see Appendix F) before conducting the research. The data collection period took seven months following the granting of approval. Those who wished to participate were given a copy of the information sheet, consent form and the survey (patient and/or carer). They joined the research voluntarily by returning the signed consent form to staff at the dialysis centre or directly to the researcher on site. It was stressed that patient decisions regarding participation would have no bearing on their treatment and care in the dialysis centre and that they would not be disadvantaged in any way. As this research explores the decision-making process about care priorities at the final stage of life among renal dialysis patients, there was potential for informants to experience emotional distress. To minimise this distress, informants were warned of this potential and professional counselling made available should it be required. Informants could approach the social worker of the hospital for counselling services whenever necessary. Prior warning was given to informants during the research explanation before they signed the consent form. This information was included in the information sheet and consent form. The data collected in the survey and focus group interviews were anonymous. As sensitive data might be expressed and collected from informants during focus group interviews, informants were offered identification numbers before commencing with which they were referred to throughout the interviews. This process is common practice for focus group interviews that concern sensitive

topics (Polit & Beck, 2012). Also, these designations were used in the field notes to record non-verbal behaviours (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davison, 2007; Goodwin & Happell, 2009; Shaha et al., 2011). All data analysis documentation used numbers to identify informants. Potential informants were informed about this data management method in the information sheet.

In addition, the computerised electronic files were password protected. Hard copies of the questionnaire and transcripts were stored in a locked filing cabinet in the researcher's office until completion of the project. Five years after publication of study results, all computer files and audio records will be erased and paper files shredded, in accordance with National Health and Medical Research Council (NHMRC), Australia guidelines. Finally, the researcher will dispose of paper records and the principal supervisor will dispose of electronic records, in accordance with NHMRC guidelines.

4.10 Research Integrity

4.10.1 Phase A validity and generalisability

Validity is defined as measuring what the researcher intends to measure (Polit & Beck, 2012). Generalisability means the accuracy of the results of a study, so that a specific sample can be transferred to others in the population (Haslam & McGarty, 2014). The original survey of Davison (2010) was developed and validated for the patient group. The author did not perform any special validity or reliability test, but developed the survey mainly based on the Davison (2010) design, with further adoption of the elements from Bowman and Singer (2001), Chan and Chui (2011) and Chan and Pang (2011); the newly developed English version of the survey was given to two renal physicians and three senior renal nurses for face validity, although face validity is acknowledged to be the least acceptable form of validity (Maltby, Williams, McGarry, & Day, 2010). The English version of the survey was translated into Chinese, with face validity assessed by a senior renal nurse and a secondary

school teacher who was teaching English and whose mother tongue was Chinese. Both versions of the survey were given to English or Chinese-speaking informants to complete at Phase A, to reassure stakeholders about the tool used to measure the study topic. As the researcher expected to collect general information through the survey at Phase A, and as the research study is qualitative driven, it might not be necessary to use a tool with powerful validity and reliability. In addition, the researcher made use of the qualitative findings in the supplement from the survey to generalise findings. Therefore, the findings of Phase A were not generalised to the studied population; instead, the qualitative component was drawn on for this.

4.10.2 Phase B trustworthiness

It is a challenge for researchers to discover and evaluate the universalities and diversities of qualitative research. Because of the detailed and rigorous data analysis process, the researcher should be knowledgeable regarding how to evaluate findings from the study to explore the meanings, characteristics and understandings of special phenomena relating to the study purpose. Following culture care theory and recommendations from the ethnonursing research method helped the researcher to assess whether the qualitative analysis criteria had been met and substantiated the research findings. These criteria include credibility, confirmability, meaning-in-context, recurrent patterning, saturation and transferability (Leininger & McFarland, 2002; Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015).

4.10.2.1 Credibility

Credibility refers to the direct sources of true, accurate and evident information from informants in the context of the phenomena studied. This emic knowledge has been substantiated by the researcher (Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015). For the study to be credible, a researcher with experience in the study topic

would recognise findings as accurate descriptions (Sandelowski, 1993). As the researcher had worked in the renal nursing field for more than 15 years, specific thoughts, attitudes and beliefs of dialysis patients and carers were encountered in previous daily practice. However, it was difficult to open dialogue while dealing with withdrawal from dialysis when patients approached their final stage of life. When, how, who and where to communicate were challenges not only for dialysis staff, but for significant others, who found no channel to discuss the situation. The ideal of maintaining reflexivity was always in the researcher's mind. Trying to increase the coverage of informants in the qualitative data collection with assistance from gatekeepers and field notes taken by other personnel during the focus group interviews increased the representativeness of the findings. The interviews were audio-recorded to provide accurate records of informant descriptions. Expert advice on the methodology and data analysis was sought from supervisors, boosting credibility.

4.10.2.2 Confirmability

Confirmability means reaffirming what the researcher has heard, seen, observed, recorded or experienced with respect to the phenomena studied. It replicates the evidence of the informants, restating the ideas and thoughts that occurred over time in familiar and natural living context (Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015). The audio-record and field notes were processed right after each focus group interview to allow ongoing review of data; this assisted the researcher to formulate and modify questions for subsequent interviews. Meetings with the field-note taker discussed the content and significant issues or phenomena after each interview. While conducting interviews, the researcher paid special attention to the verbal and non-verbal responses from informants, so as to check the confirmability of the findings.

4.10.2.3 Meaning-in-context

Meaning-in-context implied the identified findings are meaningful and understandable to the informants of the study in their naturalistic and familiar (emic) contexts (Leininger & McFarland, 2002; McFarland & Wehbe-Alamah, 2015). The terms used and open-ended questions asked in the focus group interviews were the same as in the interview guide, which helped to decrease any discrepancy for informants in understanding the context of the study. Since some of the informants were more dominate in expressing their opinions and ideas through the interviews, the researcher invited the oppressed informants to explicitly state their own viewpoint instead of following the flow and ideas of others.

4.10.2.4 Recurrent patterning

Recurrent patterning refers to documented evidence of repeated categories of expressions and experiences in way of life that are inclined to reoccur over time in a selected context (Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015). To achieve this, the researcher and field-note taker concentrated on identifying various categories in expressions and ideas from the informants. Often, the informants did not know each other; the researcher was also a stranger in the groups. By making use of the suggestions of the stranger-trust-friend enabler, ‘warm-up’ conversations were always performed before the commencement of the actual interviews. For example, informants were asked how many months they had had on dialysis or to share their fluid restriction strategy and willingness to participate in the renal rehabilitation programme. Since the study topic was relatively sensitive, informants hesitated to voice their opinions. Dead air or silence was usually found in the early stage of the interviews; after informants had warmed up and found that the questions were stimulating, most willingly expressed their emic view and seemed to feel free to say what they needed to say in the group.

4.10.2.5 Saturation

After lengthy in-depth information seeking from informants, no new data relevant to the domain of inquiry can be obtained. Redundant information appeared during the interview, with informants having nothing further to add or share (Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015). The researcher conducted comprehensive and exhaustive questioning to note for repetitive data after several interviews had been performed for both dialysis patient and carer groups. Interestingly, Chinese informants tended to answer sensitive questions in a neutral manner, with expressions such as *moderation*, *seize the day*, *and never think about it*. In some situations, the researcher had to encourage informants to address more exactly what was being asked, especially for those questions touching on taboo or bad luck issues. In the frequent post-interview meetings with the field-note taker, special findings and significant issues or phenomena were examined after each interview. As more interviews were carried out, the researcher could understand better how to enable informants to share their views and experiences.

4.10.2.6 Transferability

Transferability refers to whether the findings from a particular study have meanings and relevance that can be transferred to similar situations, contexts or cultures (Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015). Since this qualitative study was conducted in a naturalistic setting, whether the findings were applicable is determined by the degree of similarity to other contexts (Krefting, 1991). Although this study was performed in only one regional hospital in Hong Kong, it is possible to transfer the findings to other dialysis patients and carers with similar demographic patterns. Conversely, some informants were core members of the renal patient self-help group, so their thoughts and beliefs towards the study topic might have influenced other patients and carers in other dialysis centres because of frequent contact. Often, patients and carers in a similar cultural context share

similar disease trajectories and treatment. The setting, sampling, data collection procedure, data analysis method and findings are illustrated; readers can decide to transfer the findings to other populations with a similar context.

4.11 Language of Data Collection

Both English and Chinese versions of survey were developed in Phase A. Potential informants were asked which version they preferred to express their opinions. As the majority of the target population spoke Chinese, a large proportion were printed in Chinese. The number of items and contents were equivalent in both versions, so there was no problem entering data in SPSS during data analysis.

The Phase B focus group interviews were conducted in Cantonese, as were the interviews with the maid-carers, who could speak and understand Cantonese. The researcher explained the questions or special terms in detail if the maid-carers did not understand what was being asked. Clarification was offered if they were not familiar with the local culture issue. The maids were encouraged to express their ideas based on their experience and culture. All interviews were then audio-recorded and transcribed verbatim.

4.12 Translation Process

The English version of the survey developed in Phase A was translated into Chinese by the researcher, with face validity provided by a senior renal nurse and a secondary school teacher, both of whom were bilingual. Both the English and Chinese versions of the survey were used during Phase A. For the findings in the focus group interviews (Phase B), the researcher performed the transcription from Cantonese to written Chinese verbatim. A professional translator was employed to translate the transcribed relevant codes, conversations and data from Chinese to English for writing the findings chapter. Importantly, all data were double checked by the researcher to prevent any distortion of meaning after translation. Some of the significant terms and codes with specific Chinese cultural meanings

were included in the content of the findings and discussion chapters, to minimise distortion from the original meaning.

4.13 Summary

This chapter has presented the use of the mixed methods sequential explanatory design as the study design to direct the flow of the quantitative (Phase A) and qualitative phases (Phase B) of the research process. Surveys were used to collect general information from the informants related to the study topic. The ethnonursing approach served as the method for the qualitative phase. The researcher used the specific functions of ethnonursing to build cultural data and interpretations through focus group interviews and field-note reflection. With the addition of Leininger's phases of ethnonursing data analysis and criteria of qualitative analysis, research findings could be explicated, refined and made more credible and confirmable through the concurrent process of data collection and data analysis until saturation was reached. Details are provided in the next chapter. In addition, the study design, setting for the study, selection of the informants and ethical and human subjects consideration have been described. Explanations on the usage of instrumentation and enablers and the data collection process are also provided.

Chapter 5: Findings

5.1 Introduction

This chapter describes the findings on the decisions about care priorities at the final stage of life of renal dialysis patients and their carers. Of the 121 dialysis patients and 61 carers who agreed to join the survey in Phase A, 24 patients and 14 carers volunteered to participate in the focus group interviews of Phase B. The characteristics of the informants and relevant statistically significant figures are described below. In the focus group interviews, the informants revealed preferences for care for end-of-life, participants in the end-of-life decision-making discussion and influences on the end-of-life care decision. Through Leininger's phases of ethnonursing data analysis, various codes were identified from the verbatim interviews, and grouped into categories. Ultimately, three themes from the patient groups and four from the carers were delineated.

5.2 Phase A: Characteristics of the Dialysis Patient Informants

A total of 381 dialysis patients were registered to receive renal care in the regional hospital during the data collection period. Of this group, 338 patients were identified as conforming to the criteria for inclusion and approached while they were in-patients in the renal ward, receiving haemodialysis in-centre or following up at the specialist outpatient clinic. In total, 121 dialysis patients (65 males and 56 females, see Table 5.1 demographics of dialysis patients) were willing to join the study and complete the survey. They were mostly recruited at the specialist outpatient clinic and haemodialysis centre. The age of patients ranged from 25 to 84, the mean age was 59.6 and the median age group was 60–69 years (38.1%). The majority of the dialysis patients were born in Hong Kong (69.4%), with 27.3% born in mainland China. In terms of educational status of patients, 63.7% had secondary school education or higher. Most informants (90.9%) were not working. The majority of the

dialysis patients (65.3%) had no religion, with 16.5%, 9.1% and 5.8% Buddhist, Protestant and Catholic respectively.

Table 5.1

Demographics of dialysis patients.

N=121	Frequency	Percentage	Mean
Gender			
Male	65	53.7	
Female	56	46.3	
Age			
Younger than 50	23	19.0	
50-59	28	23.1	
60-69	46	38.1	
70-79	18	14.8	
80-89	6	5.0	
			59.5 (SD 12.0)
Place of birth			
Hong Kong	84	69.4	
Mainland China	33	27.3	
Education			
Illiterate	9	7.4	
Primary	35	28.9	
Secondary	63	52.1	
University or above	14	11.6	
Employment			
Employed	11	9.1	
Unemployed	110	90.9	
Religion			
Nil	79	65.3	
Buddhist	20	16.5	
Catholic	7	5.8	
Protestant	11	9.1	
Toaism	3	2.5	
Islam	1	0.8	

Since peritoneal dialysis was the first option of the dialysis modes in Hong Kong, 84 out of 121 (69.4%) informants were undergoing peritoneal dialysis, while 37 (30.6%) were receiving

haemodialysis (see Table 5.2). Duration on dialysis ranged from one month to 25 years, with a mean of 44.56 months (SD 43.91); 3–5 years (30.6%) was the median duration on dialysis. Some 67 (55.4%) dialysis patients performed the dialysis themselves; they belonged to the continuous ambulatory peritoneal dialysis or nocturnal peritoneal dialysis group. The 32 (26.4%) who needed help from renal centre staff to do the dialysis belonged to the in-centre haemodialysis modality. Further details are available in Appendix O.

Table 5.2

Dialysis information of patients.

N=121	Frequency	Percentage	Mean
Mode of dialysis			
Haemodialysis	37	30.6	
Peritoneal dialysis	84	69.4	
Duration on dialysis			
0-6 months	18	14.9	
7-12 months	15	12.4	
1-2 years	20	16.5	
3-5 years	37	30.6	
6-10 years	23	19	
>11 years	8	6.6	
			44.56 (SD 43.91)
Personnel performed dialysis			
Self	67	55.4	
Family member	15	12.4	
Domestic worker	3	2.5	
Elderly home staff	4	3.3	
Renal centre staff	32	26.4	

5.3 Knowledge and End-of-Life Decision Preferences of Dialysis Patient Informants

For the self-report knowledge of the dialysis patient informants showing in Table 5.3, nearly half (42.1%) of participating patients reported they had heard about end-of-life care. However, the majority (81.8%) had not heard about advance directives; 60.3% of patients

had not thought about what might happen to them regarding their illness in the future. Nearly 95.0% said their doctors had not told them about their lifespan. There were 19 close-ended questions in the survey to investigate dialysis patients' end-of-life preferences. All findings are shown in Appendix P.

Table 5.3

Dialysis Patients' Self-Reported Knowledge.

	Frequency	Percentage
Have you heard about the End-of-life care?		
Yes	51	42.1
No	70	57.9
Have you heard about the Advance Directives?		
Yes	22	18.2
No	99	81.8
Have you thought about what might happen to you regarding your illness in the future?		
Yes	48	39.7
No	73	60.3
Has your doctor told you about your lifespan?		
Yes	6	5.0
No	115	95.0

Patients (86%) expected their family to make medical decisions for them when they were physically or mentally incompetent, followed by doctors (33.1%) and nurses (14%) as shown in Table 5.4. Patients relied on renal doctors (73.6%), renal nurses (44.6%) and family members (34.7%) to obtain information related to their illnesses. Patients claimed that they accepted advice from doctors (82.6%) rather than following their own wishes (24.8%) or family wishes (22.3%) when they chose long-term dialysis, and majority had no regret (88.4%) about the decision to start on dialysis. Dialysis patients tended to be neutral (52.9–58.7%) about how comfortable they were discussing end-of-life issues with renal doctors, renal nurses and family members. Some patients were comfortable or very comfortable sharing their end-of-life issues with family, renal doctors and nurses (23.9%, 27.2% and 27.3%, respectively).

Table 5.4

Decision-Making of Dialysis Patients.

	Frequency	Percentage	Mean (SD)
Who would make decisions on your behalf?			
Family	104	86.0	
Doctor	40	33.1	
Nurse	17	14.0	
How to obtain medical information?			
Renal doctor	89	73.6	
Nurse	54	44.6	
Family	42	34.7	
Why chose dialysis over conservative care?			
Doctor advice	100	82.6	
Own wishes	30	24.8	
Family advice	27	22.3	
Any regrets in starting on dialysis?			
Yes	14	11.6	
No	107	88.4	
Discussing end-of-life issues with family members?			
Very comfortable	9	7.4	
Comfortable	20	16.5	
Neutral	71	58.7	
Uncomfortable	15	12.4	
Very uncomfortable	6	5.0	2.92 (0.89)
Discussing end-of-life issues with renal doctor?			
Very comfortable	5	4.1	
Comfortable	28	23.1	
Neutral	64	52.9	
Uncomfortable	18	14.9	
Very uncomfortable	6	5.0	2.93 (0.86)
Discussing end-of-life issues with renal nurse?			
Very comfortable	3	2.5	
Comfortable	30	24.8	
Neutral	66	54.5	
Uncomfortable	15	12.4	
Very uncomfortable	7	5.8	2.94 (0.84)

Table 5.5 summarises end-of-life care preferences of patients. On extending life, 38% of patients wanted to receive resuscitation when their heart stopped beating, 33.1% did not

know and 28.9% claimed they did not want resuscitation. Some 33% of patients did want to be connected to the breathing machine, while 37.2% of patients did not want to be connected. Patients preferred better quality of life (54.5%), even if lifespan would be short without life-sustaining devices. Almost 86% of patients wanted to discuss end-of-life issues with family members, 38% with renal doctors and 24% with renal nurses. However, 77.7% of patients did not discuss end-of-life care preferences with anyone, and only 19.8% communicated with family. Finally, if advance directives were offered in Hong Kong, 83.5% of dialysis patients reported that they would adopt it.

Table 5.5

End-of-Life Care Preferences of Dialysis Patients.

	Frequency	Percentage
What to do when heart stops beating?		
Resuscitation	46	38.0
No resuscitation	35	28.9
Don't know	40	33.1
What do you want your doctor to do if your heart stops beating?		
Breathing machine	40	33.0
No breathing machine	45	37.2
Don't know	36	29.8
Extending life but prolonging discomfort against relieving discomfort but shorter life?		
Improve quality of life	66	54.5
Live as long as possible	15	12.4
Don't know	40	33.1
Discussed your end-of-life care with anyone?		
No discussion	94	77.7
Family member	24	19.8
Who should be involved in discussing end-of-life issues?		
Family member	104	86.0
Renal doctor	46	38.0
Renal nurse	29	24.0
Want to make an advance directive?		
Yes	101	83.5
No	20	16.5

Chi-square test of independence was performed to examine the association between working status, type of treatment and knowledge of end-of-life care, advance directives, and lifespan. As the tests were computed for a 2 by 2 table, the values in the Continuity Correction (Yate's Correction for Continuity) should be used instead of the Pearson Chi-Square which compensates for the overestimation of the chi-square value (Pallant, 2013). As shown in Table 5.6, Chi-square tests for independent (with Yate's Continuity Correction) indicated no significant association between working status and knowledge of end-of-life care, advance directives, and lifespan; χ^2 (1, n = 121) = 0.53, p =.47; χ^2 (1, n = 121) = 0.17, p =.68; χ^2 (1, n = 121) = 0.00, p =1.0 respectively.

Table 5.6

Association between working status of dialysis patients and knowledge of end-of-life care, advance directives, and lifespan.

		Working status							
Variable	Group	Yes		No		Total		χ^2 value	P value
		n	%	n	%	n	%		
Heard of end-of-life care	Yes	3	2.5	48	39.7	51	42.2	0.53	0.47
	No	8	6.6	62	51.2	70	57.8		
Heard of advance directives	Yes	3	2.5	19	15.7	22	18.2	0.17	0.68
	No	8	6.6	91	75.2	99	81.8		
Been told lifespan	Yes	1	0.8	5	4.1	6	5.1	0.00	1.0
	No	10	8.3	105	86.8	115	95.0		

Of using Chi-square tests for independent (with Yate's Continuity Correction) indicated no significant association between type of treatment and knowledge of end-of-life care, advance directives, and lifespan; χ^2 (1, n = 121) = 0.19, p =.66; χ^2 (1, n = 121) = 0.16, p =.69; χ^2 (1, n = 121) = 0.00, p =1.0 respectively (Table 5.7).

Table 5.7

Association between dialysis treatment of patients and knowledge of end-of-life care, advance directives, and lifespan.

Variable	Dialysis treatment							χ^2 value	P value
	Group	HD		PD		Total			
		n	%	n	%	n	%		
Heard of end-of-life care	Yes	14	11.6	37	30.6	51	42.2	0.19	0.66
	No	23	19.0	47	38.8	70	57.8		
Heard of advance directives	Yes	8	6.6	14	11.6	22	18.2	0.16	0.69
	No	29	24.0	70	57.9	99	81.8		
Been told lifespan	Yes	2	1.7	4	3.3	6	5.0	0.00	1.0
	No	35	28.9	80	66.1	115	95.0		

HD = haemodialysis; PD = peritoneal dialysis

Mann-Whitney U tests were performed to assess the relationship between employment status, treatment type and comfortability discussing end-of-life issues. Table 5.8 shows that there is no significant difference between working status and comfortability discussing end-of-life issues with relatives, renal doctor, and renal nurse (U=603.5, p=0.99; U=558.5, p=0.65; U=565.5, p=0.69 respectively). Also, there is no difference between the type of treatment and comfortability in discussing end-of-life issues with relatives (U=1495.5, p=0.71, renal doctor (U=1509.5, p=0.78, and renal nurse (U=1483.5, p=0.66).

Table 5.8

Comparison of discussing end-of-life issues with relatives, renal doctor, and renal nurse by working status, type of treatment.

Characteristics	Q11	Q12	Q13
	N = 121	N = 121	N = 121
Working status	U=603.5	U=558.5	U=565.5
– Mann-Whitney U	p=.99	p=.65	p=.69
	r=.001	r=.04	r=.04
– Median	3	3	3
Type of treatment	U=1495.5	U=1509.5	U=1483.5
– Mann-Whitney U	p=.71	p=.78	p=.66
	r=.003	r=.02	r=.04
– Median	3	3	3

Q11 = Comfortable in discussing end-of-life issues with relative
Q12 = Comfortable in discussing end-of-life issues with renal doctor
Q13 = Comfortable in discussing end-of-life issues with renal nurse

Kruskal-Wallis H tests were conducted to assess the relationship between place of birth (Hong Kong, Mainland China or other), education status (illiterate, primary, secondary, and university or above), who performs dialysis (self, family member, maid, elderly home staff or Renal Unit nursing staff) and comfortability in discussing the end-of-life issues with relatives, renal doctor, and renal nurse. As illustrated in Table 5.9, there was no difference between place of birth and comfortability in discussing the end-of-life issues with a relative, $\chi^2(2, n=121) = 1.37$, $p = 0.51$, with a mean rank of 62.57; with a renal doctor, $\chi^2(2, N=121) = 3.12$, $p = 0.21$, with a mean rank of 81.89; or with a renal nurse, $\chi^2(2, N=121) = 0.38$, $p = 0.83$, with a mean rank of 62.08. When comparing education status with comfortability in discussing the end-of-life issues, the results showed no significant difference between education and comfortability, $\chi^2(3, N=121) = 5.97$, $p = 0.11$, with a mean rank of 62.58 for relative; renal doctor, $\chi^2(3, N=121) = 2.06$, $p = 0.56$, with a mean rank of 63.89; renal nurse, $\chi^2(3, N=121) = 4.97$, $p = 0.17$, with a mean rank of 66.29. There was no significant difference when comparing who conducts the dialysis and comfortability discussing end-of-life issues.

Table 5.9

Comparison of discussing end-of-life issues with relatives, renal doctor, and renal nurse by place of birth, education, dialysis done by whom.

Characteristics	Q11 N = 121	Q12 N = 121	Q13 N = 121
Place of birth	χ^2=1.37	χ^2=3.12	χ^2=.38
– Kruskal-Wallis H	p=.51	p=.21	p=.83
	df=2	df=2	df=2
– Mean Rank	62.57	81.89	62.08
Education	χ^2=5.97	χ^2=2.06	χ^2=4.97
– Kruskal-Wallis H	p=.11	p=.56	p=.17
	df=3	df=3	df=3
– Mean Rank	62.58	63.89	66.29
Dialysis done by whom	χ2=6.67	χ2=4.76	χ2=4.87
– Kruskal-Wallis H	p=.15	p=.32	p=.30
	df=4	df=4	df=4
– Mean Rank	73.97	71.10	71.63

Q11 = Comfortable in discussing end-of-life issues with relatives
Q12 = Comfortable in discussing end-of-life issues with renal doctor
Q13 = Comfortable in discussing end-of-life issues with renal nurse

5.4 Characteristics of the Dialysis Patient Carer Informants

Convenience sampling was employed when carers were seen in the dialysis centre, wards and clinics. There were 61 carers (17 male and 44 female, see Table 5.10) willing to participate in the survey. Further details on their characteristics are provided in Appendix Q. The age range was 20–76 years, mean age was 48.03 (SD 13.42) and the median age group was less than 50 years (59%). The majority of the dialysis patient carer informants were born in Hong Kong (60.7%), with 21.3% born in mainland China and 18% born in Philippines & Indonesia respectively. Nearly 63.9% were employed, and the majority (88.5%) had an educational status of secondary or more. Chinese was the most common first language (90.2%) for the informants. Most of the carer informants were not religious (52.5%), but 13.1%, 14.8%, 11.5% and 8.2% were Buddhism, Protestant and Catholic and Islam respectively.

Since peritoneal dialysis was the first option of the dialysis modes in Hong Kong, 78.7% of the informants cared for relatives undergoing peritoneal dialysis (Table 5.11). Their patient relative's duration on dialysis ranged from one month to 13 years, the mean was 44.25 months (SD 39.37) and 3–5 years (32.7%) was the median duration on dialysis. Some 22 (36.1%) of the carers were the spouse of the dialysis patient, with 19.7% a parent and 19.7% an offspring.

Table 5.10

Demographics of patients' carers.

N=61	Frequency	Percentage	Mean
Gender			
Male	17	27.9	
Female	44	72.1	
Age			
Younger than 50	26	59.0	
50-59	11	18.0	
60-69	12	19.7	
70-79	2	3.3	
80-89	0	0	
			48.03 (SD 13.42)
Place of birth			
Hong Kong	37	60.7	
Mainland China	13	21.3	
Others (Philippines & Indonesia)	11	18.0	
Education			
Primary	7	11.5	
Secondary	35	57.4	
University or above	19	31.1	
Employment			
Employed	39	63.9	
Unemployed	22	36.1	
Religion			
Nil	32	52.5	
Buddhist	8	13.1	
Catholic	7	11.5	
Protestant	9	14.8	
Islam	5	8.2	

Table 5.11

Dialysis information of carers' patient relatives

N=61	Frequency	Percentage	Mean
Mode of dialysis			
Haemodialysis	13	21.3	
Peritoneal dialysis	48	78.7	
Duration on dialysis			
0-6 months	5	8.2	
7-12 months	12	19.7	
1-2 years	10	16.4	
3-5 years	20	32.7	
6-10 years	11	18.1	
>11 years	3	4.9	
			44.25 (SD 39.37)
Personnel performed dialysis			
Parent	12	19.7	
Spouse	22	36.1	
Offspring	12	19.7	
Employee	9	14.8	
Other	6	9.8	

5.5 Knowledge and End-of-Life Decision Preferences of Dialysis Patients' Carer Informants

Nearly half (50.8%) of the participating dialysis patient carers claimed they had heard about end-of-life care (Table 5.12). However, the majority (63.9%) had not heard about advance directives. Some 65.6% of carers had thought about what might happen to their patient relative regarding the illness in the future. Nearly 88.5% claimed doctors had not told them about the patient's lifespan. A comprehensive illustration of dialysis patient carers' end-of-life preferences can be found in Appendix R.

Table 5.12

Carers' Self-Reported Knowledge.

Questions	Frequency	Percentage
Have you heard about the end-of-life care?		
Yes	31	50.8
No	30	49.2
Have you heard about advance directives?		
Yes	22	36.1
No	39	63.9
Have you thought about what might happen to your relative regarding his/her illness in the future?		
Yes	40	65.6
No	21	34.4
Has the renal doctor told you about your relative's lifespan?		
Yes	7	11.5
No	54	88.5

Carers answered as per their own thoughts and points of view instead of asking their patient relatives (Table 5.13). Knowing that Chinese families seldom talk or discuss end-of-life issues, dialysis patients and their carers might not know their family's perceptions on this topic. These findings assist to show differences of thoughts and beliefs between patients and carers. Carers expected their family (80.3%) to make medical decisions for them when they were physically or mentally incompetent, followed by doctors (49.2%) and nurses (13.1%). They sought renal doctor (59%) and renal nurse (32.8%) advice for medical information; unlike the patient informants, carers tended to obtain information from family (50.8%) and friends (41%). They sought renal doctor (59%) and renal nurse (32.8%) advice for medical information; unlike the patient informants, carers tended to obtain information from family (50.8%) and friends (41%). When their patient relatives commenced dialysis treatment, carers claimed that the patients took the advice of doctors (86.9%) rather than their own wishes (34.4%) or carer wishes (16.4%).

Table 5.13

Decision-Making of Carer Informants.

	Frequency	Percentage
Who would make decisions on your behalf?		
Family	49	80.3
Doctor	30	49.2
Nurse	8	13.1
How to obtain medical information?		
Renal doctor	36	59.0
Nurse	20	32.8
Family	31	50.8
Friends	25	41.0
Why chose dialysis over conservative care?		
Doctor's advice	53	86.9
Patient's wishes	21	34.4
Your advice	10	16.4
Any regrets on starting patient on dialysis?		
Yes	4	6.6
No	56	91.8
Discussing end-of-life issues with family members?		
Very comfortable	0	0
Comfortable	4	6.6
Neutral	33	54.0
Uncomfortable	14	23.0
Very uncomfortable	10	16.4
		Mean (SD): 3.49 (0.85)
Discussing end-of-life issues with renal doctor?		
Very comfortable	2	3.3
Comfortable	7	11.5
Neutral	30	49.2
Uncomfortable	16	26.2
Very uncomfortable	6	9.8
		Mean (SD): 3.28 (0.92)
Discussing end-of-life issues with renal nurse?		
Very comfortable	1	1.6
Comfortable	5	8.3
Neutral	31	50.8
Uncomfortable	18	29.5
Very uncomfortable	6	9.8
		Mean (SD): 3.38 (0.84)

The majority showed no regret (91.8%) about the patient starting dialysis. Carers were prone to be more negative about discussing end-of-life issues with family, renal doctors and renal nurses, with responses of neutral (49.2–54.1%), uncomfortable (23%, 26.2% and 29.5%) and very uncomfortable (16.4%, 9.8% and 9.8%) about sharing end-of-life issues with family, renal doctors and renal nurses, respectively.

On extending life, 50.8% of carers wanted resuscitation when their heart stopped beating, 24.6% did not know and 24.6% reported they wanted no resuscitation. In Table 5.14, some 42.6% of carers wanted to be connected to breathing machines, while 37.7% did not. They preferred better quality of life (73.8%), even with a shorter lifespan.

Table 5.14

End-of-Life Care Preferences of Carers.

	Frequency	Percentage
What to do when heart stops beating?		
Resuscitation	31	50.8
No resuscitation	15	24.6
Don't know	15	24.6
What do you want your doctor to do if your heart stopped beating?		
Breathing machine	26	42.6
No breathing machine	23	37.7
Don't know	12	19.7
Extending life, prolonging discomfort against relieving discomfort but shorter life?		
Improve quality of life	45	73.8
Live as long as possible	10	16.4
Don't know	6	9.8
Discussed end-of-life care with anyone?		
No discussion	52	85.2
Family member	8	13.1
Who should be involved in discussing end-of-life issues?		
Family member	58	95.1
Renal doctor	26	42.6
Friends	16	26.2
Renal nurses	9	14.8

Since the last two questions allowed the informants to make more than one choice the final percentages add up to greater than 100%. For example, only 13.1% of carers wanted to discuss end-of-life issues with family members; 85.2% preferred no discussion. When asked about who should be involved in the discussion process, carers wanted to involve family members (95.1%), renal doctors (42.6%) and friends (26.2%). However, 85.2% did not discuss end-of-life care preferences with anyone, and only 13.1% communicated with family. Finally, if there were advance directives in Hong Kong, 90.2% of carers would like to adopt this. The carers mostly lived with patients or had close contact with them. Carers' ideas or thoughts might influence the decisions made by the dialysis patients. The same tests adopted for dialysis patients, non-parametric techniques, were used to explore the relationships among ethnicity, gender, place of birth, working status, educational status, dialysis treatment and months on dialysis, with the carers' self-reported knowledge and end-of-life care preferences.

As shown in Table 5.15, Chi-square tests for independent (with Yate's Continuity Correction) indicated no significant association between working status of dialysis patient carers and knowledge of end-of-life care, advance directives, patient lifespan; χ^2 (1, n = 61) = 0.13, p =.72; χ^2 (1, n = 61) = 0.63, p =.43; χ^2 (1, n = 61) = 0.00, p =1.0 respectively.

Table 5.15

Association between working status of carers and knowledge of end-of-life care, advance directives, patient lifespan.

		Working status							
Variable	Group	Yes		No		Total		χ^2 value	P value
		n	%	n	%	n	%		
Heard of end-of-life care	Yes	21	34.4	10	16.4	31	50.8	0.13	0.72
	No	18	29.5	12	19.7	30	49.2		
Heard of advance directives	Yes	16	26.2	6	9.8	22	36.1	0.63	0.43
	No	23	37.7	16	26.2	39	63.9		
Been told lifespan	Yes	5	8.2	2	3.3	7	11.5	0.80	0.67
	No	34	55.7	20	32.8	54	88.5		

Chi-square tests for independent (with Yate's Continuity Correction) indicated no significant association between type of treatment and carers' knowledge of end-of-life care, advance directives, or patient lifespan; χ^2 (1, n = 61) = 0.31, p =.58; χ^2 (1, n = 61) = 3.35, p =.07; χ^2 (1, n = 121) = 0.00, p =1.0 respectively (Table 5.16).

Table 5.16

Association between dialysis treatment of patient relatives and knowledge of end-of-life care, advance directives, patient lifespan.

		Dialysis treatment of patient relatives							
Variable	Group	HD		PD		Total		χ^2 value	P value
		n	%	n	%	n	%		
Heard of end-of-life care	Yes	8	13.1	23	37.7	31	50.8	0.31	0.58
	No	5	8.2	26	41.0	30	49.2		
Heard of advance directives	Yes	8	13.1	14	23.0	22	36.1	3.35	0.07
	No	5	8.2	34	55.7	39	63.9		
Been told lifespan	Yes	1	1.6	6	9.8	7	11.5	0.00	1.00
	No	12	19.7	42	68.9	54	88.5		

HD = haemodialysis; PD = peritoneal dialysis

Mann-Whitney U tests (Table 5.17) were conducted to assess the association between the working status of carers and comfortability in discussing end-of-life issues with relatives, renal doctor, and renal nurse. There were no significant difference between working status of carers and comfortability in discussing end-of-life issues with relatives, renal doctor, and renal nurse (U=366.0, p=0.30; U=412.05, p=0.78; U=412.0, p=0.78 respectively). Also, Table 5.17 shows no difference between the type of treatment and the comfortability in discussing end-of-life issues with relatives (U=305.5, p=0.90, renal doctor (U=244.5, p=0.20, and renal nurse (U=300.5, p=0.83).

Table 5.17

Comparison of carers discuss end-of-life issues with relatives, renal doctor, and renal nurse by working status, type of treatment.

Characteristics	Q11	Q12	Q13
	N = 61	N = 61	N = 61
Working status	U=366.0	U=412.0	U=412.0
– Mann-Whitney U	p=.30	p=.78	p=.78
	r=.13	r=.04	r=.04
– Median	3	3	3
Type of treatment	U=305.5	U=244.5	U=300.5
– Mann-Whitney U	p=.90	p=.20	p=.83
	r=.02	r=.16	r=.03
– Median	3	3	3

Q11 = Comfortable in discussing end-of-life issues with relatives
Q12 = Comfortable in discussing end-of-life issues with renal doctor
Q13 = Comfortable in discussing end-of-life issues with renal nurse

Kruskal-Wallis H tests were conducted to assess the association between place of birth, education status, who conducts dialysis and comfortability discussing the end-of-life issues with a relative, renal doctor, renal nurse. As illustrated in Table 5.18, there is no difference between carers' place of birth (Hong Kong, Mainland China, other countries) and comfortability discussing the end-of-life issues with a relative, $\chi^2(2) = 0.40$, $p = 0.82$, with a mean rank of 33.27; renal doctor, $\chi^2(2) = 0.96$, $p = 0.62$, with a mean rank of 32.27; and renal nurse, $\chi^2(2) = 0.59$, $p = 0.75$, with a mean rank of 34.23.

When comparing educational status of carers with comfortability discussing the end-of-life issues, the results show no statistical difference between education and comfortability discussing the end-of-life issues with a relative, $\chi^2(2) = 2.39$, $p = 0.30$, with a mean rank of 39.57; renal doctor, $\chi^2(2) = 0.54$, $p = 0.76$, with a mean rank of 33.66; and renal nurse, $\chi^2(2) = 0.16$, $p = 0.92$, with a mean rank of 31.63.

There is no association between who conducts the patients' dialysis and comfortability discussing the end-of-life issues with a relative, $\chi^2(4) = 0.34$, p = 0.99, with a

mean rank of 33.39; renal doctor, $\chi^2(4) = 2.14$, p = 0.71, with a mean rank of 36.0; and renal nurse, $\chi^2(4) = 0.99$, p = 0.91, with a mean rank of 34.22.

Table 5.18

Comparison of discussing end-of-life issues with relatives, renal doctor, and renal nurse by place of birth, education, dialysis done by whom.

Characteristics	Q11 N = 61	Q12 N = 61	Q13 N = 61
Place of birth	χ^2=.40	χ^2=.96	χ^2=.59
– Kruskal-Wallis H	p=.82	p=.62	p=.75
	df=2	df=2	df=2
– Mean Rank	33.27	32.27	34.23
Education	χ^2=2.39	χ^2=54	χ^2=.16
– Kruskal-Wallis H	p=.30	p=.76	p=.92
	df=2	df=2	df=2
– Mean Rank	39.57	31.66	31.63
Dialysis done by whom	χ^2=.34	χ^2=2.14	χ^2=.99
– Kruskal-Wallis H	p=.99	p=.71	p=.91
	df=4	df=4	df=4
– Mean Rank	33.39	36.0	34.25

Q11 = Comfortable in discussing end-of-life issues with relatives
Q12 = Comfortable in discussing end-of-life issues with renal doctor
Q13 = Comfortable in discussing end-of-life issues with renal nurse

5.6 Association of Findings between Dialysis Patient and Carer Informants

In Table 5.19, Chi-square tests for independent variables indicated no significant association between dialysis patients and carers about the self-report knowledge of end-of-life care, advance directives, and patient lifespan; χ^2 (1, n = 61) = 1.34, p =.25; χ^2 (1, n = 61) = 1.69, p =.19; χ^2 (1, n = 61) = 0.48, p =.79 respectively.

Table 5.19

Association between dialysis patients and carers about self-report knowledge

	Dialysis patients				Carers							
Variable	Yes		No		Yes		No		Total		χ^2 value	P value
	n	%	n	%	n	%	n	%	n	%		
1	14	23.0	18	29.5	17	27.9	12	19.6	61	100	1.34	0.25
2	3	4.9	11	18.1	19	31.1	28	45.9	61	100	1.69	0.19
3	1	1.6	3	4.9	7	11.5	50	82.0	61	100	0.48	0.79

1 = Heard of end-of-life care; 2 = Heard of advance directives; 3 = Been told lifespan

When studying the comfortabilities of discussing end-of-life issues to informants' relatives, renal doctors and nurses; Kruskal-Wallis H tests were conducted to find out any association between dialysis patients and their carers. As illustrated in Table 5.20, there is a statistical difference of patient and carer informants on the comfortability discussing the end-of-life issues with family members, $\chi^2(3) = 12.14$, $p = 0.01$, with a mean rank of 44.60. However, there is no statistical difference showing at the aspects of renal doctor, $\chi^2(4) = 7.06$, $p = 0.13$, with a mean rank of 43.00; and renal nurse, $\chi^2(4) = 2.28$, $p = 0.69$, with a mean rank of 38.58.

Table 5.20

Comparison of dialysis patients and carers discussing end-of-life issues with the relative, renal doctor, and renal nurse.

Group	Q11 N = 61	Q12 N = 61	Q13 N = 61
Dialysis patients and carers			
– Kruskal-Wallis H	χ^2=12.14 p=.01* df=3	χ^2=7.06 p=.13 df=4	χ^2=2.28 p=.69 df=4
– Mean Rank	44.60	43.00	38.58

Q11 = Comfortable in discussing end-of-life issues with relative
Q12 = Comfortable in discussing end-of-life issues with renal doctor
Q13 = Comfortable in discussing end-of-life issues with renal nurse

*Statistical Significance

5.7 Phase B: Listening to Renal Dialysis Patients and Carers

The remainder of this chapter presents the qualitative findings from Phase B of the study. In analysing the data from Phase B, the focus group interview data were described, interpreted and analysed according to the guidelines of Leininger's phases of ethnonursing data analysis enabler (Leininger & McFarland, 2006; McFarland & Wehbe-Alamah, 2015). The data analysis process of the patient focus group interviews is illustrated first, and subsequently, the carer cohort. Each phase of the data analysis process is presented with the

findings, with reference to the domain of inquiry of this study: exploring the decision-making process and care priorities at the final stage of life of renal dialysis patients and their carers. Commencing with the code identification, gathering categories from codes with similar meanings and finalising themes development have been established.

5.7.1 Collecting and documenting raw data (patient group)

In this study, the first phase of Leininger's phases of ethnonursing data analysis focused on describing the environmental context of the dialysis centre, specialist outpatient clinic and wards in which the data collection areas were located. Detailed descriptions of the environmental context were described in Chapter 3. Adopting from the culture care model, the stranger-trust-friend enabler was used to guide the researcher in obtaining and examining the information provided by the informants.

There were 24 dialysis patients, 13 of which (54.17%) were male, participating in four focus group interviews, ranging from five to eight informants per group. As sensitive data may be expressed and collected from informants during the focus group interviews, each of the informants will be offered an identification number from one to twenty four. They will be referred to by the identification numbers by the researcher throughout the interviews. The mean age of the patient informants was 56.96, ranging from 33 to 73. They had received dialysis from 3–172 months, with a mean of 53.6 months. Some 20 were undergoing peritoneal dialysis (83.33%) at the time of study. Details are summarised in Table A.1.

5.7.2 Coding and classifying data (patient group)

The second phase of Leininger's phases of ethnonursing data analysis emphasises categorising and classifying data related to the domain of inquiry or research questions of the study. It involves the discovery of repetitions of emic data with common and diverse meanings, expressions and explanation of culture care practice. In this study, open coding was used initially to provide unrestricted coding of data, so as to open the inquiry by closely

examining and comparing the data. The main points made by each informant were drawn out, then coded. The codes are: hesitant to talk (Code of Patient 1 - CP1), trust in relatives (CP2), existential distress (**生存困境**) (CP3), wear a happy face in front of people but shed tears behind their backs (對人歡笑背人愁)(CP4), ideological burden (思想負擔)(CP5), moderation (zhong yong, **中庸之道**)(CP6), impermanence (**無常**)(CP7), belief in fate (信命)(CP8), seize the day (活在當下)(CP9), let nature take its course (CP10), good death (CP11), decisions made by eldest son (老來從子)(CP12), grasp control (CP13), loss of life control (CP14), no more suffering (CP15), banned from talking (C16), respectful care (CP17), and hygienic care (CP18). As some of the codes were similar or overlapped for all 24 patient informants, these 18 codes encompass the emic views from the key patient informants regarding their perception and thoughts on the domain of inquiry.

The first code developed through the patient focus group interviews was hesitant to talk (CP1). Collectively from the informants' viewpoint, communication issues featured significantly. This included communication breakdown between patients and their doctors, patients felt that their doctor did not understand them or their needs, patients found it hard to trust the doctor, or they were scared to talk about end-of-life. On the other hand, patients were very aware that doctors are busy and they may not have time to the patients. However, they still wanted to voice out their needs and willingness to know. When the diagnosis of end-stage renal disease is confirmed, dialysis patients face many unknowns. With rising comorbidities and increasing frailty of older dialysis patients, the care paradigm in Hong Kong shifts to become more palliative and patient-centred. The demand for information on the true prognosis and treatment plan increases. Especially when active treatment has been stopped. When key informants were asked whether they had asked their doctor about life expectancy, and what they might expect from life, they expressed their concerns about talking to the health professionals in the following ways:

Informant 5: ‘I think doctors don’t have much time to listen. The appointment is short, they ... I don’t think they can spare time to listen to ... *unimportant things*.’ [The doctors spent most of the consultation time in reading laboratory results and typing prescription. Patients had a limited chance to communicate with the doctor. Some doctors might not prepare to handle the psychosocial issues from patients who might degrade the interest of asking questions during the consultation.]

Informant 7: ‘I really want to communicate with the doctors but I couldn’t because they are always busy.’

Informant 9: ‘I felt offensive whenever starting the conversation with the doctor.’

In spite of these concerns patients thought that health professionals, especially doctors, were the most appropriate personnel to initiate and guide them in discussions about end-of-life decision-making and end-of-life care planning.

Some patients trusted their relatives (CP2) to act as their surrogate and make medical decisions on their behalf when they were no longer able to do so themselves. Some expressed they did not trust the doctor as they thought the doctor would try every means to extend their lives instead of listening and following their wills. This was clear from the following patient accounts.

Informant 12: ‘I talk to my sister most of the time because I don’t trust the doctor.’

Informant 14: ‘Even though I want to talk about this issue, I would rather talk to my family members instead of the doctors.’

Informant 1: ‘If my life is out of my control, I trust my closest family members, like my wife, they are my shadows.’

Although some informants claimed they seldom talked about end-of-life or death issues with carers, this did not appear to mean they had not thought about it in their own

mind. At the same time, they seemed to hope that when the time came their carers would know what to do and make appropriate decisions for them.

> Informant 13: '… let me go without suffering. Death is all right with me. Just don't hang there, neither living nor dead. This is the most important issue! This will only annoy my family and me, both.'

How their carers would make appropriate decisions without a prior, thorough discussion is not clear.

Existential distress (生存困境) (CP3), was coded in informant 13's expression above. Managing distress privately is evident in wear a happy face in front of people but shed tears behind their backs (對人歡笑背人愁) (CP4), in their interviews patients expressed their isolation and their need to protect their family from their impending death by hiding pain and sadness from their carers and relatives:

> Informant 8: 'No one knows where the shoe pinches like the wearer! Why family? Because they are family! It's sad to lose family, it's a great loss!'

How the patients worked with their fears and stress to decrease the burden on their family was a priority. It was captured in ideological burden (思想負擔) (CP5):

> Informant 10: 'My family is unhappy when they know I am suffering from this disease. I know pretty well if I talk about these topics, it upsets them even more!'

Attitudes and beliefs of patients about the decision-making process at the end-of-life closely related to the significant culture in each's life. Irrespective of whether they were born and raised in China or Hong Kong, Chinese culture is full of rich and complex traditions. Confucianism is considered to represent the core values of Chinese culture, through which various viewpoints about dying and loss can be understood and classified (Chen, 2012). When informants were asked about their feelings about end-of-life decisions making topic, their illness in the future and their perceptions of end-of-life care, their answers were imbued

with Chinese philosophical beliefs; for example, those related to moderation (zhong yong, 中庸之道)(CP6), impermanence (無常)(CP7), belief in fate (信命）(CP8), and seize the day (活在當下）(CP9). Moderation (zhong yong) is the concept of an inclination for the middle way between extreme choices (Shi & Feng, 2010). It is derived from one of the core Confucian tenets on social conduct. It teaches us should not go to extremes, should stay in the middle, just as the expression goes. Chinese people take this moderate attitude towards everything. The fact of Impermanence means that reality is never static but is dynamic throughout which things have no essence, permanent self, or unchanging soul (Thera, 2008).

The examples of moderation (zhong yong, 中庸之道)(CP6) includes:

> Informant 15: 'Birth, ageing, illness and death is the natural course of life.' (CP6)
>
> Informant 23: 'When I first heard of this topic, I didn't reckon it was an issue! The disease has been diagnosed for years, three to four years, many patients just let go. Even if you want to do something, it is pathetic that the end will be the same! I am at peace, very peaceful.' (CP6)

Informant stated impermanence (無常)(CP7) as:

> Informant 13: 'It is difficult for those looking after you, and it's difficult for me too if I can't do anything, so let it be.' (CP7)

The code of belief in fate (信命）(CP8) was expressed as:

> Informant 3: 'I think I should let it go. After I suffered from the disease, I didn't really feel pessimistic. I only thought it was annoying because I couldn't do anything about it!' (CP8)
>
> Informant 26: 'Now, I don't have any alternative, except for waiting to die. So, just let it go, it's all right with me.' (CP8)

Examples of seize the day (活在當下）(CP9) include:

> Informant 10: ‘I just wilfully don’t think about it. I think living in the present is the best way to do things. That is, just finish the work for today as best you can. Don’t think too much about tomorrow, the day after tomorrow, or yesterday!’ (CP9)
>
> Informant 21: ‘Performing dialysis up till now, life was a day to enjoy a day. I won’t think too much.’ (CP9)

When asked whether they had told their family what to do if they became comatose or when they were no longer able to decide for themselves, who should make medical decisions for them, and whether they had talked about end-of-life care with anyone, both neutral and negative responses were identified; for example, the neutral response, let nature take its course (CP10):

> Informant 18: ‘Accepted gradually and don’t care anymore. I prepared to die with this disease.’ (CP10)
>
> Informant 24: ‘So I am not surprised if the condition gets worse or deteriorates. It’s natural. It’s just a matter of time. So I am ready for it.’ (CP10)

Overall most count not see the point of prolonging life. They wanted to be made comfortable and allow nature to take its course without suffering. In this circumstance, they expressed concerns about their family – patients did not want them to suffer because they were. Among the patient group (irrespective of their place of birth), as in the community at large, the desire for a good death (CP11) with no more suffering (CP15) was common. Whether patients talked with others about their end-of-life concerns, it was clear that over time they reflected on what was ahead of them. For example:

> Informant 18: ‘I accepted gradually and don’t care about it anymore. I prepared to die with this disease. However, I don’t want to be punctured during resuscitation.’ (CP11)
>
> Informant 5: ‘I prefer dying naturally when I was coma rather than inserting anything into my body or giving anything to me to maintain my life.’ (CP11)

Informant 4: ‘So I told my doctor, I don’t want to suffer before I die. Just let me go without suffering!’ (CP15)

Informant 5: ‘... If my condition is critical ... don’t make me suffer! Do not resuscitate me, I don’t want others to suffer from my suffering!’ (CP15)

Informant 23: ‘I think it is good, less suffering in the critical moment. There’s no point to insist on saving life.’ (CP15)

Patients and families can only plan appropriately if they are informed and aware of the severity of the illness and prognosis. Frail patients at the end of their life either made the decisions by eldest son (老來從子)(CP12) or grasp control (CP13) on the treatment plan. In patriarchal Chinese culture, the son, especially the eldest son, is usually the prime decision-maker (Soontiens, 2007). Examples of made the decisions by eldest son (老來從子)(CP12) include:

Informant 6: ‘Of course, my eldest son will make the decision if anything happens!’ (CP12)

Informant 20: ‘Involving myself if I am conscious, adding my son and doctor.’ (CP12)

Informant 22: ‘My sons, they must be there whenever a decision has to be made. It’s fine with me.’ (CP12)

Informant 23: ‘My wife and my sons decide, no one else.’ (CP12)

Some informants expressed that they wanted to grasp control (CP13) of the care or regain autonomy:

Informants 6, 1, 2 and 3: ‘I decide it myself … I am willing to … ’ (CP13)

Informant 18: ‘It’s all right. That is, just listen to my requests and help me finish them. It sounds great!’ (CP13)

Informant 22: ‘Sure, when I am conscious, I can make decisions!’ (CP13)

For the negative responses, loss of life control (CP14) was coded because the patient informants expressed negative feeling to accept the situation without choice.

Informant 23: 'I don't have a choice, and I am ready now!' (CP14)

For banned from talking (CP16); informants were suppressed not to talk even think about death. Negative impact would occur if feelings or thoughts could not be ventilated.

Informant 15: 'I have told my families everything. I am still alive, should I mention death all the time? It's kind of bad luck. I don't feel like it. You may not be superstitious, but it's very annoying if you keep saying this.' (CP16)

Informant 7: 'They are angry whenever I talk about this. They ask me not to think about it and think about it when it comes.' (CP16)

Informant 9: 'They blamed me for talking about death all the time, they won't listen.' (CP16)

Informant 15: 'I told them but they said it's no good to talk about death always. You are still alive, aren't you?' (CP16)

The informants expressed concern about wanting to receive respectful and hygienic care if and when they became unconscious. It was clear from what patients said that most of them had either received or witnessed other patients getting different standards of care while they were hospitalised. They also observed the lack of respectful and hygienic care provided to those patients who were frail and or unconscious. It seemed to scare them that the same care might apply to them when their time came. The following examples were identified during the interviews to illustrate respectful care (CP17) and hygienic care (CP18):

Informant 2: 'Every patient needs to maintain their dignity. If I can't move but I still feel, I want to be neat and tidy, looking like a normal person!' (CP17)

Informant 9: 'For those who are incontinent, I don't think they have dignity. I would rather die sooner!' (CP17)

Informant 5: '… that is to say, be neat and tidy before someone sees me. It's not polite to see someone with dishevelled hair and things like that." (CP18)

Informant 4: 'That is, if I want to change a diaper, nurses must change it for me. This is the nursing care I want!' (CP18)

Informant 11: 'Basically someone can bath you when you cannot do it yourself; someone can feed you when you can't take it. That's it!' (CP18)

5.7.3 Developing categories (patient group)

Phase three encompasses data saturation and recurrent categories of common and diverse meanings, expressions or interpretations relating to the domain of inquiry. Categories identified are supported by various codes; codes with similar meanings were grouped together to become categories. For example, the category of 'trust and mistrust' was established from hesitate to talk and trust in relatives. Patient informants suffering from chronic illness might feel a loss of control in disease treatment and daily activities. Informants lose hope and totally rely on their carers or medical staff.

'Dependence' was another category covering the lack of advance care directive. When the patient informants suffered or felt sad, they did not want to be a bother to others, especially their significant others. They were protective of their families. Not wanting to burden loved ones with worry about their impending death or suffering seemed to stop patients from talking about it or making their needs and desires known to others.

Subsequently, the category of 'mutual protection and respect' was matched to patients' practice of wearing a happy face in front of people but shedding tears behind their backs (**對人歡笑背人愁**) and ideological burden (思想負擔).

At start of each focus group interview, informants were asked to express their thoughts and feeling topic about what they saw as priorities for their care in the final stages of life as well as how and who should make such decisions. A category of 'spiritual culture' was

drawn from the codes of the informants, including moderation, impermanence, belief in fate, seize the day and let nature take its course. Each of these codes is imbued with thousands of years of cultural development and knowledge, as discussed further in the next chapter.

Linked to spiritual aspects, it was common for dialysis patients to discuss their desire for a good death. At the same time, they did not want to waste money on long-term care. This seems to be linked to 'social culture' articulating the Chinese cultural norm. The 'social culture' category was illustrated by 'good death' and 'decisions made by the eldest son' (老來從子).

In addition, 'taboo' was a common category identified from informants, supporting the code of 'banned from talking about end-of-life'. The informants were stopped by family members whenever they commenced to talk about death. This taboo is also common among ethnic groups, including Westerners, Asians and Hispanics.

Four categories were synthesised from various codes to describe expectations of end-of-life care from the emic views of the informants: 'autonomy and independence', 'attitude towards illness', 'require dignified care' and 'existential suffering'. Codes belonging to the category, 'sense of autonomy and independence' included, 'grasp control' and 'loss of life control'. The second category, 'attitude towards illness', showed that informants faced their predicament with mixed feelings. Consistent across all reports was patients' desire for the suffering to stop. It is common for humans to want to be respected. It is unsurprising that dialysis patients suffering from chronic illness, its treatment, and more often than not, with accompanying complications over many years, yearned for 'dignified care' from healthcare professionals - especially in the decision-making process about death and dying. However, patients commonly reported that their needs were often suppressed because of lack of time during the consultation. Some informants declared that they received undignified care when in hospital. Respectful care and hygienic care were the codes in this category. 'Existential

suffering' was the last category formulated, relating to the code of existential distress. It originated from patients' expressing thoughts around why they still lived especially when their existence did not seem to them to have significant meaning to others, including family. It was a dilemma for some patients when considering decisions that might extend life, or when they thought it would burden, they wanted to leave the world without causing trouble to their families.

5.7.4 Synthesising themes (patient group)

The synthesis of data resulted in emerging themes that describe the meanings, categories and expression of the decision-making process of dialysis patients and carers. The researcher worked systematically through the whole data set to identify aspects that might form the basis of repeated categories and become themes. Mind-maps were adopted as visual representation to assist in organising this process. Some codes had been located to form main themes whereas others were characterised as categories. Thematic maps were developed for findings from patient informants showing at Figures 5.1 to 5.3; and the same process for carer informants at Figures 5.4 to 5.7.

Three themes were identified from the patient informants: communication barriers (Figure 5.1), Chinese cultural norms (Figure 5.2) and dying with dignity (Figure 5.3). The first theme, communication barriers (Figure 5.1), was formulated from the synthesis of three categories: trust and mistrust, dependence, and mutual protection and respect.

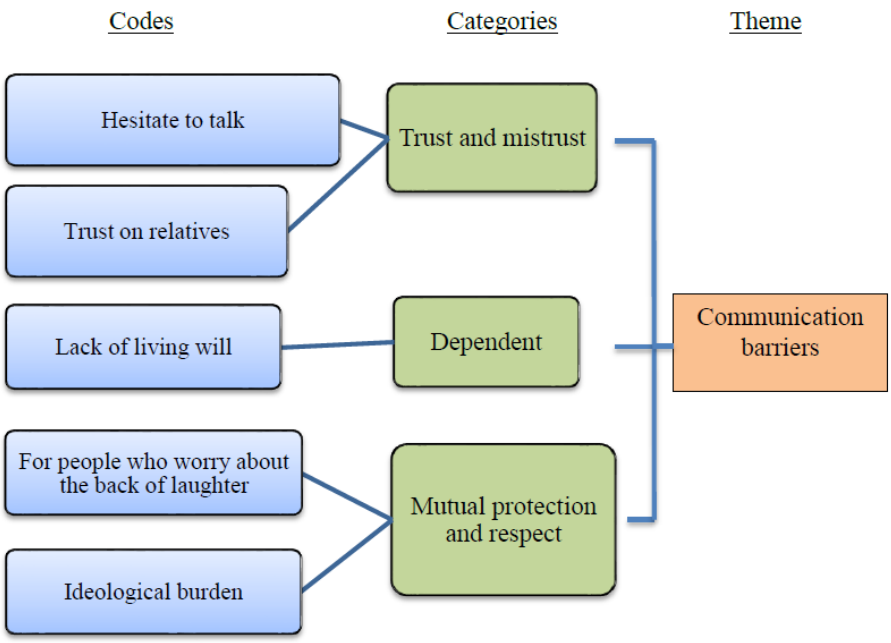


Figure 5.1 Patient theme: communication barriers.

The second theme, Chinese cultural norms (Figure 5.2), was articulated from the synthesis of three categories: spiritual culture, social culture and taboo. As the major focus of this study highlights the cultural aspects of the decision-making process of dialysis patients towards end-of-life care, norms in Chinese culture should be expected to significantly affect the ways of thought (both commonalities and diversities) among informants.

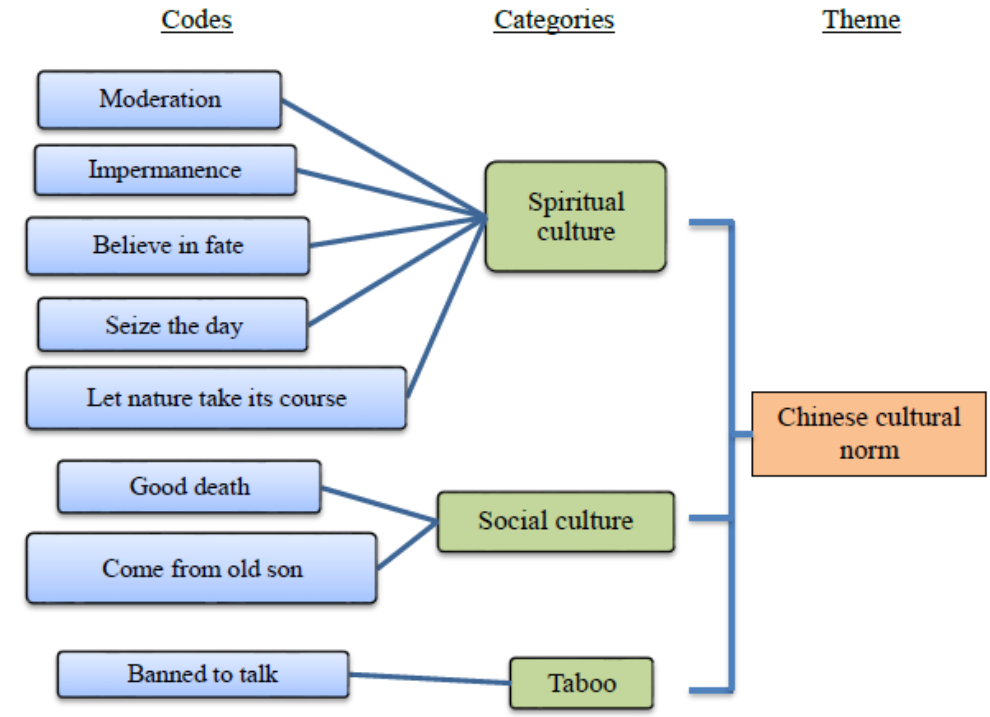


Figure 5.2 Patient theme: Chinese cultural norms.

The third theme, dying with dignity (Figure 5.3) was formulated from the synthesis of four categories: sense of autonomy and independence, attitude towards illness, require dignified care and existential suffering.

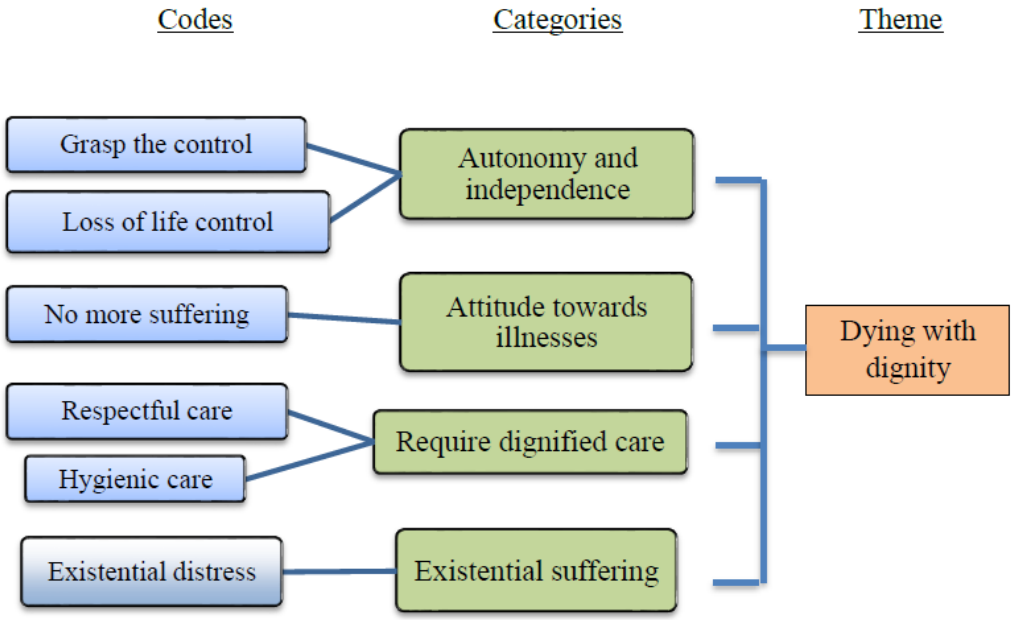


Figure 5.3 Patient theme: dying with dignity.

5.7.5 Collecting and documenting raw data (carer group)

When studying the data from the carer group, it also adopted the Leininger's four phases of ethnonursing data analysis. In traditional Chinese culture, age and gender imply well-defined roles and tight bonding in the family and family networks (Chan & Chui, 2011). The eldest male in the family makes decisions for the family. The relationships of husband and wife are also bound by the traditional Chinese marital philosophy, which reflects the lifelong commitment of caring for each other. The spouse (husband or wife) cares for the ill partner. Women play a central role in spouse and elder care in patriarchal families. Under the strong influence of Confucian norms in Chinese culture, filial piety is emphasised in the carers' manner towards ill family members (Chen, 2012). As the dialysis patients received treatment and their disease progression increasingly has psychosocial and spiritual effects on the whole family, understanding how carers perceive end-of-life care and decision making, especially under the influences of culture, would inform the presence of universality and diversity. As shown in Table A2, three out of 14 carer informants identified as Indonesian maid carers identifying a strong commitment to their Islamic faith. The remaining carers were Chinese family members. Commonalities and diversities were investigated to illustrate the impact of culture of the Chinese and Indonesian groups. The following section discusses the codes, categories and themes drawn from the key informants in the focus groups of carers.

Some 14 dialysis patient carers participated in three focus group interviews, ranging from three to six informants per group. The same strategy carried out in the patient focus groups was applied with the carers group. In the analysis, each of the carer informants was allocated an identification number from 25 to 38 as strategy for keeping their confidentiality throughout the thesis and any subsequent publications. The mean age of the informants was 49, ranging from 18 to 74. Two (14.29%) were male. The mean patient dialysis months was

61.71, ranging from six to 168. Seven were taking care of peritoneal dialysis patients (50%) at the time of the study (see Table A.2). The interviews commenced with a broad question regarding carers' feelings and perceptions as they listened to the subject of research. Subsequently, carers were asked about their observations, understandings, perceptions, and experiences about care priorities at end-of-life of the patients to gain insights into the informants' perspectives of the dialysis patient point of view as well as their own.

5.7.6 Coding and classifying data (carer group)

In the process of coding and classifying data, 26 codes were summarised. Some of the questions asked in the patient and carer focus group interviews were similar. Carers were probed for their emic views and empathetic perceptions towards the sick patients they were caring for. Eight codes were shared with the patient informants including no more suffering [Code of Carer 1 (CC1)], impermanence (無常)(CC9), moderation (中庸之道)(CC14), seize the day (活在當下)(CC18), existence distress (生存困境)(CC19), grasp control (掌握控制)(CC20), let nature take its course (CC21), and ideological burden (思想負擔)(CC26). The remaining were from the carer informants including peaceful death (CC2), respect patient's decision (CC3), meaningless to extend life (CC4), inevitable deterioration and death (CC5), sense of responsibility (CC6), cohesiveness (CC7), psychological relief (CC8), return of kindness with no regret (CC10), helplessness (CC11), dependent role of patient (CC12), knowledge deficit (CC13), earning life (CC15), sentence to death (CC16), stress and burden (CC17), family decision (CC22), respect professional knowledge (CC23), need hygienic care (CC24), and die with dignity (CC25).

Codes 1-5 are drawn from carers' responses to the opening question of the focus group interview. Like patient responses, many carers expressed a desire for no more suffering (CC1). For example:

Informant 27: ‘I am not old, just like the other guy said, just leave without suffering. It is the best wish.’ (CC1)

Informant 26: ‘She also agrees if she [patient] suffers greatly and the doctor says there is nothing more we can do ... just let her leave and don’t make her suffer, because no one can escape death. No one wants her to suffer.’ (CC1)

Informant 35: ‘Worrying is none of my concern. If doctors can help, just help patients leave peacefully. We can’t avoid suffering, just take everything easy, have a little bit more self-control, and believe that I am more blessed than others. This way, we will feel better.’ (CC1)

Examples of a peaceful death (CC2) include:

Informant 29: ‘At the terminal stage, we’d better let them leave peacefully than painfully. It is good for ourselves and our family.’ (CC2)

Informant 29: ‘I don’t think it’s necessary to keep living longer ... if the doctor says there is nothing more we can do, just take the doctor’s advice. Then, let her leave peacefully.’ (CC2)

Informant 37: ‘If there is nothing doctors can do, I think it’s good to make one more comfortable. Also, don’t waste their efforts. Simply speaking, let me leave peacefully.’ (CC2)

Example of respect patient’s decision (CC3) is as follow:

Informant 29: ‘I always respect her, let her spend life comfortably.’ (CC3)

For the code of meaningless to extend life (CC4) is:

Informant 30: ‘If it is the end of your life, it’s meaningless to sustain your life with medication!’ (CC4)

The example of inevitable deterioration and death (CC5) is:

Informant 28: ‘The condition worsens for sure, and you must prepare for the worst. As caregivers, when we see them going down … we feel helpless because we can’t do anything for them.’ (CC5)

Carer codes 6-10 were identified from carers responses to considering their thoughts and feelings about the patient’s illness into the future and whether they had talked about end-of-life care with the person they were caring for. The codes of sense of responsibility (CC6), cohesiveness (CC7), psychological relief (CC8), impermanence (無常)(CC9), return of kindness with no regret (CC10) were acknowledged:

Example of sense of responsibility (CC6) include:

Informant 30: ‘I’m not worried, but she is my family and it is my responsibility to take care of her.’ (CC6)

Drawing on the Indonesian maid carer’s Islamic faith which was coded as cohesiveness (CC7), they said:

Informant 33: ‘The illness is from God and it is a gift to me to test myself. My family will take care of me if I am sick.’ could be identified. (CC7)

From a local Chinese carer expression, another example of cohesiveness (CC7) is as follows:

Informant 29: ‘… To me, she is like my parent. I have spent more than 40 years with my master, no, nearly 50 years. If you ask me to give her up and put her in a hospice, I dare not making this suggestion.’ (CC7)

Informant 25: ‘It didn’t frighten me. As for caregivers, although I am not the patient, when they see you suffer, they will do anything to save you, incessantly, because they are family (relatives).’ (CC7)

Following is the example of psychological relief (CC8):

Informant 29: ‘This way, your family will not need to make any difficult decision for you!’ (CC8)

> Informant 36: ‘When I hear about this priority decision for the end-of-life, it’s natural for me to associate it with death and feel depressed. But when I reckon that death is part of life … When we know about this disease, we are ready for that and accept it.’ (CC8)

For impermanence (**無常**) (CC9), the following example was drawn:

> Informant 28: ‘My mother keeps talking about this every day. She told me the other day that it is just out of luck she survives!’ (CC9)

Whenever people are living together, no matter there is family relationship, master and disciple relationship or friendship; it may echo a Chinese proverb: “路遙知馬力，日久見人心。Just as distance determines the stamina of a horse, so does time reveal a person’s true heart.” Return of kindness with no regret (CC10) was coded:

> Informant 29: ‘We have mentor-mentee relationship. I have to fulfil my responsibility as a mentee. Those are the debts that I owe her and have to return.’ (CC10)
>
> Informant 32: ‘Take good care of her … let her feel happier.’ (CC10)

When carers talked about their feelings and opinions they experienced while caring for the dialysis patients the following codes were revealed: helplessness (CC11), dependent role of patient (CC12) and knowledge deficit (CC13).

Examples of helplessness (CC11) include:

> Informant 28: ‘The condition worsens for sure, and you must prepare for the worst. As caregivers, when we see them going down … we feel helpless because we can’t do anything for them.’ (CC11)
>
> Informant 30: ‘We have discussed it before making the decision: let her leave peacefully, because we can’t do anything about it.’ (CC11)

The code of dependent role of patient (CC12) includes:

Informant 25: ‘As she is dependent on me, she asks me to make the decision. So I have talked to her jokingly, this way she gives me so much pressure.’ (CC12)

Informants expressed that they had knowledge deficit (CC13) while they were caring their sick relative.

Informant 34 and 37: ‘I think I will let the doctor decide, because we don’t have that knowledge to decide ... this is annoying!’ (CC13)

While carers take their responsibilities seriously, however it can at times can be demanding and burdensome; not only with the ever persistent need to assist with daily activities and other physical care, for example, the dialysis procedure, but they often endured the patient’s labile moods and emotions. How did the carer informants face this challenge? How could they adjust their thoughts towards the disease trajectory? They were asked not only to respond from their own experience but to also reflect on what it might be like for the patient. The carer informants were able to imagine of what might be like or the person were caring for, with the issue they might be facing in their life, even though between them they did not often discuss it. From the conversations, the codes, moderation (中庸之道)(CC14), earning life (CC15), sentence to death (CC16), stress and burden (CC17) arose. Example of moderation (中庸之道)(CC14):

Informant 27: ‘I’m not afraid. Why? After having haemodialysis for so many years, I have accepted it.’ (CC14)

When thinking in a positive way and with spiritual support, informant appreciated the days they had been given.

Informant 38: ‘Well! If the moment hasn’t come ... if life can go on and God wants you to stay, just accept it. Anyway, I am blessed already.’ (CC15)

While carer informants walked along the journey with their sick relatives, they experienced the chronic disease trajectory and feelings perceived empathetically. One of them had the following expressions which were coded as sentence to death (CC16).

> Informant 37: 'We have prepared for that moment, but it seems like a death sentence, just like she will leave us at any time. I think the atmosphere is very important.' (CC16)
>
> Informant 37: 'When hearing about the terminal stage, I am shocked. It seems that it's time to ... to end life suddenly. (CC16)

Example of stress and burden (CC17):

> Informant 34: 'I can't say a word! The consequence is too big. I will die immediately!' (CC17)

As the trajectory and outcome of end-stage renal disease are mostly unpredictable, dialysis patients and carers face uncertainty and stress daily, often over many years. They found difficulty in confirming appointments with friends, life becomes unpredictable in the normal sense of orderliness: one day they are at home, the next day they might have to take care of their patient relative in the hospital. Carers adapted to the situation of lack of regularity through following codes. They understood that life was more unpredictable as the disease processes. This strategy was the way the carers managed it. The codes seize the day (活在當下)(CC18), existential distress (生存困境)(CC19), grasp control (掌握控制)(CC20) and let nature take its course (順其自然)(CC21) were identified. Individuals spend life in various ways. Examples of seize the day (活在當下)(CC18) include:

> Informant 26: 'Patient understands her own condition … She said, no one can escape it, just accept it, with pleasure. This means she has accepted it. Like what you said, when you live one more day, you have earned one more day.' (CC18)

> Informant 36: ‘When we know about this disease, we are ready for that and accept it ... Just live in the present! Some suffer more than you … So, just face it, positively!’ (CC18)

Birth, ageing, sickness and death are the norms. Carers expressed the code existential distress (生存困境)(CC19) as follows:

> Informant 25: ‘… But you know, more suffering will come afterwards, and saving him is thus cruel to me.’ (CC19)
>
> Informant 25: ‘It’s been longer than a dozen years. Particularly at the beginning, she had experienced everything, even the ICU, she has been there many times. When that moment comes, she thinks she has no reason to stay any longer.’ (CC19)
>
> Informant 30: ‘Even if we could keep her for a while, she will suffer more. Frankly speaking, if she neither lives nor dies, even though we can sustain life, we are hurting her.’ (CC19)

Life is not easy. Fear of the unknown is one of the crucial issues the carers or patients have to face whenever chronic illness is present, and life goes to the final stage. Individuals desire to make control of some areas in their life. Examples of grasp control (掌握控制)(CC20) include:

> Informant 26: ‘I have discussed with her children, they also agree with that. She also agrees. They all have accepted it. She has suffered many years and doesn’t want to suffer anymore. I also hope she can leave peacefully.’ (CC20)
>
> Informant 28: ‘So I will make the decision, the decision for her. Don’t make her suffer anymore … If it hurts, definitely, but pressure, I think is all right, there is more sorrow than pressure.’ (CC20)
>
> Informant 29: ‘I have decided to save all the trouble. Just let myself decide the process in advance.’ (CC20)

Informant 36: ‘If we know what the choices are, we will make the decision in advance. (CC20)

The following extracts illustrate the code of, let nature take its course (順其自然)(CC21):

Informant 28: ‘My mother keeps talking about this every day. She told me the other day that it is just out of luck she survives! So she has prepared for that.’ (CC21)

On being asked who should make medical decisions if a patient is unconscious and who should be involved in the discussion of end-of-life care, carers expressed similar answers to the patient informants. Also, when studying the emic view of the Indonesian maid carers (Informants 31, 32, & 33), they had a stronger vision to take care of their sick family members and did make medical decisions for them. They had a strong sense of family responsibility and caring for relatives at home. However, there was not an opportunity to follow up on how that belief affected their care of a Chinese person facing the end of their life with end-stage renal disease. Carers mostly trusted healthcare professionals and family. Some set the sequence of decision-makers as the carers themselves, healthcare professionals and families. They also asserted that the doctor and family should be involved in the discussion of care priority at end-of-life. Two new codes were identified under family decision (CC22) and respect professional knowledge (CC23):

Informant 28: ‘Let the family decide! Why? Doctors usually want to save you and sustain your life. However, you should ... talk to your family in advance!’ (CC22)

Informant 30: ‘I ... I don’t want others to make decisions for me. My life my choice ... if I don’t wake up it means ... or my family, people around me, my children!’ (CC22)

Informants 31, 32 and 33 (Indonesian maid carers): ‘I agree to let the family decide!’ (CC22)

Informant 36: ‘First, my family will discuss the condition with the doctor. If the doctor tells them clearly, let them decide.’ (CC22)

Informant 26: ‘I will choose my doctor. If he thinks there’s nothing he can do, just accept it. Children will never know if there is any chance, only the doctor knows.’ (CC23)

Informants 34 and 37: ‘I think I will let the doctor decide, because we don’t have that knowledge to decide ... this is annoying!’ (CC23)

Informant 36: If we don’t know, following the doctor’s advice will be the most appropriate choice!’ (CC23)

While treatment preferences for end-of-life care are intended by health services to be chosen by the dialysis patients themselves, the decisions were always left to the carers because of lack of prior discussion or adequate access to appropriate information. In fact, the idea of informed consent or informed decision-making where the healthcare professionals provides information to the patients in order for them to make the decisions about how to proceed. In practice, without proper prior discussion, carers became the default decision maker. The reasons may be multifactorial and are discussed in the next chapter. When carers were asked about their observations, understandings, perceptions, and experiences about care priorities at end-of-life of the patients, the findings of both Chinese and Indonesian groups were similar with what the patients had expressed – need hygienic care (CC24) and die with dignity (CC25) were classified. The Indonesian informants would prefer to die at home, while Chinese informants universally stated that hospital was the place to be cared for through the dying process.

Informant 26: ‘Cleanliness is the most important thing! Take a bath, wear nice pyjamas before leaving, I won’t expect too much.’ (CC24)

Informant 36: ‘If there is nothing a doctor can do, I think intubation and other ways of resuscitation will be in vain. As for nursing, I think when I leave, my family will clean me up and put my favourite clothes on me.’ (CC24)

Informant 29: ‘When we are in a coma, we know nothing. People can do whatever they like to us.’ (CC25)

Informant 28: ‘Leave with dignity. Right. For example, clean me up and change my diaper. This way, I can leave peacefully and contentedly.’ (CC25)

Informant 32: ‘Consulting a doctor charges a lot. Not many people have money to spend on medical consultation. Therefore, our people would like to die at home rather than going to the hospital. I feel happier to die at home with my families nearby.’ (CC25)

Informant 35: ‘If it is the terminal stage, why not leave more comfortably? Also, neatly and tidily!’ (CC25)

Informant 36: ‘If it is the terminal stage or the end, it means God is taking you home. Just let it happen, and there is no need to resuscitate me. This way, I can keep my dignity!’ (CC25)

The carers were always in a dilemma. They hoped to fulfil the traditional Chinese ideals of taking care of patient relatives unconditionally, but the burden and stress of caring threatened to make them quit or feel overwhelmed. They might wear a happy face in front of people, but shed tears behind their backs. The code ideological burden (CC26) was established:

Informant 26: ‘If she doesn’t what to go there, if we insist, I know it’s for her good, it seems that we are abandoning her!’ (CC26)

Informant 28: ‘I agree, because you must try. If you don’t want to go to places where you can’t see your family, and you put her there, she will be very unhappy because she misses her family. However, they can give better nursing care there, this may help, because they may talk to her and counsel her. This may change her mind and

attitude and she won't split hairs. She will split hairs and think negatively at home.' (CC26)

Informant 30: 'I feel painful, really painful. In the end, I convinced myself: there is nothing I can do, because I owe her in my previous life, so I must repay her in this life.' (CC26)

Informant 36: 'I think a hospice is good for her, at least there is health care. Sometimes, however ... a hospice also brings great pressure to patients and family. For example, when we visit her at the hospice, it seems like the end of the world!' (CC26)

5.7.7 Developing categories (carer group)

As with the process of analysing the dialysis patient informants' data, the recurrent categories of common and diverse expressions, meanings and interpretations of the carer informants were revealed in relation to the domain of inquiry of this study. The category of 'respecting wishes' was supported by the codes of no more suffering, peaceful death, respecting patient's decision and psychological relief. When the carers look after their patient relatives, they contribute both physically and psychologically. Codes of sense of responsibility, return of kindness with no regret and cohesiveness supported the category 'being present'. The category 'attitude towards patient' was established from helplessness and dependent role of patient.

It is nearly impossible to know what the patient wants and thinks. This is more extreme in Chinese culture because the family seldom talks about death and dying in ordinary conversation or communication. Living with and taking care of a dialysis patient requires great effort. Sometimes, understanding the patient's thoughts is not enough, carers may need to make decisions which clash with this understanding. In asking how the carer informants tackle these issues, two categories were formulated: 'avoiding thought of death' was from the

code of sentence to death and ‘encouragement’ was supported by earning life and seize the day (活在當下）.

With the impact of the end-stage renal disease, variations of the treatment regimen and social and familial role changes, three categories could be identified to illustrate the pressure on the carer informants. ‘Living with uncertainties’ was supported by stress and burden, existential distress (生存困境） and impermanence (無常）. ‘Witness of health decline’ demonstrated the feelings of carers as they watched the gradual health deterioration of their patient relative; let nature take its course (順其自然） and meaningless to extend life were the codes contributing to the establishment of this category. If, unfortunately, the patient relative was admitted, the carers ‘expect quality care’. This category was supported by the codes of respect professional knowledge, need hygienic care and die with dignity.

Carers can struggle with the caring process. They have to face treatment-related issues and the deteriorating health of the patients, as well as adjusting their life style and schedule. They may also feel pressure to instil a positive atmosphere and spirit for the patient and other family members. Three categories were identified from the transcripts of the focus group interviews. ‘Making sense of the disease’ was verbalised with the codes of inevitable deterioration and death and knowledge deficit. The second category is ‘wear a happy face in front of people but shed tears behind their backs (對人歡笑背人愁）’, which was characterised by the codes of moderation (中庸之道） and ideological burden (思想負擔）. The third category was ‘sense of autonomy’, which described the attitude of the carers during the decision-making process; family decision and grasp control (掌握控制） added to give this category.

5.7.8 Synthesising themes (carer group)

The researcher performed the same method as the patient groups to create mind-maps, then thematic maps showing in Figure 5.4 to 5.7. Four themes emerged from the carer

informants: personalising care, normalising life, sharing burdens and the carer's plight. According to the categories identified in phase three, the theme personalising care was synthesised from respecting wishes, being present and attitude towards patient (see Figure 5.4).

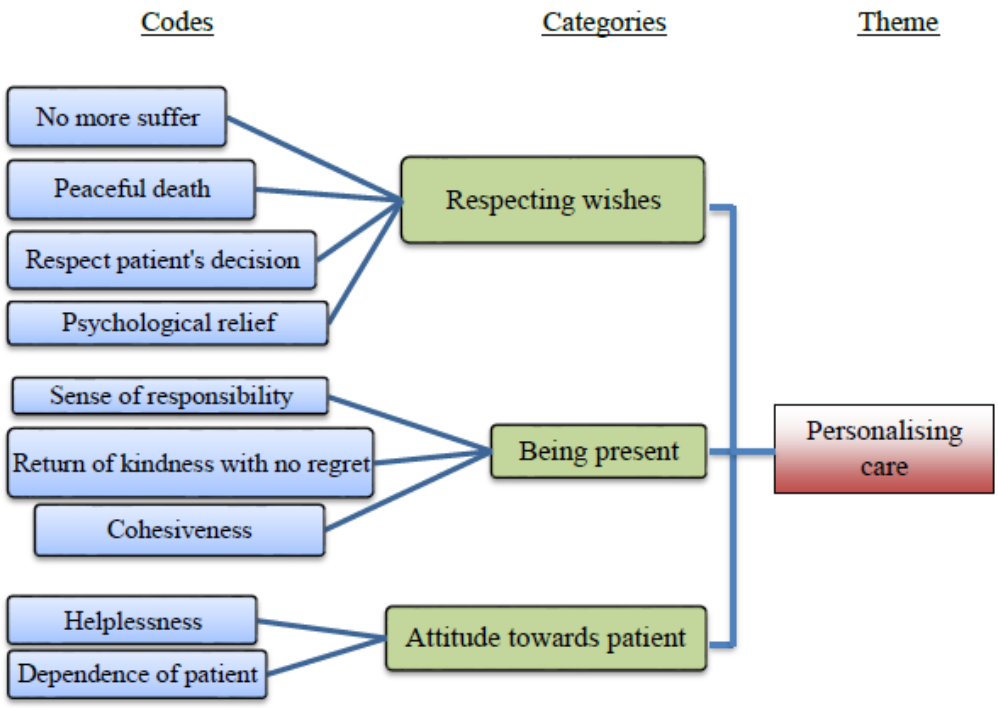


Figure 5.4 Carer theme: personalising care.

The second theme, normalising life, was articulated from avoiding thoughts of death and encouragement (Figure 5.5).

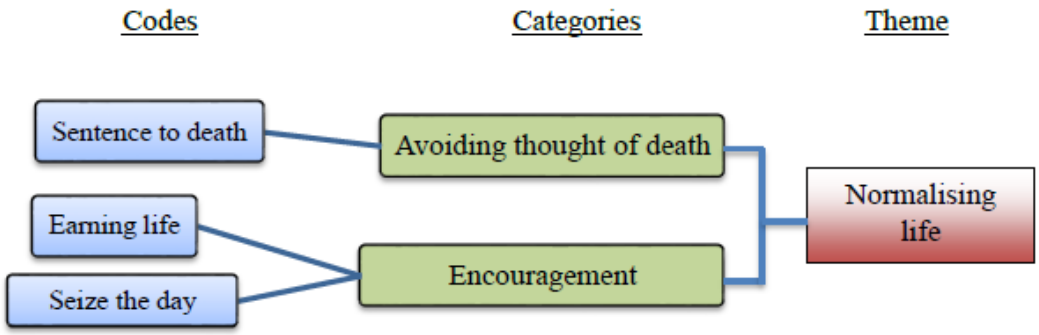


Figure 5.5 Carer theme: normalising life.

The third theme, sharing burdens, was established by living with uncertainties, witness of health decline and expecting high quality health care (Figure 5.6).

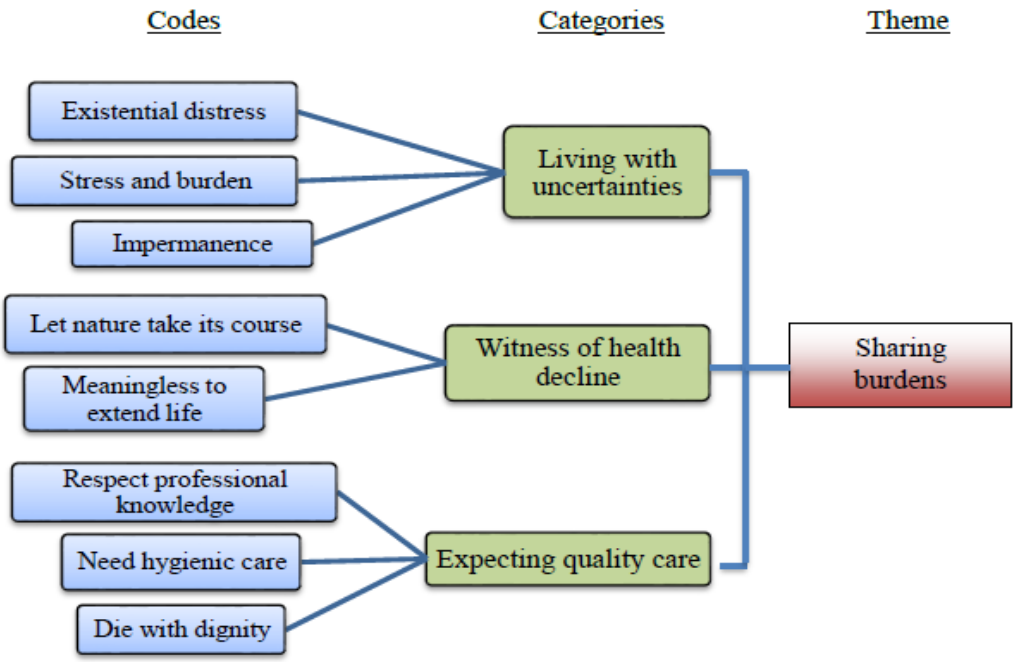


Figure 5.6 Carer theme: sharing burdens.

The fourth theme was the carer's plight, derived from the categories of making sense of the disease, wear a happy face in front of people but shed tears behind their backs and sense of autonomy (Figure 5.7).

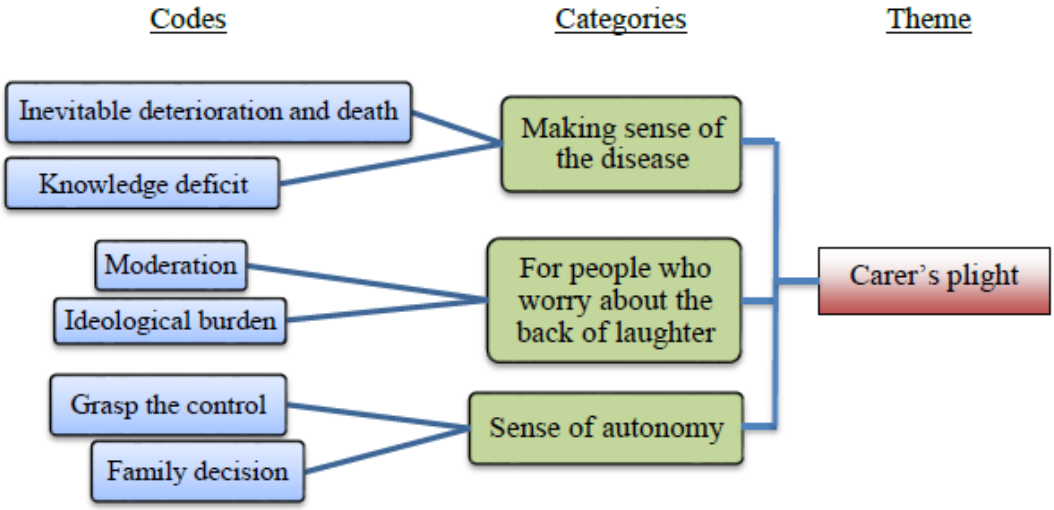


Figure 5.7 Carer theme: carer's plight.

5.8 Summary

In summarising this chapter, the findings from the survey tangentially answered the research questions: Who should participate in the discussion and decision making about end-of-life care? What should be discussed during the decision-making process? How should the decision be made? The survey findings also provide initial ideas and records of how the informants perceived the research topic. As this is a mixed methods sequential explanatory design, the survey findings were used to guide the focus group interviews. While applying Leininger's phases of ethnonursing data analysis, the emic views of the informant's feelings, perceptions, thoughts and attitudes were identified towards the care priorities at final stage of life and preferences for end-of-life care decisions. There were common and diversified ideas from both groups of informants.

Taken together, these findings suggest that there is a statistically significant association between patient and carer informants on the comfortability discussing the end-of-life issues with family members. Otherwise, no association was found among the independent variables such as place of birth, education status, working status, type of treatment, duration of dialysis, dialysis done by whom of patient and the variables of dialysis knowledge, decision-making and end-of-life care preference in the survey findings. It is coincidental that this quantitative significance connects strongly with the expression of the focus group informants about they seldom discussed end-of-life issue with their family members too. Both patient and carer informants expected their family members to make the medical decision for them even without prior discussion.

As shown in the qualitative data analysis, carer informants shared eight codes with the patient informants. Mostly the shared codes had similar meanings because the majority of the informants possessed Chinese culture in origin. Interestingly, this relationship is related to the belief in the Indonesian maid carer informants which caring for sick family member and

making the medical decision for them were also the norms. Indonesian maid carers though they were a small component in the carers' group, were open to sharing their views and beliefs being a carer and about end-of-life decision-making. Although it is difficult to generalise the findings, the perspective is insightful, given that there are growing numbers of foreign domestic helpers caring for Hong Kong Chinese people with chronic conditions because family members are working and have to outsource care of dependent family members. This growing trend in society implies that they were the people to care for the sick or responsible for reporting to the family members of what is happening about the sick patient. Further discussion will be presented in the next chapter.

The themes covered physical, psychological, social, spiritual and cultural aspects. Apart from the informants' personality, the traditional Chinese culture had a significant impact on the viewpoints and actions to be taken in facing the final stage of life. The patient informants considered communication barriers, Chinese cultural norms and dying with dignity the major themes in the decision-making process for the end-of-life care domain. In contrast, the four themes of the carer informants were expressed and delineated as personalising care, normalising life, sharing burdens and the carer's plight. The next chapter discusses these findings in relation to the existing literature in this field and implications they may have for future practice research and education about decision-making processes and end-of-life care preferences of people living with end-stage renal disease.

Chapter 6: Discussion

6.1 Introduction

Decisions about care priorities at the final stage of life from the renal dialysis patients' and carers' perspectives were revealed with the application of the ethnographic approach. This chapter discusses issues affecting the viewpoints of the informants, especially the cultural impact. Compared with the current literature, the findings of this study have both universalities and diversities; these will be reviewed first. As this research uses the qualitative-driven mixed methods sequential explanatory design, the qualitative data were scrutinised by Leininger's phases of ethnonursing data analysis enabler, to explain the domain of inquiry, as analysed later. Discussions will concentrate on the findings from the qualitative aspect. From the key patient informants, 18 major codes, 10 categories and three themes emerged; in analysing of the carer informant cohort, 26 major codes, 11 categories and four themes were identified. As shown from the findings of patient informants, communication barriers, Chinese cultural norms and dying with dignity were the themes identified in the decision-making process at the end-of-life care domain. Conversely, four themes from the carer informants were delineated: personalising care, normalising life, sharing burdens and the carer's plight. The key findings include the interactions among communication barriers, family dynamics, sharing burdens and existential distress, contributing to the core conception, 'dignified dying'.

The discussion starts with revisiting the end-of-life care issues. The universality and diversity of the findings from the dialysis patients and carers are described and compared with the current research studies under the categories of self-report knowledge and end-of-life care preference. While integrating the universalities and diversities of both dialysis patients and their carers towards decisions on care priorities at end of life, a model of overarching influence of culture in the decision-making process of dialysis patients and

carers at end of life was formulated, with interactions among the components of communication barriers, family dynamics, sharing burdens and existential distress. The core was established as ‘dignified dying’. This model explains the relevance of the findings and addresses the research questions set in the domain of inquiry. Through this research study, the ideas of good death, end-of-life care, advance care planning and advance directives could also be reflected among the informants.

A small number of carer informants were migrant maids from Indonesia. Although a minority in the focus groups, they openly shared their views and beliefs being a carer and about end-of-life decision-making. Generalising the findings is difficult. However, they provide insight and give rise to further research. Given that there are growing numbers of foreign domestic helpers in Hong Kong, there were 360,000 foreign domestic helpers in 2016. Because of an ageing population, it is estimated that the demand will grow to 600,000 in 30 years. An additional 240,000 foreign domestic helpers are needed, just for looking after elderly or chronically ill persons (The Census and Statistics Department, 2017). Moreover, the language proficiency in Cantonese of Indonesian maid carers is generally welcomed by local families which is now the second largest foreign domestic helpers (44% of total) in Hong Kong, with its number rising by eightfold during 1995-2016 to 154,000 persons (Legislative Council Secretariat, 2017). The affective aspect in the care work of foreign domestic helpers may enable their kinships with older or chronically ill people that allow them to extend to deeper relationships. Therefore, it is important to consider the cultural impact of the maid carers on the end-of-life decision-making issue of local patients with end stage renal disease.

As there is limited information about the study topic in Hong Kong, the findings of this study inform renal healthcare professionals about the emic views of the informants. End-of-life decision-making is multifaceted; it should be acknowledged that dialysis patients and

carers always experience tensions shifting between Eastern and Western culture while making end-of-life decisions in the context of Hong Kong. Thus, the decision outcomes may be perceived as individualised, situational and contextual, yet saturated with Chinese cultural values about life and death. The end-of-life discussion and decision-making are more common, have a longer history and are more established in the western health services than in Hong Kong services. The present study reflects that local people want the opportunity to talk about end-of-life issue, but they do not know when and how to raise it. Even so, people rely on cultural tradition and responsibility assuming that the family will make these critical decisions.

6.2 Revisiting End-of-Life Caring Issues

The purpose of this research is to identify and understand the central influences on the decision-making process, including the role of culture. The domain of inquiry was set as 'Exploring the decisions about care priorities at the final stage of life of renal dialysis patients and their carers'. Some 121 dialysis patients and 61 carers joined the survey in the Phase A study and 24 patients and 14 carers participated in the Phase B focus group interviews. The assumptions while performing this research were that dialysis patients and their carers were distressed by emotions and burdens, arising from physical, psychosocial and spiritual aspects. As stated in the studies of Davison (2010) and Weisbord et al., (2003) that poor quality of life is an independent risk factor for mortality in end-stage renal disease patients, and almost 50% of withdrawals from dialysis are reported to be because of poor quality of life. Sadly, in the researcher's professional experience, healthcare professionals have limited knowledge in providing advance care planning for dialysis patients and their carers which also echoed in the studies of Davison & Simpson (2006) and Tse (2010). It is hoped that this research findings can inform patients, carers and healthcare professionals with sufficient information and knowledge about the care in the final stage of life.

Despite the high rate of mortality related to withdrawal of dialysis for social issues, end-of-life care has been neglected in the dialysis population (Adams, 2010; Hopkins et al., 2011; Song et al., 2009). Prior studies, predominantly in Western countries demonstrate that less than 50% of these patients fail to complete advance directives, and not discuss their wishes for end-of-life care with healthcare professionals (Bristowe et al., 2015; Calvin & Eriksen, 2006; Ceccarelli, Castner, & Haras, 2008; Haras, 2007; Davison & Torgunrud, 2007; Hsiung, 2011). Across the world the dialysis population is getting older and the percentage of patients over 75 implies caring and financial issues for health care sectors. The decision to withhold or withdraw from dialysis treatment frequently challenges healthcare professionals caring for older patients. It is predictable that the discussion of end-of-life decisions is complicated, involving ethical, psychosocial and financial issues. The dialysis patient must face the inevitable prospect of dying, and the renal nurse is often the first person who hears of the patient's request to withdraw from dialysis (Germain et al., 2007; Rabetoy, 2006).

At present, most end-stage renal dialysis patients do not have advance care planning and advance directives in Hong Kong. In addition, family members or carers and healthcare professionals are unsure about their preferences for care at the final stage of life. The situation will become worse when patients are at a stage of mental incompetence, such as advanced dementia and coma. This study shows that patients expect their family members will implicitly know what they need and to make important end of life care decisions. None of the patient informants had advanced care directive. The end-of-life care decision may be made by their carers if no advance directive is available. But this depends on whether the health professional raises the issue with them. Whether the burden falls on the carer or the dialysis patient, self-decision (advance directives) about end-of-life care this study shows that

patients and carers would welcome the opportunity to discuss these matters with the clinicians who care for them.

6.3 Universality and Diversity of Findings

The findings show the universality and diversity of the informants. The knowledge and beliefs towards end-of-life care issue are reflective of the findings from the survey. As expected culture plays a role in the significance of the Hong Kong Chinese and Mainland Chinese. There is a statistically significant association of dialysis patients and carers when discussing end-of-life issue with family members. This significance will be examined under the end-of-life care preferences aspect. There is no statistical significant difference when testing the place of birth, working status, educational status, and dialysis treatment of dialysis patient and carer informants with the self-report knowledge questions and end-of-life care preferences. The following paragraphs start with discussing the quantitative findings with referred to the self-report knowledge.

6.3.1 Self-report knowledge

Some 42.1% of dialysis patient informants reported that they had heard about end-of-life care. However, the majority (81.8%) had not heard about advance directives. Comparing with other studies, 81% of the participants from Ting and Mok's (2011) study on Hong Kong Chinese elders with chronic disease had not heard about advance directives, while 96% and 95.3% of the informants from Chu et al. (2011) and Ni et al. (2014) based on older adults in nursing homes in Hong Kong and mainland China had not heard of advance directives. Large percentages of the Chinese population had not encountered advance directives because of death-related sensitivity, which sees the topic as to be avoided and counted as bad luck (Wong et al., 2012). In this study, 83.5% of dialysis patients would adopt advance directives if available. Globally, this figure among the highest in Hong Kong and mainland China. Pang, Wong and Dai (2006) reported based on a general public survey that 76.4% of the

informants were in favour of advance directives, lower than the 88% in Chu et al. (2011). Among the chronic disease or malignancy group, Mok et al. (2010) reported only 49.3% and Wong et al. (2012) reported 63% would accept advance directives. In mainland China, only 31.5% were willing to make an advance directive (Ni et al., 2014), though 79.3% of cancer patients acknowledged the need for advance directives (Ivo et al., 2012). Patients with poor prognoses were more willing to engage with advance directives (Wong et al., 2012). Dialysis patients are followed up regularly, and they can also contact the dialysis centre for health advice by hotline if necessary. This linkage might contribute to the knowledge transfer on advance directives, ultimately increasing acceptance rates. When patients have more insight and knowledge about their disease trajectory, they tend to accept the concept of advance directives more easily (Chu et al., 2011; Mok et al., 2010; Wong et al., 2012). In view of the findings from this study, dialysis patients in Hong Kong are willing to engage with discussions with their health professionals about end of life care and advances directives.

Compared with dialysis patients on the self-report knowledge aspect, it seems carers had more knowledge of end-of-life care (50.8%) and advance directives (36.1%). Carers initiated the search for more information related to the lifespan and future of illness of patients. However, both patient and carer informants expressed hesitation about asking health professionals those questions during consultation. This phenomenon is in line with other studies showing that patients often wait for healthcare professionals to initiate discussion on end-of-life care (Axelsson, Randers, Hagelin, Jacobson, & Klang, 2012; Berzoff, Swankowski, & Cohen, 2008; Davison 2006). Neither group had received sufficient education on the disease trajectory, and communication between healthcare professionals, dialysis patients and carers was limited. This may imply that patients expect more information and discussion concerning end-of-life issues. Therefore, communication is a critical component of end-of-life processes that enables the patient and carer to make

informed decisions and receive sufficient psychosocial support (Sullivan, Silva, & Meeker, 2015). These findings guided the researcher to explore limitations in the communication process between the healthcare professionals and informants further in the qualitative phase.

6.3.2 End-of-life care preferences

It is not common for Hong Kong Chinese family members to share their thoughts, viewpoints and feelings about end-of-life preferences among themselves. Knowing the differences might help to facilitate decision-making or even resolve conflict. One of the research questions of this study is to examine the decision on end-of-life care, which includes resuscitation, artificial feeding or hydration, and use of restraints. The majority of patient informants (86%) expected their family to make these medical decisions for them when they were mentally incompetent, followed by doctor (33.1%) and nurses (14%). Conversely, Mok et al. (2010) showed that 39.1% of old-age home residents requested their family to make medical decisions for them. The discrepancy of dialysis patients and old-age home residents might be related to the strength of the family relationships. It is quite common that family members or carers are living with the dialysis patients, creating a strong bonding. Comparatively, the relationships of the old-age home residents and their families are usually distant, such that they might not want to bother each other, though under Confucian philosophy, the role of eldest son and daughter is strongly infused and it is expected that they make decisions on the behalf of their elders. This also falls under the influence of filial piety in Chinese cultural beliefs (Ho & Sanders, 2015; Ni et al., 2014). Further analysis will be presented later in this chapter.

The quantitative findings showed that there was a statistically significant association in patients and carers about discussing end-of-life issue with their family members. From the survey data, dialysis patients felt less uncomfortable to discuss end-of-life issue with family members when compared to carers who expressed more discomfort in such discussions. This

finding is contrary to the previous study of Davison (2010) suggested that chronic kidney disease patients were comfortable in discussing end-of-life issues with both family (69.7%) and renal staff (65.6%). However, for the European study of Janssen et al. (2013) on dialysis patients, 65% were not ready to talk. Further, the majority of the patient and carer groups (86% and 95.1%) in this study had not discussed end-of-life care matters with anybody which is similar to Miura et al. (2006) and Janssen et al. (2013). It led to some in-depth questions being asked in the focus group interviews to explore these issues. Some themes developed from the carer informants such as personalising care, sharing burdens and carer's plight reflected the caring attitude of the carers. It might imply that carers had a strong desire not to trouble their family members with such discussion.

Based on this study and congruent with Chinese beliefs patients prefer their family to make decisions for them when they were mentally incapable even though there was probably no prior discussion of this. It also indicated they would obtain information from renal doctors before making personal decisions regarding health and wellbeing. This coincided with previous findings from Morton, Tong, Howard, Snelling and Webster (2010). When there is a sudden and terminal change in condition, cognitive impairment is quite common in dialysis patients (Khatri et al. 2009), leaving carers and renal clinicians to decide when to withdraw from dialysis or therapy (Luckett et al. 2014). Davison and Simpson (2006) found that dialysis patients lack insight into the severity of their disease. They expected healthcare professionals to initiate discussions. The previous local literature reported that patients with chronic illness also had this idea, which is linked to the intensely family-centred nature of Chinese societies (Ting & Mok 2011). Therefore, patient–clinician communication, patient–surrogate congruence in end-of-life preferences and completion of advance directives have become immediate issues (Perry et al., 2005; Song et al., 2012; Song et al., 2010).

Obviously, lack of congruence between the surrogate decision-maker and the patient on the end-of-life care plan would affect the quality of care provided to the patient. It is increasingly important that healthcare professionals understand the complex and evolving needs and preferences to optimise the care provided (Russ & Kaufman, 2012; Bristowe et al. 2015). Since patients seldom communicate or have little chance to communicate with carers or healthcare professionals, and in addition, patients decide not to decide or defer their decision-making process, shifting responsibility to their surrogates, prognostic information should be carefully and explicitly discussed with patients and carers. Importantly, patients should be reassured that they will not be abandoned at the end of life. International best practice shows that adequate information sharing and decision-making should be provided to every dialysis patient, commencing from the initial dialysis (Bradshaw, Smith, & Sinclair, 2016).

Many patients commence dialysis therapy without fully understanding as a replacement therapy and life-sustaining treatment, especially those who require it urgently; it is also palliative (Song et al., 2013). There may have been a misconception among patients and carers when they made the decision that life-sustaining treatment and advance care planning are independent (Miura et al., 2006; Davison 2010). When approaching final stage of life, carers do not know how to manage and intervene specifically when the patient is critically ill or unconscious. In Pang et al. (2006), 17% of informants did not accept resuscitation; Davison (2010) and Evans, Pasman, Deeg and Onwuteaka-Philipsen (2014) found 36.6% and 46% of informants respectively expected full resuscitation. Interestingly, in this study, about one-third of the patient informants would like to have resuscitation, one-third did not want to have resuscitation, and another one-third had no idea what they would choose if their hearts stopped beating. These findings are similar to those of Ting and Mok (2011). In contrast, in the West, most patients reported a preference for (Miura et al., 2006;

Janssen et al., 2013; Evans et al., 2014). In fact, 50.8% of the carers would request resuscitation themselves if their heart stopped beating. This created a discrepancy in the decision-making process when it is left to carers to make decisions in the absence of prior discussion about the desires of the patient.

Preferences regarding life-sustaining treatment may change over the course of a chronic illness (Janssen, Spruit, & Schols, 2012). Levels of understanding about the end-of-life treatment of the dialysis patient and carer informants may affect preferences (Chu et al., 2011). Therefore, in discussing life-sustaining treatment, patients and carers have to be involved, together with the renal physician, so the best possible medical decisions can be made (Janssen et al., 2013). In this study, 54.5% of patient informants preferred palliative treatments that would keep them comfortable, even though such treatments might shorten their lifespan; this figure was 88% in Chu et al. (2011) and 71.3% in Mok et al. (2010), studying residents of an old-age nursing home. Conversely, the findings of Davison (2010) for the US were 57.2%, similar to the findings of this study, and for the same disease group. Most of the dialysis patients had suffered over the course of the disease and treatment-related complications. The sense of existential distress, including the codes of ‘lack of living will’ and ‘wear a happy face in front of people but shed tears behind their backs’ may follow the patient informants until the final stage of life.

Although the majority of the informants in this study had not heard about advance directives, they stated that if available they would adopt it after explanation. This phenomenon is well supported by other emergent Hong Kong and mainland China research (Bowman & Singer, 2001; Kwak & Haley, 2005; Zhang, Xie, Xie, & Liu, 2016). One of the key differences between these findings and that of previous research is the need for a decision-making style that incorporates Chinese values to support families to discuss end-of-life care and come to decisions together.

6.4 Overarching Influence of Culture

Death is the natural path for every human being, but only a minority in Chinese culture would choose to talk about death with others, or even think about it. Further, talking about death is perceived as taboo, not only among the Chinese, but in other ethnic groups, such as African-Americans and another Asians (Ho & Sanders, 2015; Searight & Gafford, 2005; Sun, 2013; Wicher & Meeker, 2012; Wong-Kim & Burke, 2013). With recent promotion from various organisations, this has been challenged, as shown in Chan and Pang (2010), which asked nursing home residents if they were prepared to discuss death and dying without fear of taboo. The term 'end-of-life' is also sensitive, because of fear, unknowns, suffering, pain and separation from loved ones; further, it is believed to cause bad luck to individuals and families (Fung, Lam, & Lui, 2010). Unlike in Western countries, individualism is less important in Chinese culture (Janssen et al., 2013). Older Chinese patients tend to consult and discuss with their relatives, especially spouses or eldest sons, before making important decisions (Ni et al., 2014). However this was not the case for the majority of informants in this study, where this expectation was more implied than expressed. Therefore, families play an essential role in the surrogate decision-making process at the final stage of a dialysis patient's life, leading to substantial psychological burden (Zhang et al., 2015). This was a key reason for involving carers in this study, so as to inform healthcare professionals about carers' attitudes, beliefs, perceptions and thought processes regarding end-of-life care issues.

When patients, carers and healthcare professionals are confronted with serious illness and difficult decisions, the impacts of cultural differences become prominent (Gysels et al., 2012). Cultural factors affect not only patient responses to death and dying issues, but doctor–patient relationships (Searight & Gafford, 2005) and carers' strategies in dealing with difficult moments, for example, protecting terminally ill patients from knowledge of their

condition. Sometimes, when cultural differences are overlooked or inadequately addressed, a lower level of care occurs (Bosma et al., 2010). Thus, understanding Chinese culture as regards death and dying can significantly enhance the communication and treatment plans for dialysis patients' end-of-life care (Sun, 2013). Conversely, culture and ethnicity are often quoted as barriers in effective and satisfactory relationships between doctors and patients (Schouten & Meeuwesen, 2006). From the findings synthesised from the qualitative phase, a model was drawn to illustrate the phenomenon of overarching influence of culture in the studied population.

The model shows the interrelated effect of communication barriers, family dynamics, existential distress and sharing burdens, contributing to the core of the decision-making process that has been established as 'dignified dying'. Together, the tension expressed by the dialysis patient and carer informants formulates the definition of dignified dying in the emic view of the informants. The following sections discuss how culture leads to communication barriers in the emic view of dialysis patients and carers.

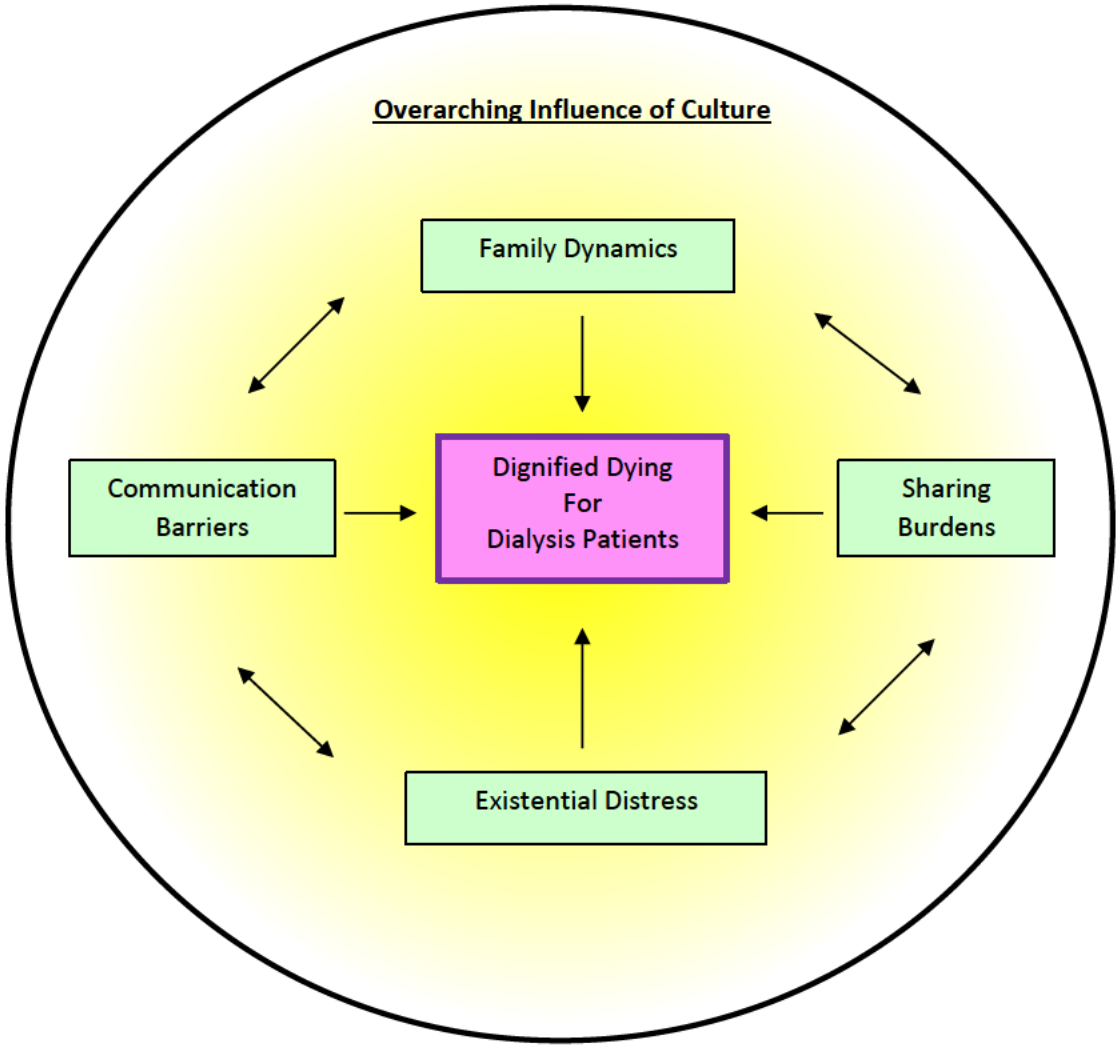


Figure 6.1. Overarching influence of culture in the decision-making process of dialysis patients and carers at the final stage of life.2

6.4.1 Communication barriers

Communication is an important factor in maintaining and enhancing trustful relationships and improves coordination of the end-of-life decision-making process among healthcare professionals, carers and patients (Cipolletta & Oprandi, 2014). Although end-of-life conversations are difficult for patients, carers and healthcare professionals, they provide an opportunity for patients and carers to express their concerns, unknowns and wishes about care priorities at the final stage of life (Wright, Zhang, & Ray, 2008). Therefore, communication about end-of-life care has been increasingly recognised by patients, carers

and healthcare professionals (Roscose & Tullis, 2015). End-of-life communication allows patients to express their preferences for life-sustaining treatments. Knowledge transfer and respecting end-of-life wishes can improve patients' and carers' sense of control. Moreover, holistic care can be applied to provide adequate symptom control, facilitate medical decision-making and prepare for a good death (Kehl, 2006). In fact, the response from the informants of this study shows not only unsatisfactory end-of-life communication between patients and doctors, but much more fundamentally, various obstacles to smooth and effective communication between patients and carers. These issues are discussed in the following paragraphs. Knowledge is a significant predictor of end-of-life communication; informants with greater knowledge about advance care planning are keen on engaging in end-of-life communication (Ko & Lee, 2009). Obviously, it is preferable that patients and carers pursue appropriate and accurate medical knowledge from their healthcare professionals, rather than the internet or other sources.

6.4.1.1 Communication channels among healthcare professionals, patients and carers

As dialysis patients often lack insight into the severity of their disease and seldom initiate discussions concerning advance care planning, they expect healthcare professionals to take the lead. This idea supports the finding from Davison & Simpson (2006). Although dialysis patients and carers showed interest, the informants in this study received inadequate information about life expectancy, the nature of renal disease and critical condition management strategies during consultations with healthcare professionals. They claimed that doctors did not have time to listen to their questions and appointment times were short. Most wanted to ask questions related to their health but could not because the doctors were always busy. Some felt doctors were too abrupt and tension was always present; either patients hesitated to ask or doctors had no time to answer, leading to misunderstanding and even regret.

It appears the communication barrier issue does not just occur locally. Grudzen et al. (2011) in the US found that communication regarding the goal of care between patients and doctors was particularly poor, and was complicated by cultural barriers and health literacy. Similar findings were identified in Janssen et al. (2013) for European countries. A Canadian study (You et al., 2014) argued that patients and their families rated communication with healthcare professionals as a high priority for improving end-of-life care, however, it was seldom achieved because of communication barriers. Given the paternalistic environment in Hong Kong, such as the traditional practice of doctors knowing best for patients; doctors are considered to hold specific medical knowledge and expertise, and be capable and bound to patients via a moral duty (Bowman & Singer, 2001). Chinese traditions value a compassionate form of medical paternalism, and prefer that doctors are always trustworthy and respectful (Tung, 2010). However, many doctors believe that they are acting in the patients' interest by practicing paternalism (Muthalagappan, Johansson, Kong, & Brown, 2013). Schell (2012) argued that the disease knowledge of dialysis patients and their interaction with renal doctors could strongly influence treatment decisions.

Conversely, Ceccarelli et al. (2008) showed that renal doctors feel unprepared for end-of-life communication, and avoid discussing patient's prognosis and disease trajectory because of difficulties in predicting the outcomes of these situations. This leaves patients with a sense of uncertainty that may lead to being unable to be involved in the communication process (Schell, 2012). As dialysis patients are normally under the care of the renal health care team from commencing dialysis treatment until passing away, the team has the opportunity to maintain long-term trusting relationships with patients and carers. This lengthy, established therapeutic relationship hinders the disclosure of prognosis and end-of-life communication, because of fear of causing unnecessary distress for patients and carers (Ngo-Metzger et al., 2008; Yee, Seow, & Tan, 2011). Further, lack of proper communication

training leads to a rise in stress levels when dealing with patients' and carers' critical questions (Bristowe et al., 2015). In fact, communication about prognosis disclosure and end-of-life issues is an essential component in advance care planning.

Patients or carers might reasonably expect that when they have to make medical decisions, doctors will tell them what they need to know, and doctors should have the skills to communicate honestly and appropriately. The focus group findings show that patient informants consistently said that communication obstacles prevent them from pursuing appropriate information. Although carers are often wanted information about the decision-making role, they reported a lack of knowledge and understanding of the specific tasks from the doctors. When doctors raise end-of-life issues, they tend not to involve the family much. In turn, patients rarely discuss these issues with their family members, which left them with unanswered questions and sometimes doubt about decisions they were expected to make. Yet, it is believed that by gathering information from renal doctors and nurses as well as other family members, together with surrogates' subjective impressions of the patient's relative condition, surrogate treatment decisions can be formulated and supported and stress alleviated (Burkett & Morris, 2015; Calvin et al., 2014).

6.4.1.2 Communication channels between dialysis patients and carers

Traditionally, Chinese elders try not to share their expectations related to death and dying with family members because they do not want to trigger sad feelings; it is a form of mutual protection. Patients do not want to jeopardise their relationships with carers by talking about end-of-life care. Further, talking about dying and death maybe a low priority compared with meeting everyday needs when the patients are still physically and mentally competent. Dialysis patients indicated that their carers have the crucial role regarding end-of-life treatment decisions in this study. In fact, most family carers were responsible for the domestic work or the breadwinner in the family. For some spouses, they had the role of

preparing nutritious food that met the dietary restrictions of their dialysis relatives. It is difficult and overwhelming for them to make medical decisions without prior communication. Further, talking about dying and death is very personal and difficult, even with familiar or intimate persons. Although dialysis patients trust carers to act as their surrogates in medical decisions if they were comatose, they seldom let them know their preferences and wishes; they had not thought through how their carers could make an appropriate decision without a thorough prior discussion. For both patient and carer informants, the code 'wear a happy face in front of people but shed tears behind their backs (對人歡笑背人愁)' arose when dealing with daily activities, emotions and communication issues, and especially in making medical decisions.

Patients trust carers because they are present, available and have similar beliefs about the unpredictability of life and illness. Carers care for, support, understand and respect patients, regardless of the extent that patients express their end-of-life wishes to them. In Chinese culture, asking advice from family members is common. Family tends to make decisions collectively. This was similar for the Indonesian maid carers' view. Kwak and Haley (2005) reported that Asian and Hispanic patients in the US always discussed with their family members before making health care decisions. A better communication channel should be established to link patients and carers, to facilitate sharing of this sensitive topic.

Indeed, lack of support for carers affects willingness to accept and acknowledge the decision-making process for the patients' end-of-life issues (Funk, Stajduhar, Toye, Grande, & Todd, 2010; Goodridge, 2010; Ward-Griffin, McWilliam, & Oudshoorn, 2012). Healthcare professionals sometimes miss the needs and roles of carers, as they are paying attention to the requests of patients, but in many ways, the needs of carers are far greater (Funk et al., 2010). Therefore, renal health care professionals should assess and address carers' needs frequently

and early, so as to provide supportive interventions in a sensible way (Grande et al., 2009; Keefe, Guberman, Fancey, Nahmiash, & Barylak, 2008).

To achieve the goal of smooth communication, the first step is to ensure the availability of specially trained healthcare professionals to answer questions and offer support before the medical decision-making event. Second, surrogates should receive frank, lay information that they truly understand from healthcare professionals about the condition of their sick patient relatives. Even when receiving bad news, honest information may help surrogates to gain a broader understanding of the situation of the patients and facilitate the decision-making process. This allows them to make the medical decision without regret (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007).

6.4.2 Family dynamics

The majority of the patient and carer informants in this study were Chinese, whether they were born in mainland China or Hong Kong. However, as Hong Kong was a British colony for over 150 years, it was thought the effect of Western culture might alter the decision-making process of the informants. However, informants' thoughts, beliefs and attitudes were influenced deeply by traditional Chinese culture. There was no significant difference from those born in Mainland China. The manner of caring could be traced from the strong influence of the Confucian norm in Chinese culture; for example, in 'personalising care' and 'normalising life', themes established from the key informants of this study within the scope of family dynamics. Importantly, the influence of Chinese philosophies gives meaning to how and why the patient and carer informants behaved and thought regarding the end-of-life decision-making process in this study.

6.4.2.1 The influence of Chinese philosophies

Chinese culture is full of rich and complex traditions that guide the beliefs of people in encountering various situations. Confucianism is considered by most Chinese to present

the core values of Chinese culture. The traditional understanding of death and dying in Confucianism can be demonstrated by the idea that the meaning of life lies in this present life (Chen, 2012). Although life and death are two extreme states, they form an integral whole (Ji et al., 2010); death is a form of birth, that is, the death of one thing is the birth of another.

The classical understanding of death and dying in Confucianism is found in the phrase that the meaning of life lies in this present life; thus, it is believed that if patients' wellness can be assured in this life, the matter of death can be resolved. In reflecting the words of Confucius, 'How can you know what death is before knowing what life is?' (未知生，焉知死?) Individuals are preoccupied with their characters or self-images, and refuse to allow that image to change. During the dying process, dialysis patients have to give up important parts of their identities; they may feel the extinction of themselves as death approaches. Their self-image fragments continue to disappear: work and sexual identity, identity as parents, spouses, lovers and friends, all the identity of the doubt. Carers also feel the loss as they concentrate on caring for their sick relatives at the final stage of life. Fear, ignorance and lack of clarity build in their lives, especially if the communication with renal staff is vague. The knowledge deficit diminishes the comfort and stability of the patients' and carers' lives. It is a common desire for patients to maintain their lifelong sense of uniqueness and their feelings of safety and control. However, death destroys the hope of revitalisation of patients, leading to fear. Confucius attaches importance to life; that is, the value of life and the realisation of life. First is to meet the value of this world by exploring the dead side of the world. From this basic standpoint, knowledge of death is not regarded as part of knowledge of the objective world, but serves human values. If renal staff cannot satisfy patients' wishes, they cannot go through death in a dignified and holistic manner.

Therefore, healthcare professionals should pay more attention to life than to death. It is believed that if they can deal with patient's wellness in life, the matter of death can be

resolved. When clinicians do not understand or satisfy patients' wishes, they cannot understand and go through death in a dignified and holistic manner with their patients. This is the main philosophy of promoting advance care planning and end-of-life care for chronically ill patients, especially dialysis patients. The root of the Chinese philosophical traditions of Confucianism, Taoism and Buddhism involve Hé (和), zhong yong (中庸) and tianren heyi (天人合一); some of the findings in this study will be described and illustrated based on these three domains. It is shown that these traditional Chinese philosophical domains influenced the thoughts, beliefs and attitudes expressed by the informants in the focus group interviews.

6.4.2.2 Hé (和), zhong yong (中庸) and tianren heyi (天人合一)

Zhong yong (中庸) (moderation) stresses moderation and modesty in the interest of achieving and maintaining interpersonal harmony. When people deal with a difficult moment, they usually think of the whole picture (holism). In fact, zhong yong encourages focusing on social morals and aims to provide guidelines for behaviour and attitudes. In principle, people should consider things from various perspectives, avoiding extremes and maintaining interpersonal harmony (Sun, 2013). That is the reason why even if dialysis patients had suffered from end-stage renal disease and practised dialysis for years, they could still exhibit calm and moderation while they were asking about their disease nature, treatment plan, relationship with healthcare professionals and family and death and dying issues. It might be a possible confounder of selection bias. Individuals who volunteer for a study may possess different characteristics than the average individual in the target population. Bias will be introduced if the association between exposure and a health (Polit & Beck, 2012). They noted the norms of life: birth, ageing, illness and death comprise the natural course of life, and cannot be altered by humankind. Some patient informants had been performing dialysis for years, and they had merged the dialysis life with their everyday life. Letting go of unpleasant events and trying to maintain a peaceful mind and life draw on the beliefs 'seize the day (活

在當下)' and 'let nature take its course'. As patients wanted to maintain harmony in the family when encountering end-of-life issues, they might not talk about this. Taoism in drawn on in explaining deferment of decision-making to others, via reference to the central Taoist concept of flow with nature (Hsin & Macer, 2006), which suggests being in a state of inaction or inactivity (wu-wei, 無為), indicating an attitude of not engaging in any activity that is opposite to nature (Sun, 2013). Instead, dialysis patient informants perceived wu-wei as the absence of interference in obtaining absolute happiness. They tried to allow their burdens to work themselves out, in line with their fundamental principles (Yip, 2004).

As the role of the Chinese family accentuates interdependency, obligations and responsibilities to sick relatives, the dialysis patient informants might think that the choice of medical treatment would be decided assertively by their children, to show a sense of respect and duty provoked by filial piety. With filial piety, children are perceived to have an obligation to protect their parents' and family's health and wellbeing. Conversely, under Confucianism, children agreeing to their sick parents' refusal of treatment can be seen as violating the principle of filial piety. Dialysis patients were in a dilemma: they had their own preferences regarding end-of-life issues, but tried not to impose these on carers. In contrast, trying not to make medical decisions for themselves, might imply they did not want conflict with healthcare professionals or carers. Also, both dialysis patients and carers understood that the decision-making process at end-of-life was difficult, and tried to protect each other from worries, burdens and frustration. The idea of hé (和) implies trying not to argue or quarrel in daily life; tianren heyi (天人合一) implies all things, from nature to man, are interrelated parts of a unified whole (Shi & Feng, 2010). It can be seen that dialysis patient informants tried to maintain harmony (hé, 和), especially a harmonious society; for the same reason, they were hesitant to ask too much during clinic consultations, to avoid burdening doctors and causing conflict. This was also associated with avoidance of an active, autonomous role in

discussing life-sustaining treatments and searching for information on their disease and delaying end-of-life care decision-making until they could no longer make the decision.

It should be pointed out that the belief of tianren heyi (天人合一）serves to promote the interrelation and balance between man and nature, as well as human and human. The belief is a much wider concept than the Western understanding of harmony (Leung, 2010). Tianren heyi (天人合一）involves the diversity and balance of harmony, rising and resting (Ji et al., 2010). It can be applied to issues of withdrawal from dialysis and treatment preferences at the final stage of life of dialysis patients. It also places attention on the matter of human rights in the treatment trajectory of dialysis patients. Nevertheless, the balance between individualism and collectivism from the patient and carer informants' point of views is complicated and complex. Ultimately, the quality of care provided to patients at end-of-life is influenced by the balance between carers' and healthcare professionals' interpretation of various cultural issues, and consequently, whether a shared decision-making channel is able to be established.

6.4.2.3 Gender roles and stereotypes

From the demographic data of the key carer informants in the focus group interviews, 12 out of 14 (85.71%) were female. Most were the spouse of the dialysis patients. Under the Confucian five cardinal relationships (wǔ lún 五倫), husbands and wives are one of the dyadic relationships in the cycle (others include emperors and ministers, fathers and sons, brothers, and friends) (Goodwin & Tang, 1996). Women were assigned differential roles in the family and society. Three obediences and four virtues were assigned to women by Confucian principles, emphasising obedience and subservience of women to their father when young, to their husband when married and to their sons when widowed (Tang et al., 2010). In a family, women's roles were defined as reproducing offspring, serving and caring for family members and maintaining household order. Women were seen as natural carers. In

helping sick relatives with dialysis and accompanying them to frequent follow-up appointments and urgent admissions, carers, especially female spouses, are extremely overwhelmed. Carers with a high acceptance of traditional Chinese family values most likely have a stronger affiliation with Chinese culture, values and beliefs (Chan & Chui, 2011). They would not consider discontinuing the role of carer, which would be perceived as going against the philosophy of Chinese marriage and the proper role of wives. As such, rigid gender norms and gendered social hierarchy should also be considered by healthcare professionals in dealing with end-of-life decision-making issues with surrogate carers.

Men traditionally have more power and status than women, given their differential role assignment in the family and society (Tang et al., 2010). Usually, men are the breadwinners and family heads, who manage major decision-making in the family. Under Confucianism, older people tend to have a belief that decisions should be made by eldest son (老來從子) (Sun, 2013). The eldest son in the family is usually the prime decision-maker. It is not surprising that dialysis patients had this belief. They expressed trusting the eldest son to make decisions if anything happened. They thought their sons must be there when decisions had to be made. In addition, when the father dies, the eldest brother is respected as the father (長子為父) (Mak & Chen, 2010; Shi & Feng, 2010). This further reinforces the role of male carers in the patriarchal culture of the Chinese community. They not only take on the role of breadwinner, but acted as decision-maker. While male carers are more accepted as medical decision-makers, if there is no son in the family, the eldest daughter would take on this role. With change in the sociological environment of Hong Kong, an increasing number of females are becoming more educated and financially independent (Hong Kong Census and Statistics Department, 2012). They are more attentive than male counterparts, and female carers tend to ask for details of the disease and caring process during family interviews and medical consultations, which might enhance the advance care planning process. Hence, the concept of

filial piety as historically influenced by Confucianism is enriched whether the carers are male or female. The uniqueness of filial piety to the dialysis patient carers is revealed in several ways. It acts as the most important ethical value of the Chinese and defines intergenerational relationships, marked by respecting authority and hierarchy and obedience of the young towards the old in the family. The younger generations are willing to contribute to provide material comforts for their parents. For example, love and respect for parents, obedience to parents, attending to parents' needs, providing physical and emotional sustenance to parents and loving and caring for oneself in the family were expectations of carers of dialysis patients. Filial piety can act as glue to bind the family together in a stable and harmonious state when difficult medical decisions have to be made. Further, individuals' roles in the family can be defined according to their positions on the hierarchical ladder, and the authority of the elder patients is never challenged. Stability and moderation can enhance family bonding too.

Patients tend to trust their carers with unpredictable issues in medical treatment and illness. Carers share and appreciate the ups and downs that the patients experience. Family identity is the origin of individual identity, and family interdependence is valued over independence (Holmes, 2014). Thus, when one of the family members has a chronic illness, it will be seen as a family issue rather than an individual one, and the family will be obliged to act as carers (Ho & Sanders, 2015). But still, some carer informants expressed that they felt uncomfortable making end-of-life treatment decisions for their patient relatives. Although this expression was multifactorial, it coincided with findings from studies in the United States, Japan and Canada (Calvin et al., 2014; Miura et al., 2006; Song et al., 2015; Ward-Griffin et al., 2012).

6.4.2.4 Islamic Indonesian impact

Like Chinese culture, Indonesian families have strong bonds and cohesiveness that are involved in caring for sick relatives. The family gives psychosocial support by providing encouragement, love, and empathy for the patient (Anggraeni & Ekowati, 2011). Whenever someone is admitted to hospital, all close family members, relatives, friends, and neighbours will visit and help the patient. Divergent from the present findings of the Chinese culture, Indonesian patients and families feel comfortable sharing their autonomy and psychosocial concerns with their own family but not the healthcare professionals (Effendy, Tejawinata, & Vernooij-Dassen, 2015).

Employing a foreign domestic helper, to fulfil caregiving needs has become common in Hong Kong in recent decades. Although the tasks performed by the Indonesian maid carers may be cleaning, cooking, and caring, such caring requires emotional engagement that involves interaction, affection, and attachment. In future, the connection between the dialysis patients and maid carers would not only be just as the employer-employee relationship but also extend to concern about the patients with mutual regard.

The socio-cultural background of Indonesian maid carers influences their perspectives, values, beliefs and behaviours about health and wellbeing. It may affect the encounters between carer and patient where end-of-life decision-making and interaction are concerned. The Islamic culture is distinctive from the Chinese culture. It is directly associated with a health-related behaviour, influences the acceptance and adaptation of the health education message. As asserted by the Prophet of Islam that patients are encouraged to seek proper treatment in times of illness (Begum & Seppänen, 2017). However, the Indonesian maid carer informants had deviating belief especially if they suffered from a chronic or terminal disease. They would rather stay at home and looked after by relatives and preferring to die at home. Not knowing these thoughts were affected by economic or cultural reason.

This insight is the opposite with the local Chinese view that patients prefer dying in the hospital. The quality of care may be insufficient if healthcare professionals fail to recognise and understand the cultural impact of dialysis patients and their maid carers. It is unknown what effect maid carers had on family relationships and expectations around end of life discussions and decision making as it was inappropriate to raise this in the focus groups.

6.4.3 Sharing burdens

Chronically ill patients often find the burden of symptoms from the original condition are further complicated by multi-morbid conditions (Kurella Tamura, Goldstein, & Perez-Stable, 2009). Major changes in the epidemiological and demographic background have led to increasing numbers of patients with chronic diseases, such as diabetes mellitus, chronic lung disease and chronic kidney disease. These patients present with help-seeking behaviours and illness trajectories that mean healthcare professionals have to deal with complex and costly policies and uncontrollable care demands (Holman, 2006). Chronic kidney disease and dialysis treatment place heavy burdens on both patients and carers.

Dialysis patients in this study reported being distressed by emotions; for example, guilt and helplessness, role reversal, financial constraints, changes in body image and the burden of performing peritoneal dialysis. These findings affirm the results of previous studies by Luk (2001) and Mok, Lai and Zhang (2004). Other studies have reported on the stress and burden of patients of dialysis and subsequent impairment of quality of life (Al-Arabi, 2006; Griva et al., 2016; Stavrianou & Pallikarakis, 2007). Together with various comorbidities, the subjective burden of dialysis patients was still an important issue. In addition, psychiatric morbidity of anxiety and depression are also common in the dialysis population (Cohen, Norris, Acquaviva, Peterson, & Kimmel, 2007). It is reported that dialysis patients' symptom burden and rate of hospitalisation is very high (Germain & Cohen, 2008). Patients entered in the dialysis programme encounter various burdens and difficulties, affecting their quality of

life (Weisbord et al., 2003; Al-Arabi, 2006). Regrettably, health care providers have limited knowledge about the relationship between patient quality of life and end-of-life care. As older dialysis patients are accepted, the focus of care needs to shift beyond extending life to relieving the burden of symptoms and palliative care. Importantly, it is believed that if patients choose to withdraw from dialysis, provided that adequate information and palliative care are offered, the subsequent death can be good (Cohen & Germain, 2004; Murtagh, Cohen & Germain, 2007).

Based on the findings of this study, the burdens increased in direct proportion to dialysis months. This echoes the findings of Cowan (2016), who studied patients and carers living with end-stage renal disease and haemodialysis. The burdens are not confined to the treatment, but stretch to engagement with medical services and therapeutic modalities.

Patients with chronic illness are concerned about imposing an intolerable burden on family (McPherson, Wilson, & Murray, 2007); patients with life-threatening illness tend to think themselves a burden to society, which has a negative effect on the maintenance of dignity at end-of-life (Mair & May, 2014). Five dimensions of burden were described in the research: general harm to family, financial pressure, emotional cost to family, physical care demands and being a drain on society. The results also showed that being a burden to others could be described as the emotional burden of witnessing the informant's death and the potential burden of replacement decision-making. This was one of the reasons for withdrawal from the treatment. As dialysis patients experience growing demands to organise and coordinate their care, self-monitoring regimens, complying with the treatment and meeting different expectations from renal staff and families, they may struggle in their daily life (May et al., 2014). As the burdens accumulate, some patients are overwhelmed, leading to poor outcomes of the treatment process. Consequently, this may induce decreased compliance and over-utilisation of health care services (Eton et al., 2012). That may be the reason why renal

care professionals still cannot eliminate episodes of poor fluid, diet and drug compliance of dialysis patients, poor techniques inducing peritonitis, malnutrition and other complications. These poor outcomes increase the demands, strain and worry on carers, as discussed later in this chapter.

There are no unique, concise, disease-centred guideline maps for the needs of patients and clinical practice. Further, fragmented and poorly coordinated pre-dialysis or end-of-life care planning cannot alleviate the burdens and worries of dialysis patients and carers. This is an under-investigated phenomenon (Mair & May, 2014; May et al., 2014). Although there is much web-based knowledge related to the topic of advance care planning, it is not common for the older patients to obtain this information since they are not familiar with computer technology. They mostly rely on what healthcare professionals provide in the education talks or during the follow ups in the consultation room, but time is limited.

The social network of dialysis patients is limited in comparison with their carers, simply because their illness induces physical inability and self-isolation influenced by psycho-socio-emotional status. According to the findings of this study, dialysis patients expressed that they seldom shared their feelings and sadness with others, including family members or carers. They did not want to bother them, to protect them. Thus, the category of ‘mutual protection and respect’ was identified and matched with the codes of mutual pain-free, protecting relatives, ideological burden and wear a happy face in front of people but shed tears behind their backs. In fact, Chinese tend to use more avoidant or emotion-focused coping while dealing with stressful situations (Cheng et al., 2010).

The concept of carer burden can be traced back to the 1960s, when it was defined in terms of the costs, for close friends and family, of providing care and assistance to a person with chronic illness or at final stage of life (Dumont et al., 2008). Carer burden is commonly used to describe the negative physical, mental, emotional, social and economic consequences

of carers providing end-of-life care (Carretero, Garces, Rodenas, & Sanjose, 2009; Williams et al., 2011). This kind of caregiving may lead to anxiety and depressive symptoms in carers. As the majority of dialysis patient informants were undergoing home-based peritoneal dialysis, the responsibility for exchanging the peritoneal dialysis bags is often shared with the carers. The increasing demands of managing dialysis skills and caring capacity increased the stress on carers' physical, social and emotional wellbeing. As other research has shown, carers experience depression, anxiety, fatigue, social isolation and relationship strains (Cukor, Cohen, & Peterson, 2007; Tong, Sainsbury, & Craig, 2008). It is apparent that taking care of a person with a chronic illness is a burden. As carers play a major role in the caring and decision-making process, they further share the stress and burden of patients regarding the disease process, health deterioration and communication between the patient, family, health professionals and health organisations. Carers expressed that they had to deal with issues from the patients first, but that they did make use of internal and external resources from the psycho-sociological, spiritual and cultural domains, to facilitate the decision-making process for advanced care planning of patient relatives at their final stage of life. In addition, the carers felt responsible for causing harm to their patient relatives if they altered any treatment or nursing care applying to the patients at end-of-life. When they made medical decisions for patients, carers always found uncertainty difficult (Phillips, Brennan, Schwartz, & Cohen, 2005). When the carer informants were asked to step into the position of the dialysis patients during the focus group interviews, they would rather express their preferences for care at their end-of-life to their family members in the early stage of the illness—they did not want their significant others to carry the burden of making medical decisions on their behalf when they were physically and mentally incompetent.

Obviously, both patients and carers had a general sense of burdening others as showing in this research. McPherson et al. (2007) noted that this is called self-perceived

burden, defined as the empathic distress provoked by the impact on others because of the patient's illness and care needs. This distress leads to guilt, worry, feeling of responsibility and diminished sense of identity. Self-perceived burden behaviour has been recognised as a concern for patients at the final stage of life (Wilson, Curran, & McPherson, 2005). It also influences the decision-making of patients relating to the aspects of quality of life, good death, existential distress and dignity (Ashby, op't Hoog, & Kellehear, 2005; McPherson et al., 2007).

6.4.4 Existential distress

The primary goal of offering dialytic therapy to end-stage renal disease patients is to improve their quality of life. End-stage renal disease is an illness with progressive loss of kidney function that affects the wellbeing of the patients. Death is the inevitable event in the trajectory of the illness, triggering existential concerns. Such concerns may pertain to faith and belief, forgiveness and giving, harmony and connectedness, meaning and purpose, and life and death (Boston, Bruce, & Schreiber, 2011; Henoch & Danielson, 2009). Dialysis patient informants mentioned they did not know what to do and what the meaning of life was once they were informed of their diagnosis. They could not foresee the effect of the medical treatment; sometimes the renal doctor could not either. It was difficult for the dialysis patient informants to adjust or adapt their lives because of the uncertainty of the illness; at any moment, they might be admitted. All these uncertainties influenced the patients to not want to extend their lives, especially if in pain. They expressed hopelessness, burdening family members, loss of dignity and loss of will to live, consistent with previous studies (Chochinov et al., 2006; Henoch & Danielson, 2009; Okon, 2005; Vachon, 2009; Vivat, 2008). This crisis violates basic assumptions about sense of control and ability to predict the future. This sort of stress that dialysis patients and carers experience can be referred to as existential distress (Leung & Esplen, 2010).

Existential distress is defined as ‘spiritual or philosophical suffering that may or may not include ideas of intrinsic religiosity’ (Fehring, Miller, & Shaw, 1997). Informants suffering from end-stage renal disease and living with dialysis experienced existential distress strongly correlated with end-of-life despair. They felt threats to important aspects of existence in their dialysis life, as also found in Axelsson et al. (2012). Some of them, especially peritoneal dialysis patients, might experience significant ‘social death’, hiding themselves at home for the bag exchange procedure. Their physical stressors and body image did not allow them to go out. They shared in the focus groups that they had lost the meaning of present life, lost social role functioning, and felt dependent, a burden on others and guilty. Although some of the patient informants expressed a desire to let go without suffering and accepted that death was the end point for all humans, they did not want to annoy their family by adding burdens. As a result, they chose not to talk about preferences for care at end-of-life with their family. Knowing that individuals need to have a strong sense of being in order to find meaning in their lives and create connection with life, but it seems this concern may have a break with the self-identity as well as relational and existential loss (Boston et al., 2011). Unfortunately, dialysis patients do not have this luxury. They attempted to maintain their sense of existentialism, and feel accepted and respected in their families and community. These findings showed commonalities with Axelsson et al. (2012) and Rehnsfeldt and Eriksson (2004), which found the alleviation of suffering to be an existential encounter involving attention and understanding. There should be a close connection between dignity and no more suffering.

Research has been carried out to stress on patients’ existential wellbeing as an essential component of provision of quality care (Boston et al., 2011). The influence of culture on existential distress has also been taken into consideration. Of different ethnocultural groups, Asians, particularly Chinese, suppress their upset feelings or negative

emotions to maintain harmony in the interactions between family members (Mak & Chen, 2010). Various factors contribute to dialysis patients' existential suffering at end-of-life. In fact, existential suffering can be difficult to understand and heal (Boston et al., 2011; Henoch & Danielson, 2009). Though disease-related concerns and treatments are important to dialysis patients, the loss of control, isolation, dependence, loss of sense of dignity and loss of status determine the quality of life (Chochinov, 2006; Leung & Esplen, 2010). Therefore, healthcare professionals in the renal field should consider embedding existential distress as an important issue in their daily practice. Unfortunately, many renal doctors or nurses lack the knowledge, training and experience to deal with patient existential distress. Nurses, taking care of the patients 24 hours a day, should be aware of their existential needs and act accordingly (Boston et al., 2011). When the symptoms are relieved effectively by applying compassionate and skilled care in the end-of-life programme, patients and carers benefit.

Care preferences and end-of-life decision-making will lessen the burden to carers or healthcare professionals if an advanced directive has been made after a thorough discussion among dialysis patient, carer and healthcare professional. Such decision need to align with the wishes of the sick patient they are caring for. However, this is not the situation how Chinese culture works, how the relinquishing decision-making for the right choice. By accompanying the patients through existential distress, hope can be restored, and help to resolve meanings of prognoses with treatment decisions.

6.5 Dignified Dying

While dying is part of the human life progression, everyone hopes to leave the world in a dignified way, without regret. All key patient informants in this study were aware of death as a possible consequence of end-stage renal disease. In facing this challenge, some were calm and accepting. From the emic views of the dialysis patient and carer informants, the interrelated effects of communication barriers, family dynamics, sharing burdens and

existential distress were formulated. Those aspects contribute to the core idea of dignified dying in Chinese culture. From the expressions of dialysis patient informants, they were expecting to be cared for and kept neat and tidy during hospitalisation, especially at the end-of-life moment, as a respect. When they wanted to change diapers, they expected someone would do it without delay. Further, they would be fed if they were not able to feed themselves. Of course, cleanliness and hygiene should always be maintained. All these requests simply belong to the basic physiological needs of an ordinary human. However, it reflects the deprivation of and craving for dignified care of the informants' emic view. Therefore, it is necessary to understand the patient perception of dignity in the caring process.

Dignity is an important topic of study in end-of-life care. As a universal characteristic, dignity is regarded by both Eastern and Western cultures as the worth of a person (Koehn & Leung, 2008). As such, preserving dignity is important for maintaining a person's sense of wellbeing (Tao & Lai, 2007). Dignity can also be perceived as feeling important and valuable to others (Guo & Jacelon, 2014; Matiti & Trorey, 2008). Lin, Watson and Tsai (2013) stated that dignity can be a cultural concept where attitudes, values and perceptions are related to the maintenance of dignity. Primarily, people in the West understand dignity as innate personal worth, whereas the East emphasises dignity as worth acquired from social relationships (Koehn & Leung, 2008). In health care settings, patients are vulnerable to losing their dignity. Thus, the maintenance of dignity is upheld as a virtue in both the medical and nursing code of ethics. The Royal College of Nursing (2008) asserted,

> Dignity is concerned with how people feel, think and behave in relation to the worth or value of themselves and others. Nurses, should treat all people in all settings and of any health status with dignity, and dignified care should continue after death. (code 003 298)

Therefore, nurses should understand that respect is an essential human quality that they should value according to patients' needs.

Lin, Tsai and Chen (2011) explored patients' perspectives on dignity in care in Taiwan. The participants believed that dignity involved being respected as a person, preventing body exposure, care from the nursing staff, maintaining confidentiality of disease information and prompt response to needs. This study shows that dignity is conceptualised in both intrinsic and extrinsic dimensions of a person, and respect is a crucial element in maintaining dignity. In Chinese culture, the key informant groups of this study expressed their need to receive basic physiological care and general cleanliness and tidiness as commonalities. These findings appear in previous local and overseas studies of old-age home residents and cancer patients (Chan & Pang, 2011; Davison, 2012; Ho et al., 2013; Ni et al., 2014). Being severely ill may imply losing control over life. Informants voiced that they had to rely on others to perform basic care such as using the toilet, eating and dressing, self-cleansing and bag exchanges for peritoneal dialysis patients. Dignity was threatened in the long run, leading to existential distress, as echoed in other studies (Birrell, Thomas, & Jones, 2006; Calnan, Badcott, & Woolhead, 2006).

The dignity of dialysis patients can be compromised as they undergo dialysis treatments and admissions. The patient informants revealed perceptions of powerlessness and of being disregarded by doctors. They said that doctors had little time for them, they only paid attention to the computer screen, searching for investigation results and typing prescriptions without looking at the faces of the patients at the follow-up clinics. When patients or carers asked questions relating to end-of-life issues, there was usually no response. It is a frequent phenomenon in the waiting hall of clinics in this study that patients complain of waiting to see a doctor for hours before being seen for minutes. The lack of understanding and respect from doctors may have undermined dignity. Previous studies show that patient

dignity is affected by the attitudes and behaviours of health care providers, as well as the culture of institutions (Gallagher, Li, Wainwright, Jones, & Lee, 2008). Patients lose dignity when they feel powerless or perceive that they are not being treated seriously (Gennip et al., 2013).

Poor communication and lack of information in medical decision-making further reinforced the sense of losing control; medical professionals using jargon and patients being neglected during ward rounds or medical consultations increased the feeling of being depersonalised. Knowing the complexity of the comorbidities of end-stage renal disease with dialysis treatment, patients may feel insecure in coordinating their individual medical treatment and care without support from healthcare professionals. Dignity is different across individuals, but people often fear they will lose it as they near the end-of-life (Wiegand & Petri, 2010). Attempting to have control in a life with illness is also a challenge in maintaining dignity at the final stage of life. As Heijkenskjöld, Ekstedt and Lindwall (2010) concluded, from the nurses' perspective, dignity could be revealed to nurses to maintaining patients' dignity. To maintain dialysis patient dignity, nurses should encourage patients to speak about their lives and participate in their own care processes. Unfortunately, sometimes nurses violate patient dignity, seeing patients as objects without emotions or feelings. As mentioned by patient informants, some nurses did not respect the will of the patients. When patients called for assistance with toileting or body cleansing, they were frequently kept waiting and felt abandoned. Nurses should realise that dignity is an important human need, and it is the right of patients to receive care with dignity.

6.5.1 Expecting good death

Dignity is considered an attribute of a good death for patients at end-of-life. Therefore, a meaningful dying process was perceived by dialysis patients as being supported by family, friends and carers physically, psychologically, spiritually and emotionally at the

final stage of life. Lin et al. (2013) claimed that dignity is an overarching value or goal that outlines care services to provide to dying patients and their carers. In this study, a majority of the key informants in the focus group interviews stated that they were expecting a ‘good death’. According to the report of the Institute of Medicine in the United States of America (Field & Cassel, 1997), a good death is defined as a patient dying with no avoidable distress and suffering for himself, his family and his carer. Importantly, it accords with the patient’s and carer’s wishes, consistent with clinical, cultural and ethical standards. In fact, healthcare professionals may not be certain about the meaning of dignity in dying and what a good death is from the view point of the patient (Cipolletta & Oprandi, 2014). Commonalities were found in this study and studies from Axelsson et al. (2012), Chochinov (2006), Davison (2010), Huges et al. (2008), Kehl (2006), Kendall et al. (2007), Meier et al. (2016), Sneesby, Satchell, Good, & van der Riet (2011), Vig & Pearlman (2004), and Wiegand & Petri (2010) that patients expected the following as characteristics of a good death: dying while asleep, achieving a sense of control, awareness of dying, no knowledge of dying, free from discomfort, dying peacefully, dying quickly, being prepared for death, achieving a sense of completion, saying goodbye, and surrounded and cared for by family.

From the emic view of the carer informants, they shared the ideas of no more suffering and peaceful death of their patient relatives at the end-of-life moment. Free from avoidable distress and suffering for patients were mentioned as components of a good death.

6.5.2 Pursuing autonomy

Control of treatment preferences and the dying process were the desires of both the dialysis patient and carer informants. From the patient point of view, they had lost control of the body and basic functions with end-stage renal disease. Extending their life for further suffering is thus cruel to them. It is meaningless to sustain life with machines and medication if it is the end-of-life. They require respect in discussing the idea of withdrawal from dialysis,

treatment options and preferences of care at their final stage of life. Conversely, carers would rather not make medical decisions for the patients to prevent conflict or deviations from will. In providing dignified care, there is a strong relationship between dignity, autonomy, responsibilities and communication (Coventry, 2006).

Feelings of dignity can be influenced by interactions with others, particularly close relatives and carers. The nature of Chinese is conservative, humble and low-profiled. Patients might not want to disclose their sadness, suffer, worry and wish to others including their closed families. Importantly, there is not much autonomy in the medical decision-making process especially at final stage of life under the present medical system in Hong Kong. When discussing end-of-life issue, whether people adopt the Chinese or Western perspective, may depend on the cultural belief. Patients want to be more informed but do not expect to make the decision. It is entirely different to the majority of the literature around the world which end-of-life decision-making relies upon autonomous and individualised manner with patient's right. Obviously, patient autonomy has to be recognised by healthcare professionals and families. Bostwick and Cohen (2009) stated Americans were progressively demanding to take charge of their own choices about living and dying. Since Hong Kong is a multicultural society, with influence from Western culture, some informants valued individual autonomy. As traditional Chinese, some informants might adopt the family-centred decision-making approach to explaining preferences for end-of-life care. This approach originated from the philosophical foundation of Confucianism, which emphasises the bonding of human relations instead of the rights of individualism (Kim, 2015).

The nuclear family system has replaced the traditional large family in the past few decades, and this might diminish the impact of filial piety and support for sick patient relatives. Renal care professionals should fine-tune the policy and management styles for these care recipients. Attention should be paid to situations where the family has a lack of

communication and trust, as there might be disagreements in the medical decision-making process. The findings argued that it might be necessary to understand whether a given family functions more in the family-centred or Western autonomy style.

In this study, carers believed the patients would have extra relief if they had more sense of control and avoided an inappropriate prolongation of dying. Conversely, carers wished the patients had made clear decisions before entering the mentally incompetent end-of-life stage. In such cases, carers could follow patients' wills without the hesitation of making the wrong or inappropriate decision, leading to regret. The Eastern and Western models of caring have differing influences on caring strategies. In Hong Kong, there is a strong tradition of familial-centred approaches to making medical decisions, especially at end-of-life, given its deeply rooted Confucian cultural domain (Krishna, 2011a). End-of-life decision-making is multifaceted and an added factor of familial involvement in the local context further complicates the patient and healthcare professional relationship. Conspiracy between families and healthcare professionals is obvious; sometimes families attempt to protect what they perceive to be the best interests of the patient by withholding negative information (Li, Yuan, Gao, Yang, Jing, & Yu, 2011). This is in direct contrast with Western culture, which advocates full disclosure of information to the patient (Foo et al., 2012).

Promoting independence and individualism, as in the Western model, may contradict the local practice. For example, carers may request the case doctor not to disclose the prognosis and disease process to the patient, so as not to increase the burden and suffering. The carers agreed that greater preparation for their sick relatives' care priorities at end-of-life provided a sense of completion. Grasping control and regaining autonomy were mentioned in both informant groups. Ho et al. (2013) stated that personal autonomy was one of the major pillars of dignity among Chinese terminal cancer patients. Applied to dialysis patients, personal autonomy may help patients to gain a degree of control over their treatment

preferences and lives, and further, not become totally dependent on others, decreasing the sense of burden.

Death not only threatens the self-esteem of patients, but their sense of control. Autonomy of patients refers to having a sense of control over actions, decisions and life events (Pleschberger, 2007; Rodriguez-Prat, Monforte-Royo, Porta-Sales, Escribano, & Balaguer, 2016; Tait & Hodges, 2009; Vosit-Steller, White, Barron, Gerzevitz, & Morse, 2010). In Western culture, autonomy is usually regarded as a supreme right that must be upheld by medical practice. Lack of control over life events not only reduces personal autonomy, but leads to diminished dignity overall (Martin, 2015). For the purpose of this study, autonomy is used in its general sense, referring to the belief that patients can execute their exclusive right to choose what has been, is being and will be done to them. Dialysis patient informants experienced tensions in trying to push death away with the sense of taboo, but simultaneously trying to grasp control of care preferences before death to maintain autonomy. Patients expressed that they had discussed death planning with their family or carers, which reflected the family-centred approach of Chinese culture to the decision-making process. The swinging between a wish for vicinity and need for autonomy could explain informants' contradictory management of this moral issue (Moestrup & Hansen, 2015). It is the responsibility of healthcare professionals to respect the patient as a whole instead of as fragmented, and provide sufficient and appropriate knowledge related to the disease and treatment progression instead of hiding the facts.

Similar to this study, Ho et al. (2010) and Krishna (2011b) suggested that patients are increasingly asserting their autonomy. Yet, this emphasis on patient autonomy may be lost when the patient is mentally incompetent. In that case, healthcare professionals will face a dilemma regarding whether they should comply with the family's wishes or the patient's, if the patient has expressed these. Therefore, healthcare professionals should understand the

struggles of patients and carers when encountering having to make medical decisions. Comprehensible and supportive interventions should be made, to facilitate and empower their decision-making process.

6.6 Summary

In this study, the interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress were formulated from the emic views of the dialysis patient and carer informants. The core of the decision-making process for care priorities at final stage of life for dialysis patients is established as ‘dignified dying’. Efficient and honest communication among patients, carers and healthcare professionals can not only enhance independence and autonomy in making medical decision, but facilitate the family-centred system for the purpose of shared decision-making. Since end-of-life communication allows patients to express their preferences for life-sustaining treatments, knowing and respecting end-of-life wishes can improve the patients’ sense of control as well as help prepare for good death. Family bonding and filial piety are major components of the traditional Chinese culture, although there is growing demand for the Western autonomy system from the patient informants.

Some patients are overwhelmed, leading to poor treatment outcomes. Dialysis patients had to comply with treatments and meet various expectations of renal staff and families, and some also organised and coordinated their own care and self-monitored their regimes. They may struggle with these burdens in their daily life. When burdens accumulate and shift to existential concerns or even distress, the dialysis patient informants did not know what to do and what the meaning of life was. With the help of the model formulated in this study—the overarching influence of culture in the decision-making process of dialysis patients and carers at end-of-life—the universalities and diversities of both dialysis patients and their carers in the end-of-life decision-making process and preferences were

demonstrated. The model helps to illustrate the main findings from the study and answer the research questions derived from the domain of inquiry: Who should participate in the end-of-life care discussion? What should be discussed during the decision-making process? How should the decision be made? The results and findings from the quantitative or qualitative phase meet the aims of the study.

Respect for the patient means maintaining and affirming the dignity of the patient as a person, because each person is unique. The findings of this study share this universality with other studies, from the East and the West. Although healthcare professionals cannot completely control the physical suffering of patients, the psychological needs of patients cannot be ignored. This study reminds carers and healthcare professionals to start with daily life, to face death with a positive attitude and preparation, and thus, give positive meaning to life. For awareness of decisions regarding the advancement of medical instructions, a clear decision process and an effective communication channel should be established with renal doctors, renal nurses and carers. Consequently, the need for hospice and palliative care should be promoted, to care for the dialysis patients' body and mind. Let them have a sense of integrity and preparedness to die, with the understanding of their physical and psychological needs; so as to face the changes and prepare and plan appropriately and accordingly. In this way, crucially, dialysis patients can leave the world in a dignified manner.

6.7 Reflection on Using Culture Care Theory

Leininger's culture care diversity and universality theory and the ethnonursing research method is especially useful in studying how culture affects the decisions people make about health care and what sorts of culturally related care can be applied to clients (McFarland & Wehbe-Alamah, 2015). Leininger (1997) believes that care is the dominant or central focus of nursing. Culture Care Theory helps to advance transcultural nursing

knowledge and practices. The generalisation may influence nurses providing sufficient attention to the patients' cultural values. In keeping with Leininger's theory of transcultural nursing practice, recommendations can be taken from the findings of studies on patients' and carers' perspectives to guide nursing practice. Importantly, addressing the patients' and carers' perspectives, care can be adopted to move to a more person-centred care approach in the work of people with end-stage renal disease.

The researcher used the enablers to facilitate the research process, and eventually, the emic view of the informants could be acknowledged. Care concepts have been developed through Leininger's work and supported by many nurse researchers. Ethnonursing research has been applied across many patient populations, however, no previous studies focusing on renal dialysis patients were located. The findings of this research cannot be directly compared with the current literature using the ethnonursing approach, as the appropriateness of adoption and application of tenets and enablers in this study cannot be examined; that said, it offered the chance to implement culture care theory freely in the renal arena, without preconceptions.

In this study, the conceptualisation of culture care of renal dialysis patients and their carers was achieved through the rigorous implementation of the ethnonursing method design, as described in the theoretical framework chapter. As one of the purposes of this study is to inform healthcare professionals about the decision-making process from the viewpoints of dialysis patients and their carers, the findings can positively influence nursing practice, education, administration and research in the renal field. The credentials of this research have been demonstrated via satisfying conditions for credibility, confirmability and transferability.

The researcher's long-term engagement (over 15 years of services as a dialysis nurse) offered credibility to the findings; the specific thoughts, attitudes and beliefs of the dialysis patients and carers had been encountered in previous daily practice. As a novice researcher,

demonstrating rigour when undertaking qualitative research is challenging because there is no of accepted consensus about the standards by which such research should be judged (Rolfe, 2006). The credibility of the researcher could become the researcher bias if several measures have not been attended. Attention was paid to minimise researcher bias by ongoing observation and interviewing throughout the data collection and analysis periods. This process allowed the researcher time to develop an in-depth understanding of various components of the decision-making process of the key informants from a cultural perspective. The researcher has substantiated this emic knowledge. Conversely, it was always difficult to open a dialogue while dealing with withdrawal from dialysis and talking about end-of-life; the enablers, such as the stranger-trust-friend enabler, proved advantageous to the researcher in communicating with the key informants, both dialysis patients and carers, during the data collection period. Informants responding to open-ended questions raised quite different issues to those provided for closed-ended results of the survey. The balance required to maintain reflexivity was always in the mind of the researcher. Increasing the coverage of informants in the qualitative data collection with the assistance of gatekeepers and field notes taking by other personnel during focus group interviews increased the representativeness of the findings. The interviews were audio-recorded to provide accurate records of informants' descriptions. Expert advice on the methodology and data analysis was sought from the supervisors, boosting credibility.

Confirmability was performed by the researcher to reaffirm what had been heard, seen, observed, recorded or experienced with respect to the phenomena to be studied (McFarland & Wehbe-Alamah, 2015). The audio-record and field notes were processed right after each focus group interview to allow an ongoing review of data and assisted the researcher to formulate and modify questions for subsequent interviews. It also provided the researcher with a mechanism to test for misinformation and distortion. Frequent meetings

with the field-note taker discussed the content and significant issues or phenomenon after each interview. Moreover, the researcher paid special attention to verbal and non-verbal responses of informants while conducting the interviews, so as to check the confirmability of the findings. The researcher scheduled discussions with the doctoral supervisors to review the codes, categories and conceptualisation of the themes.

Although member-checking was suggested by Lincoln & Guba (1985) as the fundamental technique for establishing creditability, it was not be practical in this study. Member-checking refers to giving the transcribed interview or the final analysis back to the informant to obtain additional information or to correct data (Morse, 2015). As the analysis of findings is usually a synthesis of all of the interviews and the text is abstracted, it is unlikely that the informants would recognise their stories in the combined text (Morse, 2015). Further, from the period of data collection to the final interpretation took many months and the informants might not engage with what they had said in the interviews (Harvey, 2015). Findings generated are designed for a broad audience and will differ from the account of an individual informant simply because of the different roles of each person in the research process (Morse, Barrett, Mayan, Olson, & Spiers, 2002). From the ethical viewpoint, Goldblatt, Karnieli-Miller, & Neumann (2011) suggest that member-checking distresses the re-engagement of informants with highly sensitive topics, for example, end-of-life care issue. For these reasons, member checking was not part of this study.

Knowing that the researcher in qualitative research cannot specify the external validity, the transferability of this study's findings can only be recognised by the users of the research. Through the description of research findings using direct quotations from the emic view of the informants, as well as the rich description of the research setting and context, users who are interested in the domain of the study are able to determine the applicability of the findings for their context. This qualitative study was conducted in a naturalistic setting;

whether the findings are applicable should be determined by the degree of similarity to other relevant environments and situations. This study was performed in one regional hospital in Hong Kong; it is possible to transfer the findings to the other dialysis patients and carers in a similar context, unless the cultural content or demographic information are different. Most patients and carers share similar disease and treatment burdens in the same cultural context.

In summary, Leininger's culture care theory and the ethnonursing research method provided fertile information for a novice researcher to apply components throughout the research process. The model itself is comprehensive; though not all tenets or enablers could be selected when performing this research study, such as the religious parts and economic factors in the sunrise model, the observation-participation-reflection enabler and the acculturation health care assessment enabler. Selection depends on the scope or domain of the research. The phases of data analysis were found useful to assist the researcher to perform the data analysis process step-by-step. The universality and diversity discovered via the ethnonursing method can facilitate the research process as evidence-based and culturally competent care specific to the renal dialysis patients and carers. It is assumed that the findings help to promote multidisciplinary, coordinated and integrated cultural planning of care for dialysis patients approaching end-of-life.

Chapter 7: Conclusion

7.1 Introduction

This study is the first study to apply Leininger's ethnonursing approach and culture care theory to explore the decisions about care priorities at the final stage of life of renal dialysis patients and their carers in the context of Hong Kong. The findings contribute to Hong Kong's emerging research on the topic. This final chapter reiterates the key findings from the study, then, discusses the limitations of the study, presents implications for nursing practice and recommends directions for future study. It concludes with a summary of the study.

When end-stage renal disease patients are diagnosed, the majority are offered dialytic therapy. Patients usually follow the treatment and end-of-life care plans established by healthcare professionals. Rarely are they or their carers consulted or involved in these crucial decisions. There are comorbidities for dialysis patients, and risks of life-threatening complications arise not only from the disease but also from treatment and therapy. These burdens undoubtedly influence both patients' and carers' quality of life, and non-compliant behaviour or withdrawal from dialysis can arise as a result. This study shows that, as there is insufficient and ineffective communication among patients, carers and healthcare professionals, patients may not understand their prognosis, the right to decide care priorities and treatment preferences cannot be ensured. Family members and carers seldom discuss end-of-life issues with patients. Participants in this study commonly refer to discussions about death and end of life issues as taboo in traditional Chinese culture. Regrettably, there is not much training for healthcare professionals in counselling and preparing patients and carers to deal with end-of-life issues. It is quite common for both healthcare professionals and carers do not know the patient's will for the final stage of life. Despite the high rate of

mortality related to withdrawal from dialysis, end-of-life care has not been promoted in the dialysis population locally.

This study used an ethnographic methodology, with the assistance of mixed methods sequential explanatory design, the flow of the quantitative (Phase A) and qualitative (Phase B) phases in the research progressed in an orderly process. The findings deepen the understanding of the effect of culture involved in the end-of-life care decision-making process in the Hong Kong context. This research explored the decision-making process and care priorities of dialysis patients and their carers at end-of-life. Renal nurses practice in a caring profession, and often accompany patients and families through many difficult situations, including the final stage of life. Leininger's culture care theory, derived from the nursing profession, provided the theoretical framework. This approach is specifically useful in studying how culture affects decisions people make about health care and offers support to health care professionals in their decisions about what sorts of culturally related care can be provided. With the help of the ethnonursing research method, the researcher could understand the cultural context of informants' beliefs and behaviours as well as gain access to informants' views on information that they might hesitate to share in other events.

The findings from the survey tangentially answered that dialysis patients and carers prefer their family members to make the medical decision and participate in the discussion of end-of-life care process. On the other hand, they would like to take more control about the care preferences at their final stage of life. Based on the qualitative findings, the overarching influence of culture in the decision-making process of dialysis patients and carers at end-of-life was developed, including the interrelated effect of communication barriers, family dynamics, sharing burdens and existential distress on the core of 'dignified dying'. These key findings are summarised in a diagrammatical model.

7.2 Limitations of the Study

This study aimed to explore the effect of culture on communication about the decision-making process and to learn more about a previously hidden topic in the context of end-stage renal care in Hong Kong. However, the findings should be understood with caution. As a qualitative-driven mixed methods design was used in this research, the role of the survey is comparatively less important. Its role was to give preliminary information and guide the setting up of questions to be asked in the focus group interviews (Creswell & Plano-Clark, 2011).

This was a single-centre study, and the target population was 338. The total population of people undergoing dialysis in Hong Kong was 5,009 (Leung, Cheung, & Li, 2015). As the response rate of patient informants in the survey (Phase A) was 35.8%, the sample size was relatively small (n=121 for dialysis patients and n=61 for carers) and as such may not be generalisable to other populations or contexts. However, the findings did assist the researcher to proceed to the next phase of the research by guiding the development of research questions for the focus group interviews.

The informants were recruited through convenience sampling and may have contributed to the homogeneous demographic characteristics of those persons who chose to participate in the study. This is a well-known limitation of convenience sampling and may limit transferability and generalisability of the findings to the broader dialysis patient population in Hong Kong. This sampling method inevitably involves sampling bias (Polit & Beck, 2012). Since not all eligible dialysis patients and carers have an equal chance of being included in this study (external validity), the generalisable inference is limited because of informant characteristics. While the findings may not be generalisable to other settings, a trend towards the need for better end-of-life care is evident in this study and supports the need for future research in this area of renal health care.

Cultural perspective occupies an essential component of this research study. The target population of this research were the people undergoing dialysis and their carers including a small number of migrant maid-carers. Only two Filipino and three Indonesian maid-carers were willing to complete the survey. The three Indonesian maid-carers also joined the focus group interview. The inclusion of these ethnic minority groups was intended to test for any significance in the findings when comparing with local-born Chinese and mainland-born Chinese. It was postulated that different cultures might have specific contributions to make to the attitudes, thoughts and beliefs of the decision-making process. However, although no statistical significance was noted the findings, might not be generalizable because of the small number of maid carers included.

It is acknowledged that the involvement of healthcare professionals such as renal doctors or nurses may have enriched the context of the study findings as they are an essential part of the context of end-of-life decision making. However, in keeping with the majority of the studies using Leininger's culture care theory and methods, this study focuses on patients' and or carers' perspectives, practitioners of this method seldom explore the standpoint of nurses or other healthcare professionals. While acknowledging this as a limitation of the study, it is hoped that this research will contribute to the further studies that include clinicians' perspective.

Finally, some readers may have noticed a time delay between the collection of data and the finalisation of the thesis. This issue is a hazard for part-time mature aged PhD students whose candidature spans 6-8 years while they work full time. While this may make some clinical data less relevant, a search of the literature to update and finalise the review in Chapter 2 did not show any recent conflicting findings.

7.3 Implications for Nursing Practice

The findings of this small study support the premise that patient and carers have needs that often go unrecognised by healthcare providers. For renal nurses, this means they need to give more attention not only to meet the physical and psychosocial care needs of patients during the treatment trajectory but specifically they need to pay attention to the cultural influences on patient preferences for care in the final stage of life. Renal nurses have a long-term relationship with their patients. They take care of dialysis patients and their carers from the time patients are first diagnosed with end-stage renal disease until finishing their life journey. Usually, renal nurses act as a bridge between the patients, carers, renal physicians and other healthcare professionals in gaining an understanding of the patients' preferences for care. End-of-life care is a particularly stressful role for nurses in Chinese society (Lambert, Lambert, Petrini, Li, & Zhang, 2007). There is a need for nurses to understand patients' perspective in order to fully utilise the World Health Organisation (1990) definition of palliative care. Integrating practice that focuses more on person-centred care, promoting patient engagement is required. There is a recognised need for nursing education regarding the provision of palliative care in dialysis patients.

Knowledge of cultural factors may make interactions with patients and carers more positive and reduce stress and burnout for renal nurses. To be a competent nurse in a specialist practice context renal nurses incorporate not only physical, emotional, spiritual and educational factors, but also, significantly, cultural factors into an optimal care plan (Haras, 2008). Of all healthcare professionals, nurses have the most frequent contact with patients over their stay in hospitals and renal clinics. The contacts among renal nursing staff, carers and dialysis patients who are severely ill or dying are often informal and personal. Understandably, patients are likely to speak to nurses about their hopes, wishes and concerns. Albers, Francke, de Veer, Bilsen, & Onwuteaka-Philipsen (2014) in Belgium found that 71%

of the nurse respondents believed that assisting patients to make end-of-life decisions was part of their job; and 74% agreed that they should be involved in the whole process of end-of-life decision. This similar study has not yet been done in Hong Kong or other Chinese countries. While recommendations from research such as Haras (2014) advocate change, it is also important to include a focus on supporting nurses to make such changes in busy, high-pressured and too often resource-poor practice settings, and like this study, they should be involved in decisions about their continuing education needs.

Notwithstanding the limitations of this small study, its findings add to the emerging body of knowledge to inform healthcare professionals in the renal field to readjust or modify the care given to dialysis patients at their final stage of life in Hong Kong. It may also assist nurses to appreciate the special needs of carers in facing the difficult situation of decision-making on their sick relatives' behalf. Importantly, from a patient and carers perspective the communication channels among dialysis patients, carers and healthcare professionals need to improve in order to facilitate shared decision-making and to promote advance care planning for renal patients at their final stage of life. Further investigation is required to develop culturally appropriate strategies in the context of practice in Hong Kong.

7.3.1 Enhancing the communication channels

The findings of this research have significant implications for understanding that communication is a key component in the patient-provider partnership, especially in the context of renal nursing in Hong Kong. It is essential for healthcare professionals to have the necessary skills to engage in end-of-life discussions and caring processes if they are to work within the World Health Organisation (1990) definition of palliative care and end-of-life decision-making. The presence of communication barriers is a key finding of this research study and as the discussion chapter shows is well supported by the literature. Informants expressed that they seldom communicated with family members and had limited

opportunities to communicate with healthcare professionals. The attitudes of healthcare professionals about dying and death are likely to influence the communication process and channel. They often hesitate to discuss end-of-life care with patients because of lack of knowledge and training. Moreover, they also fear to destroy hope and sense that patients and families may not be ready (Dunlay et al., 2015). In addition, patients in this study preferred to defer their medical decision-making process to their surrogates. Therefore, how to disseminate treatment and caring information to patients and carers in an effective way must be carefully and explicitly discussed. The opportunity to communicate and reaffirm close personal or familial relationships may be a channel that links quality of life socially and spiritually at the final stage of life (Prince-Paul & Exline, 2010).

Improving communication is important to form, maintain and modify relationships among family members and healthcare professionals. Knowledge, especially medical knowledge, is a significant predictor of end-of-life communication; informants with greater knowledge about care planning are keen on engaging in end-of-life communication. Patients should pursue appropriate and accurate medical knowledge from doctors and nurses (the internet or other sources although important, may be misleading). Breaking bad news and discussing prognoses with patients and families about end-of-life care plans is sensitive, emotional and requires particular skill in healthcare professionals. Nevertheless, this study supports international research showing that it is crucial that dialysis patients should not be abandoned at the end-of-life stage (Janssen et al., 2013; Ngo-Metzger et al., 2008).

It is essential to educate and support healthcare professionals to communicate effectively with dialysis patients and carers. As the literature shows many renal healthcare professionals claimed they were unprepared for end-of-life communication with patients and lacked proper training in communicating with them, an advanced communication training programme could be developed to meet the specific requirements of renal staff (Bristowe et

al., 2015; Clayton, Butow, & Tattersall, 2005; Connolly et al., 2010). Training in communication skills for healthcare professionals working with patients cannot be separated from education on the issues of awareness and knowledge. The content of the communication training should focus on skills to enhance patient-centred care, prevent misunderstandings and explore patients' contexts. The Such training programmes should include multiple strategies such as; lectures, group exercises and role-play sessions to enable the staff to practice skills, which include empathetic listening and creating an open environment in which patients and carers are free to talk (Boyd, Merkh, Rutledge, & Randall, 2011). The focus group findings from dialysis patients and their carers may contribute to training programmes that are directed toward improving the confidence levels of staff regarding advance care planning discussions with patients.

Taken together, the findings of this study suggest a role for strategies in promoting and facilitating the communication process and end-of-life conversation among healthcare professionals, dialysis patients and carers. Better communication provides an opportunity for patients to express their fears, clarify their concerns and be supported to make decisions about care known to health professionals. Chinese people are believed to be not keen on sharing and discussing this sensitive issue. While this may be so, this study shows another story and one that is culturally appropriate and supports patients need to be involved in their health care. Both patients and carers in this study, show that it is possible to hold both traditional beliefs and at the same time want to be supported to be involved in decisions about their care. Several studies have proposed and evaluated successful strategies to facilitate communication; for example, Chan and Pang (2010) designed a qualitative study of Hong Kong nursing home residents titled, 'Let Me Talk' to enable a semi-structured conversation to assist residents to express their deepest concerns about end-of-life care. Menkin (2007) evaluated a discussion aid title, 'Go Wish' cards that were specifically designed to facilitate

communication with renal patients, carers and healthcare professionals. This strategy helps to focus discussions on the dialysis patients' understanding of their illness, personal experiences with death, and goals and values for the final stage of life. Although translated into a variety of languages for American residents including Chinese it would need to be evaluated for use in Hong Kong practice.

7.3.2 Facilitating shared decision-making

This study points toward the need for shared decision-making as a process of matching treatment and care choices to patients' values and preferences. Shared decision making is a fundamental principle of patient-centred care and can be applied to the management of critically ill renal patients and their carers by healthcare professionals. For dialysis patients, it involves renal staff sharing information with the patient and carer regarding their medical condition and promoting accommodation of the patient's values and beliefs about their disease and treatments. The exchange of information can facilitate the contribution to, agreement on and taking responsibility for the ultimate treatment decision, with the decision made based on the renal professionals' medical expertise and the patient's values and preferences. Carers should be included in the decision-making process with the aim of reducing suffering and discomfort. Before decision-making, renal staff can involve the potential carer decision-makers in the advance care planning discussions they have with their patients. The timing should be when the dialysis patients are relatively stable.

Apart from sharing information, sharing what is in mind is a main theme in the shared decision-making paradigm. New ideas emerge through the sharing of thoughts, feelings, perceptions, meanings and intentions of all parties concerned in the decision-making process (Epstein & Street, 2011; Zlatev, Racine, Sinha, & Itkonen, 2008). When dialysis patients and carers communicate, their subjective experiences can be shared explicitly through language and expressions of emotion. The process can be seen as a discovered and created a practice.

However, this sharing was not common in the Hong Kong context of culture based on the findings of this study. With this awareness, the surrogates and renal care professionals can decide appropriate care priorities and treatment preferences with prior consensus from patients, even when the patients are physically and mentally incompetent. In summary, good communication, mutual trust and robust patient–carer–clinician relationships can facilitate shared decision-making to achieve a successful outcome.

7.3.3 Promoting advance care planning

Patient–carer–clinician communication and patient–carer congruence in end-of-life preferences and advance care planning have become imminent issues, as demonstrated by the participants in this study. Such findings are well supported by local and overseas studies (Briggs, Kirchhoff, Hammes, Song, & Colvin, 2004; Calvin & Eriksen, 2006; Chan & Pang, 2011; Ceccarelli et al., 2008; Davison & Simpson, 2006; Davison & Torgunrud, 2007; Detering et al., 2010; Haras, 2007; Hui, 2010; Janssen et al., 2013; Jeong, Higgins, & McMillan, 2011; Mok et al., 2010; Song et al., 2015; Tse, 2010). Advance care planning provides a platform for individuals, families and healthcare professionals to communicate personal wishes for end-of-life care, but such dialogues should not be limited to a medical-oriented focus, as wishes have to be interpreted in a personal context (Bristowe et al., 2015; Haras, 2007; Hui, 2010). In fact, the planning process is never straightforward because the trajectory of the patient's illness is full of uncertainties and the influences of personal experiences; values, beliefs and culture increase variability across individuals. It is necessary to fine-tune planning strategies so that patients do not perceive that they are being forced to confront issues before they are ready. A patient centred approach helps build rapport among the relevant parties; this is the foundation of advance care planning. It enables the planning process to be conducted in a continuous, meaningful and consistent manner according to the dialysis patients' needs and concerns.

While the practice of end-of-life decision-making has been in place in Western countries since the 1990s, unfortunately, advance care planning is much more recent in Hong Kong and has not often been used, especially for dialysis patients. Although it has the potential to enhance the caring plan and the quality of life for patients at end-of-life, healthcare professionals have been hesitant to adopt the idea. Yuen, Suen, Kwok, Yong and Tse (2016) suggested that renal doctors should initiate detailed discussions with end-stage renal disease patients and carers to assist them in expressing desires about end-of-life. The idea of 'self-help' should be introduced to patients for advance care planning so that it seems more comfortable, simpler and clearer instead of leaving the decision to someone else (Jeong et al., 2011). Conversely, the wishes discussed among patients, carers and healthcare professionals in the advance care planning must be honoured. The advantages of executing advance care planning include the promotion of patient autonomy (Davison, 2010; Emanuel & Scandrett, 2010; Tse, 2010), improving communication and trust among patients, carers and healthcare professionals (Evans et al., 2014; Ko & Lee, 2009), and making decisions easier and with more confidence (Morton et al., 2010; Song et al., 2013; Weissman, 2004). For the purpose of future treatment priorities and preferences, advance care planning focuses on improving the quality of life as the end-of-life approaches as well as addressing family dynamics and conflict (Kane, Vinen, & Murtagh, 2013). Therefore, a continuing dialogue among patients, carers and healthcare professionals about end-of-life care promotes patient self-determination and may simultaneously prevent moral disharmony.

Advance care planning is an ongoing process and not limited to the completion of advance directives (Houben, Spruit, Wouters, & Janssen, 2014). Patients, carers and healthcare professionals should review the goals of care, life support treatments, end-of-life care preferences and surrogate decision-making throughout the patient's journey. Although patients and carers often expect and prefer renal doctors to discuss advance care planning

with them, renal nurse consultants, who have specific skills to facilitate communication about end-of-life care, are well placed to take up this role, especially given that doctors have so little time to spend with patients. They have the capability and responsibility of walking the end-of-life path with both patients and carers. Additional training can provide prognostic information and support patients' expectations by understanding and communicating with the individual patient, focusing on the patient's quality of life and rapport building. Advance care planning meetings could be arranged in nurse clinics run by the renal nurse consultant. Queries about the treatment plan and care priorities could be explained and discussed with dialysis patients and carers during the meetings. The renal doctor could join the meetings at a later stage, to make the advance directives after a comprehensive explanation.

Although the Hospital Authority in Hong Kong has been using a newly created advance directives form for chronic illness patients since 2010, it has not been applied thoroughly in the clinical setting because of lack of time to explain it to case doctors and has not enough trained staff to follow up the care plan. In addition, there is a renal palliative care programme for newly diagnosed end-stage renal disease patients, but this has not been extended to the current renal dialysis patients who, it could be argued, have a more pressing need. Therefore, advance care planning should be extended to cover all dialysis patients to enable dignified dying care.

7.4 Recommendations for Future Research

Four closely related recommendations are suggested for future research. The first recommendation concerns exploring attitudes of healthcare professionals' (physicians, nurses and others in the multi-disciplinary team) towards caring for dialysis patients and their end-of-life issues. The quality of clinical practice is affected by healthcare professionals' attitudes. Poor quality of care result if the values of the dialysis patients and carers have not been identified, if care preferences are not coherent, and if renal physicians and nurses fail to

engage in the timely decision-making process (Sorensen & Iedema, 2009). Attitudes to end-of-life issues originate from personal, professional, organisational and cultural aspects. In the local context, healthcare professionals' attitudes about communication with end-of-life patients might be influenced by the culture where their beliefs about dying and death developed.

Secondly, intervention research is required to test evidence-based strategies to support Hong Kong healthcare professionals, including nurses, initiate and facilitate discussion with dialysis patients and carers about expressing their end-of-life care preferences. This study found that culture plays a vital role in discussions about end-of-life care issues and is essential for dialysis patients and carers. In addition, international research shows that person-centred and practice-oriented interventional research can act as a means to demonstrate strategies to open conversation for patients and carers to express their care needs and expectations. Culturally appropriate interventional research is exploring communication strategies, aids and tools may assist patients and carers as well as busy clinicians to engage in much needed and timely discussions about end-of-life concerns.

Thirdly, a survey of Hong Kong healthcare professional education programme to identify relevant content and learning processes that focus on communication relevant to supporting clinicians to initiate and sustain the critical and emotional communication with dialysis patients and carers, especially at the end-of-life moment (Delgado-Guay et al., 2016). Improving the communication process should start with educating renal healthcare professionals.

Finally, an interventional study should be performed with the aim of promoting and endorsing an advanced care planning service for dialysis patients in Hong Kong. Although as Chapter 1 and 2 of this study show that there is an emerging recognition in Hong Kong about the importance of end-of-life decision making and advanced care planning, at present Hong

Kong renal palliative care programmes only caters for end-stage renal disease patients choosing not to enter into renal replacement therapy. Likewise, there is no systematic integration of advance care planning and or palliative care in the dialysis population. There is a need for both interventional and evaluation research to establish a programme to promote advance care planning for dialysis patients and their carers. While such projects would be possible in individual health service sites the outcomes would be strengthened by collaborative research across multiple renal health services in Hong Kong.

7.5 Conclusion

In conclusion, renal dialysis is not only a treatment provided to end-stage renal disease patients to sustain their life but a burden affecting patients' and carers' daily life. Healthcare professionals in the renal speciality often find themselves in a dilemma when encountering seriously ill dialysis patients who have not expressed or made decisions related to withdrawal from life-sustaining therapy or end-of-life care. As there is very little information about dialysis patients' and carers' treatment preferences and care priorities at end-of-life in Hong Kong, the findings of this small study may provide initial information and direction for the end-of-life decision-making process of dialysis patients and carers in the cultural context. It may help to guide healthcare professionals to reflect on their practice, the experience of their patients and their carers. It also prompts the need to consider practice-based and person-centred advance care planning for dialysis patients in their care early in the care cycle when patients are more able to engage with complex issues and made sound decisions.

With the globalising world becoming increasingly linked by communication, media and transport external cultural influences are likely to escalate. As shown in this small study, in the Hong Kong cultural context, individuals often find difficulty communicating with each other. In the wider context, the doctor–patient–carer relationship has led to significant debate

in care provision. Likewise, the role of nurses in this complex care environment need to be re-visited. Healthcare professionals all need to have the capacity to initiate and support discussions with patients and carers about end-of-life care planning. The Chinese traditional belief in the balance between paternalism and shared-decision making raises concerns as the shift to person-centred care takes a firmer grip in practice. This shift raises the need for culturally appropriate communication in a global context.

In fact, cultural differences in preferred forms of care and decision-making process can be explained by the collectivism–individualism dichotomy. As demonstrated in the findings of this study, the interrelated effects of communication barriers, family dynamics, sharing burdens and existential distress were formulated from the emic views of renal dialysis patient and carer informants. The core of the decision-making process for care priorities at the final stage of life for dialysis patients is established as ‘dignified dying’. Efficient and honest communication among patients, carers and healthcare professionals not only enhances independence and autonomy in making medical decisions but also supports the family-centred system for shared decision-making. Understanding Chinese culture could facilitate and reinforce the decision-making process.

Further, strategies have been suggested to normalise and facilitate discussion about concerns, fears, preferences, and care priorities along the trajectory of end-stage renal disease patients on dialysis. Discussions about end of life care and advance care planning provide an opportunity for all concerned to express their end-of-life care preferences, and subsequently, examine, and reflect on their own lives. Although some of the patients, carers and healthcare professionals may not be ready to communicate about the advance care planning process, the findings of this study bring us a step closer to verifying the importance of dialysis patients’ and carers’ engagement in the end-of-life care planning process.

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Appendix Tables

Table A.1

Demographics of Dialysis Patient Key Informants in Focus Groups

FG1_Patient

No.	Sex	Age	Dialysis months	HD/PD
1	M	60	72	HD
2	M	75	120	PD
3	F	56	97	PD
4	F	43	26	PD
5	F	53	94	PD
6	M	68	18	PD

FG2_Patient

No.	Sex	Age	Dialysis months	HD/PD
7	F	68	172	HD
8	F	66	48	PD
9	M	52	26	PD
10	F	43	38	PD
11	F	46	22	PD

FG3_Patient

No.	Sex	Age	Dialysis months	HD/PD
18	F	68	76	PD
19	M	68	44	PD
20	M	33	35	HD
21	F	68	38	PD
22	M	69	56	PD

FG4_Patient

No.	Sex	Age	Dialysis months	HD/PD
23	M	51	24	PD
24	F	63	36	PD
25	M	51	6	PD
26	M	62	84	PD
27	M	39	24	PD
28	F	65	3	HD
29	M	55	120	PD
30	M	45	8	PD

Total: 24

Total	13 M:11 F	56.96	53.63	HD 4: PD 20
Mean	54.2%:45.8%			16.7%:83.3%

Notes: M: Male, F: female, HD: haemodialysis, PD: peritoneal dialysis, FG: focus group.

Table A.2

Demographics of Dialysis Patient Carer Key Informants in Focus Groups

FG1_Carer

No.	Sex	Age	Patient dialysis months	Ethnicity	HD/PD
12	F	52	168	Mainland Chinese	HD
13	F	63	18	Hong Kong Chinese	HD
14	F	58	38	Hong Kong Chinese	PD
15	F	56	126	Hong Kong Chinese	PD
16	F	36	36	Hong Kong Chinese	PD
17	F	62	10	Hong Kong Chinese	PD
Mean		54.5	66		

FG2_Carer

No.	Sex	Age	Patient dialysis months	Ethnicity	HD/PD
31	F	28	26	Indonesia	HD
32	F	18	12	Indonesia	HD
33	F	42	158	Indonesia	HD
Mean		29.33	65.33		

FG3_Carer

No.	Sex	Age	Patient dialysis months	Ethnicity	HD/PD
42	M	60	38	Hong Kong Chinese	PD
43	M	74	146	Hong Kong Chinese	HD
45	F	58	7	Hong Kong Chinese	PD
46	F	49	9	Mainland Chinese	PD
47	F	30	6	Hong Kong Chinese	HD
Mean		54.20	41.20		

Total: 14

Total	2 M : 12 F	49.0	61.71	HD 7: PD 7
Mean	14.3%:85.7%			50%:50%

Notes: M: Male, F: female, HD: haemodialysis, PD: peritoneal dialysis, FG: focus group.

Appendix A: Advance Directive Form

[redacted]	**ADVANCE DIRECTIVE**[1]	Please Use Block Letter or Affix Label SOPD / Hospital No. : ..... Name : ..... I.D. No : .....Sex .....Age..... Dept : .....Team :.....Ward/Bed :.../.....

Section I : Personal details of the maker of this advance directive

Name : ..... *(please use capital letters)*

Identity Document No.: .....

Sex : **Male / Female**

Date of Birth : _____ / _____ / _____
(Day) (Month) (Year)

Home Address : .....

.....

Home Tel. No. : .....

Office Tel. No. : .....

Mobile Tel. No. : .....

Section II : Background

1. I understand that the object of this directive is to minimise distress or indignity which I may suffer or create when I am terminally ill or in a persistent vegetative state or a state of irreversible coma, or in other specified end-stage irreversible life limiting condition, and to spare my medical advisers or relatives, or both, the burden of making difficult decisions on my behalf.

2. I understand that euthanasia will not be performed, nor will any unlawful instructions as to my medical treatment be followed in any circumstances, even if expressly requested.

3. I, _____ (please print name) being over the age of 18 years, revoke all previous advance directives made by me relating to my medical care and treatment (if any), and make the following advance directive of my own free will.

4. If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state or in other specified end-stage irreversible life limiting condition as diagnosed by my attending doctor and at least one other doctor, so that I am unable to take part in decisions about my medical care and treatment, my directives in relation to my medical care and treatment are as follows:

(Note: Complete the following by ticking the appropriate box(es) and writing your initials against that/those box(es), and drawing a line across any part you do not want to apply to you.)

[1] The Form was proposed by the Law Reform Commission on 16 August 2006; amended as in Food and Health Bureau Consultation Paper on 23 December 2009; modifications made and footnotes added by the Hospital Authority in May 2010 and in Jun 2014.

Sample

(A) Case 1 – Terminally ill

(Note: In this instruction –

"Terminally ill" means suffering from advanced, progressive, and irreversible disease, and failing to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months; and the application of life-sustaining treatment would only serve to postpone the moment of death, and

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

- ☐ **Cardiopulmonary resuscitation (CPR)**
- ☐ **Others: _____**

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[2]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

- ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

(B) Case 2 – Persistent vegetative state or a state of irreversible coma

(Note: In this instruction -

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration[3]. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

- ☐ **Cardiopulmonary resuscitation (CPR)**
- ☐ **Others: _____**

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[4]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

- ☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

---

[2] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

[3] Note that to withdraw artificial nutrition and hydration (ANH) in a non-terminally ill patient who is in a persistent vegetative state or a state of irreversible coma (PVS/IC) can be contentious even in the presence of an AD. For patients presenting with such a directive and in PVS/IC, advice should be sought from the HCE/CCE and HAHO to consider whether an application to the Court is required. A patient wishing to make a directive to withdraw ANH, or to withdraw all life-sustaining treatments under this Section, should be alerted about this special caution.

[4] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.

Sample

(C) **Case 3 – Other end-stage irreversible life limiting condition, namely:**

_____

(Note: In this instruction -

"Other end-stage irreversible life limiting condition" means suffering from an advanced, progressive, and irreversible condition not belonging to Case 1 or Case 2, but has reached the end-stage of the condition, limiting survival of the patient. Examples include:

(1) patients with end-stage renal failure, end-stage motor neuron disease, or end-stage chronic obstructive pulmonary disease who may not fall into the definition of terminal illness in Case 1, because their survival may be prolonged by dialysis or assisted ventilation, and

(2) patients with irreversible loss of major cerebral function and extremely poor functional status who do not fall into Case 2.

"Life-sustaining treatment" means any of the treatments which have the potential to postpone the patient's death and includes, for example, cardiopulmonary resuscitation, artificial ventilation, blood products, pacemakers, vasopressors, specialised treatments for particular conditions such as chemotherapy or dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. (Artificial nutrition and hydration means the feeding of food and water to a person through a tube.))

☐ **I shall not be given the following life-sustaining treatment(s):**

☐ **Cardiopulmonary resuscitation (CPR)**

☐ **Others:** _____

_____

☐ **Save for basic and palliative care, I shall not be given any life-sustaining treatment[5]. Non-artificial nutrition and hydration shall, for the purposes of this form, form part of basic care.**

☐ **However, I want to continue to receive artificial nutrition and hydration, if clinically indicated, until death is imminent and inevitable.**

5. I make this directive in the presence of the two witnesses named in Section III of this advance directive, who are not beneficiaries under:

(i) my will; or
(ii) any policy of insurance held by me; or
(iii) any other instrument made by me or on my behalf.

6. I understand I can revoke this advance directive at anytime[6].

_____ _____

Signature of the maker of this advance directive Date

Section III : Witnesses

Notes for witness :

A witness must be a person who is not a beneficiary under –
(i) the will of the maker of this advance directive; or
(ii) any policy of insurance held by the maker of this advance directive; or
(iii) any other instrument made by or on behalf of the maker of this advance directive.

[5] Care should be taken to ensure that the patient has really decided not to consent to receive "all" life-sustaining treatment.
[6] A written revocation can be directly signed on the advance directive form, or written and signed on a separate piece of paper and attached to the advance directive form.

Sample

Statement of Witnesses

First Witness

(Note: This witness must be a registered medical practitioner, who, at the option of the maker of this directive, could be a doctor other than one who is treating or has treated the maker of this directive.)

(1) I, _____ (please print name) sign below as witness.

(a) as far as I know, the maker of this directive has made the directive voluntarily; and

(b) I have explained to the maker of this directive the nature and implications of making this directive.

(2) I declare that this directive is made and signed in my presence together with the second witness named below.

_____ _____
Signature of 1st witness Date

Name: .....

Identity Document No. / Medical Council Registration No. [7]: .....

Office Address: .....

.....

Office Tel. No. : .....

Second Witness

(Note: This witness must be at least 18 years of age)

(1) I, _____ (please print name) sign below as witness.

(2) I declare that this directive is made and signed in my presence together with the first witness named above, and that the first witness has, in my presence, explained to the maker of this directive the nature and implications of making this directive.

_____ _____
Signature of 2nd witness Date

Name: .....

Identity Document No.[8]: .....

Home Address / Contact Address : .....

.....

Home Tel. No. / Contact No. : .....

[7]. It is not necessary for HA staff to provide the Identity document No. / Medical Council Registration No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 1st witness.

[8]. It is not necessary for HA staff to provide the Identity document No. since staff code or address of hospital ward/unit would be sufficient for the identification of the 2nd witness.

Sample

Appendix B: Patient Focus Group Interview Guide

Introductory question	Could you please tell us about your feeling of coming back to discuss this topic?
Transition question	Have you talk about this issue with anyone before? Why do you want to come back to participate in this group?
Focus question	Have you thought about what might happen to you regarding your illness in the future?
	Have you heard about the end-of-life care?
	Have you discussed with anybody about your choice concerning your end-of-life care?
	How do you feel when you discuss the end-of-life issues with somebody?
	If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your behalf? Why?
	Who should initiate the discussion on EoL care?
	Who should participate in the discussion?
	What should be discussed in the decision-making process?
	Have you completed any of the following?
	Will, Enduring power of attorney, or Advance directives.
	Would you like to make an advance directive if it is available?
Summary question	What will you expect on the health care professional should do when you are approaching final stage of life?
Concluding question	Is there anything we should talk but we haven't talk?

Debriefing statement:

Thank you for coming back to share your ideas related to the topic. Just reassure you that all the information collected will not be disposed to anyone. The results from this study will initially be presented in a form of thesis. In addition, papers for publication in scholarly journals and for presentation at specialist conferences will be prepared. The findings of this study will be offered to participants upon completion of the research.

Appendix C: Carer Focus Group Interview Guide

Introductory question	Could you please tell us about your feeling of coming back to discuss this topic?
Transition question	Have you heard about the end-of-life care?
Focus question	Have you thought about what might happen to your relative regarding his/her illness in the future?
	What will you expect on end-of-life care?
	Have you discussed with anybody about your relative's choice concerning his/her end-of-life care?
	How do you feel when you discuss the end-of-life issues with somebody?
	Has your relative completed any of the following?
	Will, Enduring power of attorney, or Advance directives.
	If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort; or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?
	If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your behalf? Why?
	If you were the patient, would you like to make an advance directive if it is available?
Summary question	What will you expect on the healthcare professional should do when you are approaching final stage of life?
Concluding question	Is there anything we should talk but we haven't talk?

Debriefing statement:

Thank you for coming back to share your ideas related to the topic. Just reassure you that all the information collected will not be disposed to anyone. The results from this study will initially be presented in a form of thesis. In addition, papers for publication in scholarly journals and for presentation at specialist conferences will be prepared. The findings of this study will be offered to participants upon completion of the research.

Appendix D: Leininger's Phases of Ethnonursing Data Analysis Enabler

Fourth Phase (Last Phase)

Major Themes, Research Findings, Theoretical Formulations, and Recommendations

This is the highest phase of data analysis, synthesis, and interpretation. It requires synthesis of thinking, configuration analysis, interpreting findings, and creative formulation from data of the previous phases. The researcher's task is to abstract and confirm major themes, research findings, recommendations, and sometimes make new theoretical formulations.

Third Phase

Pattern and Contextual Analysis

Data are scrutinized to discover saturation of ideas and recurrent patterns of similar or different meanings, expressions, structural forms, interpretations, or explanations of data related to the domain of inquiry. Data are also examined to show patterning with respect to meanings-in-context and along with further credibility and confirmation of findings.

Second Phase

Identification and Categorization of Descriptors and Components

Data are coded and classified as related to the domain or inquiry and sometimes the questions under study. *Emic* or *etic* descriptors are studied within context and for similarities and differences. Recurrent components are studied for their meanings.

First Phase

Collecting, Describing, and Documenting Raw Data (Use of Field Journal and Computer)

The researcher collects, describes, records, and begins to analyze data related to the purposes, domain of inquiry, or questions under study. This phase includes: Recording interview data from *key* and *general* informants; making observations, and having participatory experiences; identifying contextual meanings; making preliminary interpretations; identifying symbols; and recording data related to the DOI or phenomenon under study mainly from an *emic* focus. Attention to *etic* ideas is also recorded. Field data from the condensed and full field journal can be processed directly into the computer and coded, ready for analysis.

Figure 3-6 Leininger's Phases of Ethnonursing Data Analysis Enabler for Qualitative Data

Source: McFarland & Wehbe-Alamah, 2015, pp. 89.

Appendix E: Ethics Approval, University of New England

Ethics Office
Research Development & Integrity
Research Division
Armidale NSW 2351
Australia
Phone *02 6773 3449*
Fax *02 6773 3543*
jo-ann.sozou@une.edu.au
www.une.edu.au/research-services

HUMAN RESEARCH ETHICS COMMITTEE

MEMORANDUM TO: Dr Glenda Parmenter, Dr Yoni Luxford & Mr Chi Lee

School of Health

This is to advise you that the Human Research Ethics Committee has approved the following:

PROJECT TITLE:	Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong.
APPROVAL No.:	HE12-085
COMMENCEMENT DATE:	15 May, 2012
APPROVAL VALID TO:	15 November, 2013
COMMENTS:	Nil. Conditions met in full

The Human Research Ethics Committee may grant approval for up to a maximum of three years. For approval periods greater than 12 months, researchers are required to submit an application for renewal at each twelve-month period. All researchers are required to submit a Final Report at the completion of their project. The Progress/Final Report Form is available at the following web address:
http://www.une.edu.au/research-services/researchdevelopmentintegrity/ethics/human-ethics/hrecforms.php

The NHMRC National Statement on Ethical Conduct in Research Involving Humans requires that researchers must report immediately to the Human Research Ethics Committee anything that might affect ethical acceptance of the protocol. This includes adverse reactions of participants, proposed changes in the protocol, and any other unforeseen events that might affect the continued ethical acceptability of the project.

In issuing this approval number, it is required that all data and consent forms are stored in a secure location for a minimum period of five years. These documents may be required for compliance audit processes during that time. If the location at which data and documentation are retained is changed within that five year period, the Research Ethics Officer should be advised of the new location.

[redacted]

Jo-Ann Sozou
Secretary/Research Ethics Officer

14/06/2013 A12/193

Appendix F: Ethics Approval, Regional Hospital

[redacted]

Ethics Committee, HKEC

3 Lok Man Road
Chai Wan
Hong Kong

20 November 2012

Mr. LEE Chi Wai
Professional Consultant

The Nethersole School of Nursing
CUHK

Ref: HKEC-2012-048

Dear Mr. LEE,

The Ethics Committee (EC) of HKEC is authorized by the Cluster Chief Executive to review and monitor clinical research. It serves to ensure that research complies with the Declaration of Helsinki, ICH GCP Guidelines, local regulations and HA policy. It has the authority to approve, require modifications in (to secure approval), or disapprove research. This Committee has power to terminate/suspend a research at any time if there is evidence to indicate that the above principles and requirements have been violated.

The Committee has reviewed your research application dated 31 August 2012 by an expedited process, and reached the following decision basing on the documents submitted.

The Committee approves your application and the following documents, and requires you to adhere to the attached conditions:

Title of Study	Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong.
List of investigators	1. Mr. LEE Chi Wai, Professional Consultant, The Nethersole School of Nursing, CUHK 2. Ms. HO Hau Sim, Advanced Practice Nurse, Department of Medicine, PYNEH
Protocol title and version	Research Proposal (Version 1, 26th Jul 2012)
Consent Form versions	1. English Consent Form for Participants (Appendix IX July 2012 Version 1) 2. Traditional Chinese Consent Form for Participants (Appendix VII July 2012 Version 1)
Information sheet title and versions	1. English Information Sheet for Participants (Appendix VIII July 2012 Version 1) 2. Traditional Chinese Information Sheet for Participants (Appendix VI Nov 2012 Version 2)

3 Lok Man Road, Chai Wan, Hong Kong 香港柴灣樂民道三號 Tel 電話 : +852 2595 6111 Fax 傳真 : +852 2515 0794

Certificate of indemnity/insurance	N.A.
Other Documents	1. English Questionnaire (Appendix IV Nov 2012 Version 2 Patient) 2. Traditional Chinese Questionnaire (Appendix II Nov 2012 Version 2 Patient) 3. English Questionnaire (Appendix V Nov 2012 Version 2 Carer) 4. Traditional Chinese Questionnaire (Appendix III Nov 2012 Version 2 Carer) 5. Reply email from LEE Chi Wai Paul dated 5 November 2012 to EC, HKEC, regarding feedbacks about the questions from the vetting members. 6. Revised Application Form
Conditions	1. The Principal Investigator is responsible and accountable for the confidentiality of the personal data of the study subjects they hold. The Principal Investigator must also ensure that there is appropriate arrangement to protect the security of personal data when it is stored, sent or received. 2. Apply a clinical trial certificate from department of health if applicable. 3. Do not deviate from, or make changes to the study protocol without prior written EC approval, except when it is necessary to eliminate immediate hazards to research subjects or when the change involves only logistical or administrative issues. 4. Report the following to EC: (i) study protocol or consent document change (use 'HKECRE001F7')*, (ii) serious adverse event (use 'HKECRE001F8')*, (iii) study progress (use 'HKECRE001F9')* (iv) new information that may be relevant to a subject's willingness to continue participation in the study, (v) final report upon completion of study (use 'HKEC001F9b')*. 5. Report first study progress to EC by 19 November 2013 and thereafter at 12 monthly intervals until study closure. 6. Submit Research Final Report Form (use 'HKECRE001F9b')* to EC upon completion of study.

* *Download forms from the HKEC intranet for use*

Please report the progress of the study according to the time schedule stipulated in Clause 5 of Conditions shown above for the Cluster REC to consider whether the approval status can be maintained. Upon completion of the study, kindly furnish the EC with a final report using the form mentioned in Clause 6 of Conditions.

Yours sincerely,

[redacted]

for Chairman of EC, HKEC

cc. COS(MED), PYNEH

Ref: HKEC-2012-048

Ethics Committee
Hong Kong East Cluster

Panel for Expedited Review

Membership Category	Title and Name	Occupation	Gender
Member	Dr. K Y YEUNG	Consultant, Paediatrics & Adolescent Medicine, PYNEH	M
	Dr. Leo CHU	Associate Consultant, Anaesthesia, PYNEH	M
	Dr. K K CHAN	Senior Physicist, Medical Physics, PYNEH	M
	Dr. P G KAN	Chief of Service, Accident & Emergency, RHTSK	M
Lay/Non-scientific Member	Rev. William LAM	Hospital Chaplain i/c, PYNEH	M
	Ms. Ophelia CHAN Chiu Ling	HGC Member, PYNEH	F

Appendix G: Information Sheet (English Version)

School of Health
Faculty of The Professions
Armidale NSW 2351
Phone 61 2 6773 3683
Fax 61 2 6773 3666
Email: gparment@une.edu.au

INFORMATION SHEET for PARTICIPANTS

Research Project:
Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong.

I wish to invite you as a renal dialysis patient or carer to participate in my research on the above topic. You must be over the age of 18 years to participate in this study. The details of the study are as follows and I hope you will consider being involved. I am conducting this research project for my PhD at the University of New England in Australia. My supervisors are Dr. Glenda Parmenter and Dr. Yoni Luxford of the University of New England. They can be contacted by email at gparment@une.edu.au and yluxford@une.edu.au or by phone on 612-67733683 and 612-67732547. I can be contacted by email at clee37@une.edu.au or phone on 96682617.

Aim of the Study:
The main aim of this study is to explore the decision making process about care priorities at the final stage of life among renal dialysis patients and carers in Hong Kong. A secondary aim is to inform health care professionals regarding approaches to care priorities for renal dialysis patients and carers.
The study has 2 phases:

Phase 1:
You will be invited to participate in completing a survey. This survey will take approximately 15 minutes to complete. It will ask for some personal demographic data and about your decisions regarding care priorities and preferences for care at the final stage of life.

Phase 2:
You will be invited to participate in a focus group interview, lasting 60 minutes. It will be conducted in Pamela Youde Nethersole Eastern Hospital. If you are interested in participating in this group discussion, you can approach your dialysis staff who will pass your details to me. Alternatively, you can contact me directly by email at clee37@une.edu.au or phone on 96682617.
During the focus group interview, I will ask some questions to help the group explore this sensitive issue. We are very interested in finding out more about your thoughts, feelings and experiences you have around decision about care priorities at the final stage of life.

Surveys and interviews:
All surveys are anonymous and the focus group interviews will be audio-recorded with your permission. Following the interviews, transcripts will be generated for data analysis. Any information or personal details gathered in the course of the study will remain confidential. While some of the information participants provide may be used as direct quotes in publications, no individual will be identified by name. Your name will be replaced by a pseudonym, this will ensure that you are not identifiable.
Participation is completely voluntary. If you decide to participate, you are free to withdraw from the project and discontinue at any time without having to give a reason. Your decision to

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participate will in no way affect your access to treatment or care at the Pamela Youde Nethersole Eastern Hospital.
It is unlikely that this research will raise any personal or upsetting issues but if it does, you may wish to approach Ms. Rebecca Wong Social Worker of the Patient Resource Centre in Pamela Youde Nethersole Eastern Hospital for counselling service whenever necessary. Her phone number is 25956468.
Surveys and voice recordings will be kept in a locked filing cabinet at the researcher's office. The transcriptions and other data will be kept in the same manner for five years following thesis submission and then all will be destroyed according to National Health and Medical Research Council (NHMRC) guidelines in Australia. Only the researcher named below will have access to the data.

Research Process:
It is anticipated that this research will be completed by the end of 2015. The results will be presented in a PhD thesis, at conferences and in scholarly journals without any identifying information. In addition, upon completion of the research a seminar presentation will be offered to participants to discuss the findings of this study.
This project has been approved by the Human Research Ethics Committee of the University of New England (Approval No. HE12-085, Valid to 15/05/2013)
Should you have any complaints concerning the manner in which this research is conducted, please contact the Research Ethics Officer at the following address:

Secretary
Ethics Committee
The Pamela Youde Nethersole Eastern Hospital
3 Lok Man Road, Chai Wan,
Hong Kong SAR
Telephone: 25956111

Research Services
University of New England
Armidale, NSW 2351
Australia
Telephone: 612-67733449
Facsimile 612-67733543
Email: ethics@une.edu.au

Thank you for considering this request and I look forward to further contact with you.

Regards

[redacted]

LEE Chi Wai

Appendix VIII
July 2012 Version 1

Appendix H: Information Sheet (Chinese Version)

School of Health
Faculty of The Professions
Armidale NSW 2351
Phone 61 2 6773 3683
Fax 61 2 6773 3666
Email: gparment@une.edu.au

參與研究人士的資訊

研究項目：
生命末端時之優先護理決策：聆聽香港透析病人和照顧者的心聲。

本人正修讀澳洲新英格蘭大學的博士學位，現誠邀閣下作為透析病人或照顧者參加上述主題的研究，你必須是年滿 18 歲。詳細的研究內容稍後將有更多資訊提供，希望你能考慮參與。
本人的監督員是蘭達.帕門特博士和約尼.勒克斯福德博士，她們的聯絡方法可透過電郵或電話，
電郵: gparment@une.edu.au 及 yluxford@une.edu.au
電話: 612 - 67733683 及 612- 67732547。
至於本人的電郵則為: clee37@une.edu.au 電話: 96682617

研究目的：
這項研究的主要目的，是探討香港透析病人和照顧者，對有關在生命最後階段時，決定優先護理過程的看法。其次是令專業醫護人員得知，怎樣關顧生命處在最後階段時的透析病人及其照顧者。這項研究分兩階段進行：
第一階段 ：
邀請你填寫一份大約需時十五分鐘的調查。調查內容包括收集一些個人資料及諮詢有關在生命最後階段時，優先護理之決策過程和個人取向的問題。
第二階段：
如果你有興趣及願意參加焦點小組訪談，可聯絡腎科職員或直接透過電子郵件 clee37@une.edu.au 或電話 96682617 與本人聯絡。然後，本人會安排你參與在東區尤德夫人那打素醫院進行，為時六十分鐘的焦點小組訪談。在訪談中，本人會提出一些對本研究有關的問題，目的是讓你能進一步發表多些在生命末端時，對決定接受優先護理的概念、看法及態度。同時亦鼓勵焦點小組參與者之間的討論，以達至話題被充分探討。

調查及訪談：
所有調查是以不記名的方式進行。同時，在參與者的許可下，訪談內容會作電子錄音紀錄，並加以轉錄以作研究之用。參與者提供的信息，可能在出版刊物中被直接引用。有關資訊或研究過程中所收集的個人資料全屬保密，你的真實名字不會出現在研究文獻中，或以假名代之，以確保你的身份不會被識別。
參與者全屬自願性質，你可以在參與過程中，在不需提供任何理由下隨時退出研究，而你的退出更不需承擔任何後果。不論你決定參加與否，都絕不會影響你在東區尤德夫人那打素醫院的治療或護理。這項研究將不會提及個人私隱或詢問一些令人反感的問題，但訪談中的內容可能會令你不安。若你有此感覺，可致電 25956468，與醫務社工黃姑娘聯絡，以作出輔導跟進。
此外，調查的文件和訪談的錄音紀錄均保存在研究員辦公室的上鎖文件櫃內，只有命名的研究員才可使用調查和訪問的數據。所有研究的資料都是高度保密，在提交論文後，有關資料只保存五年；然後，按澳洲國家衛生和醫學研究理事會指引全部銷毀。

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Phone 61 2 6773 3683
Fax 61 2 6773 3666
Email: gparment@une.edu.au

研究過程：
預計這項研究將於二零一五年年底前完成，結果將在本人之博士論文中提交。研究結果也會在剔除個人資料後，於學術會議和學術期刊中展示。此外，在研究完成後，本人亦會向是次參加者，以研討會的形式公報研究結果。是項專題研究已獲新英格蘭大學的道德事務委員會審批。
(批准文號: HE 12-085 ，有效期至: 2013 年 5 月 15 日)

如果你對這項研究有任何投訴，可致電研究倫理主任：

倫理委員會秘書
東區尤德夫人那打素醫院
柴灣樂民道三號
香港特區
電話： 25956111

Research Services 研究服務
University of New England 新英格蘭大學
Armidale, NSW 2351 阿米代爾，新南威爾士州 2351
Australia 澳大利亞
電話: 612-67733449，傳真: 612-67733543
電郵: ethics@une.edu.au

感謝你考慮本人誠意的邀請，期待能進一步與你聯絡。

此致

[redacted]

李志偉

Appendix I: Consent Form (English Version)

School of Health
Faculty of The Professions
Armidale NSW 2351
Phone 61 2 6773 3683
Fax 61 2 6773 3666
Email: gparment@une.edu.au

Consent Form for Participants

Research Project:
Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong.

I, _____, have read the information contained in the Information Sheet for Participants and any questions I have asked have been answered to my satisfaction.	Yes / No
I agree to participate in this research project, realizing that I may withdraw at any time without penalty.	Yes / No
I am over the age of 18.	Yes / No
I agree that research data gathered for the study may be published using a pseudonym and that direct quotes will be used.	Yes / No
I agree to the interview having my voice recorded and transcribed.	Yes / No

_____ _____
Signature of participant Date

_____ _____
Signature of researcher Date

Appendix J: Consent Form (Chinese Version)

School of Health
Faculty of The Professions
Armidale NSW 2351
Phone 61 2 6773 3683
Fax 61 2 6773 3666
Email: gparment@une.edu.au

參與研究者同意書

研究項目：

生命末端時之優先護理決策：聆聽香港透析病人和照顧者的心聲。

本人 _____ 已經閱讀附上之有關資訊，我的查詢已獲滿意解答。 是 / 否

我同意參與這一研究項目，並明白我可以隨時退出而不必承擔任何後果。 是 / 否

我已年滿 18 歲。 是 / 否

我同意這項研究收集我的資料，而研究結果可能於剔除個人資料後，以假名或被直接引用在學術會議和學術期刊中。 是 / 否

我同意訪談時作錄音紀錄及加以整理。 是 / 否

參與者簽署： _____ **日期：** _____

研究員簽署： _____ **日期：** _____

Appendix K: Patient Survey (English Version)

Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong

The main aim of this survey is to explore the decision making process about care priorities at the final stage of life among dialysis patients and carers in Hong Kong. Participants are requested to fill in the demographic data before completing the survey. All the information of this survey will be kept strictly confidential and will be destroyed according to National Health and Medical Research Council (NHMRC), Australia guidelines five years after the completion of the study.

If you and/or your carer are interested in participating in a focus group interview, you can approach your dialysis staff who will pass your details to me or, you can contact me directly by email at clee37@une.edu.au or phone on 96682617.

A) Demographic data

Please fill in the blank or tick ☑ the box most suitable for you at each statement.

Sex: Male ☐ Female ☐	Age: _____
Marital status: Single ☐ Married ☐ Divorced ☐ Widowed ☐	Place of birth: Hong Kong ☐ Mainland China ☐ Others: _____
Working: Yes ☐ No ☐	Education: Illiterate ☐ Primary ☐ Secondary ☐ University or above ☐
First language: Chinese ☐ English ☐ Others _____	Type of treatment: Haemodialysis ☐ Peritoneal dialysis ☐
Months on dialysis: _____	Dialysis done by: Myself ☐ family member ☐ Maid ☐ Elderly home staff ☐ Renal Unit Nursing Staff ☐
Do you have: (can tick more than one) Hypertension ☐ Diabetes Mellitus ☐ Chronic lung disease ☐ Chronic liver disease ☐ Coronary heart disease ☐ Cancer ☐ Stroke ☐ Other _____	
Religions: Nil ☐ Buddhist ☐ Catholic ☐ Christian ☐ Taoism ☐ Muslim ☐ Other _____	

B) Patient survey

Please fill in the blank or tick ☑ the box most suitable for you at each statement.

1. Have you heard about the End-of-life care?

   Yes ☐ No ☐

2. Have you heard about the Advance Directives?

   Yes ☐ No ☐

3. Whom do you rely on for social and emotional support for your illness and treatment? (can tick more than one)

   Family ☐ Friends ☐ Doctor ☐ Nurse ☐ Social worker ☐ Spiritual advisor ☐
   Other _____

4. If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your medical care? (can tick more than one)

   Family ☐ Friends ☐ Doctor ☐ Nurse ☐ Social worker ☐ Spiritual advisor ☐
   Other _____

5. How do you normally obtain information that will help you make a personal decision regarding your health / well-being? (can tick more than one)

   Renal doctor ☐ Family doctor ☐ Nurse ☐ Family☐ Friends ☐ Social worker ☐
   Spiritual advisor ☐ Paper resources ☐ Internet ☐ Television / media ☐
   Other _____

6. Why did you choose dialysis over conservative care? (can tick more than one)

   Doctor's advice ☐ Your own wish ☐ Family's advice ☐ Friend's advice ☐

7. Do you regret the decision to start on dialysis?

   Yes ☐ No ☐

8. Have you thought about what might happen to you regarding your illness in the future?

   Yes ☐ No ☐

9. Has your doctor told you about your life span?

   Yes ☐ No ☐

10. Have you completed any of the following? (can tick more than one)

    Will ☐ Enduring power of attorney ☐ Advance directives ☐ None ☐

11. How comfortable are you in discussing the end-of-life issues with family members?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

12. How comfortable are you in discussing the end-of-life issues with your renal doctor?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

13. How comfortable are you in discussing the end-of-life issues with renal nurse?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

14. What do you want to be done when your heart stops beating?

    We will try to restart your heart beat if possible (resuscitation) ☐
    We will not try to restart your heart (no resuscitation) ☐
    Do not know ☐

15. There are a number of things doctors can do to try to revive someone whose heart has stopped beating. This usually includes a machine to help you breathe. Based on your current condition, what would you want your doctor to do if your heart stopped beating?

    Restart my heart, if possible, including using a breathing machine ☐
    Let me die, do not try to restart my heart or use a breathing machine ☐
    Do not know ☐

16. If you had to make a choice when your health condition deteriorated to a state of limited life expectancy, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort; or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?

    Relieve pain or discomfort and improve quality of life as much as possible ☐
    Live as long as possible, indifferent to prolonged pain and discomfort ☐
    Do not know ☐

17. Where would you prefer to die?

    Home ☐ Hospital ☐ Nursing home ☐ Hospice care centre ☐
    Other _____

18. During the past 12 months, have you had a discussion with any of the following people about your choice concerning your end-of -life care? (can tick more than one)

I have not had a discussion with anybody ☐
Family member ☐ Friend ☐ Renal doctor ☐ Family doctor ☐ Renal nurse ☐
Social worker ☐ Spiritual advisor ☐ Other _____

19. Who would you like to involve when discussing about the end-of-life issues? (can tick more than one)

Family member ☐ Friend ☐ Renal doctor ☐ Family doctor ☐ Renal nurse ☐
Social worker ☐ Spiritual advisor ☐ Other _____

20. When would you like to have these end-of-life conversations?

Before I start dialysis ☐
After I start dialysis but before becoming ill ☐
When I become seriously ill ☐
When the need arises as defined by my medical team ☐
When I specifically request it ☐

21. How often would you like to have your end-of-life care plan reviewed?

Whenever need arises ☐
Whenever I ask for this plan to be reviewed ☐
On a regular basis (i.e., yearly, half-yearly) ☐
Other _____

22. Where would you like to have these end-of-life discussions?

During dialysis session ☐ During dialysis session but in a private room ☐
During follow-up ☐ At home ☐ Anywhere when needed ☐

23. Would you like to make an advance directive if it is available?

Yes ☐ No ☐

END OF SURVEY

THANK YOU

Appendix L: Patient Survey (Chinese Version)

生命末端時之優先護理決策：聆聽香港透析病人和照顧者的心聲

是次調查的主要目的，是探討香港透析病人和照顧者，對在生命最後階段時之優先護理決策過程的看法。參加者首先填寫一些統計資料，然後回答一些調查問題。是次調查的所有資料是絕對保密的，並在研究完畢之五年後，根據澳洲國家衛生和醫學研究理事會指引全部銷毀。
此外，如果你和/或你的照顧者有興趣參與焦點小組訪談，你可聯絡腎科職員或直接透過電子郵件 clee37@une.edu.au 或致電 96682617 與本人聯絡。

一）統計資料

請在每句最適合你的方塊中加上剔號或在空白處填寫最適合你的答案。

性別： 男 ☐　女 ☐	年齡：_____
婚姻狀況： 單身 ☐　已婚 ☐　離婚 ☐ 喪偶 ☐	出生地點： 香港 ☐　中國內地 ☐ 其他：_____
在職： 是 ☐　否 ☐	教育程度： 從未受教育 ☐　小學 ☐　中學 ☐ 大學或以上 ☐
慣常用語： 中文 ☐　英文 ☐ 其他：_____	治療類型： 血液透析 ☐　腹膜透析 ☐
接受透析月數：_____	施行透析： 自助 ☐　家庭成員 ☐　傭工 ☐ 護老院職員 ☐　腎科護士 ☐
你的病歷包括：（可選多項） 高血壓 ☐　糖尿病 ☐　慢性肺病 ☐　慢性肝病 ☐　冠心病 ☐ 癌症 ☐　中風 ☐　其他：_____	
宗教信仰： 無 ☐　佛教 ☐　天主教 ☐　基督教 ☐　道教 ☐　回教 ☐ 其他：_____	

二）調查問題

請在每句最適合你的方塊中加上剔號或在空白處填寫最適合你的答案。

1. 你有沒有聽說過「臨終護理」這個名詞？

有 □　　沒有 □

2. 你有沒有聽說過「預設醫療指示」？

有 □　　沒有 □

3. 當你在患病及治療過程中，遇到社交和情感問題時，你會依靠誰人？（可選多項）

□ 家人　　朋友 □　　醫生 □　　護士 □　　社工 □

神職人員 □　　其他 _____

4. 如果你在生理上或精神上無法自己做決定時，你會授權誰來助你選擇醫療護理的決定呢？（可選多項）

□ 家人　　朋友 □　　醫生 □　　護士 □　　社工 □

神職人員 □　　其他 _____

5. 你通常從何處取得資訊，來幫助你作出個人健康或治療的決定？（可選多項）

腎科醫生 □　　家庭醫生 □　　護士 □　　家人 □　　朋友 □

社工 □　　神職人員 □　　報章雜誌 □　　互聯網 □　　影視/媒體 □

其他 _____

6. 你為什麼會選擇透析治療，而不選擇保守性治療？（可選多項）

醫生建議 □　　自己的意願 □　　家人建議 □　　朋友建議 □

7. 你有否後悔當初接受透析治療的決定？

有 □　　沒有 □

8. 你有沒有想過，你未來的病情是怎樣的呢？

有 □　　沒有 □

9. 你的醫生有沒有告訴過你的壽命？

有 □　　沒有 □

10. 你有沒有安排以下任何一項？（可選多項）

遺囑 □　　持久授權書 □　　預設醫療指示 □　　沒有 □

11. 當你與家人討論臨終問題時的感覺如何？

非常舒服 □　　舒服 □　　一般 □　　不舒服 □　　非常不舒服 □

12. 當你與腎科醫生討論臨終問題時的感覺如何？

非常舒服 □　　舒服 □　　一般 □　　不舒服 □　　非常不舒服 □

13. 當你與腎科護士討論臨終問題時的感覺如何？

非常舒服 □　　舒服 □　　一般 □　　不舒服 □　　非常不舒服 □

14. 當你的心臟停止跳動時，你願意接受什麼急救方案？

我們盡能力恢復你的心跳（心肺復甦）　□

我們不會嘗試恢復你的心跳（不進行心肺復甦）　□

不知道　□

15. 當病人的心臟已停止跳動時，醫生可以做一些事情，用以恢復他的心跳，這包括用一台人工呼吸機幫助呼吸。根據你目前的身體狀況，如果你的心臟停止了跳動，你願意你的醫生做些什麼？

如果可能的話，恢復我的心跳，包括使用人工呼吸機 □

讓我辭世，不要試圖恢復我的心跳或使用人工呼吸機 □

不知道　□

16. 當你的身體健康狀況正在惡化及在壽命有限的狀態下，如果你必須作出決定，你會選擇一個盡可能延長壽命的療程，但可能意味著延長疼痛和不適；或你會選擇一個盡可能減輕疼痛和不適為重點的護理計劃，即使這意味著活得不久？

減輕疼痛或不適，但盡可能提高生活質素　□

盡可能延長生命，即使要忍受長期疼痛和不適 □

不知道　□

17. 你寧願在哪裡過世？

在家裡 □　在醫院 □　在護老院 □　在臨終關懷中心 □

其他 _____

18. 在過去十二個月，你有沒有與下列人士討論任何有關你對「臨終護理」的選擇？(可選多項)

我還沒有與任何人討論 □

家庭成員 □　朋友 □　腎科醫生 □　家庭醫生 □　腎科護士 □

社會工作者 □　神職人員 □　其他 _____

19. 當進行討論任何有關臨終問題時，你願意與下列哪類人士討論？(可選多項)

家庭成員 □　朋友 □　腎科醫生 □　家庭醫生 □　腎科護士 □

社會工作者 □　神職人員 □　其他 _____

20. 你覺得何時是適當的時候談及有關臨終的問題？

在我開始接受透析之前 □

在我接受透析之後，但在病情轉差前 □

當我的病情轉為嚴重時 □

在我的醫療團隊認為有需要時 □

當我特別要求時 □

21. 你希望你的「臨終護理計劃」檢討頻密次數是？

每當有需要時 □

每當我要求這個計劃進行檢討時 □

定期進行，例如每年或每半年 □

其他 _____

22. 你願意在何處進行這些臨終問題探討？

在進行透析過程中 □　在一個私人房間進行透析的過程中 □

在覆診時 □　在家裡 □　有需要時，任何地方都可以 □

23. 你是否願意設立一個「預設醫療指示」？

願意 □　不願意 □

問卷完畢

謝謝

Appendix M: Carer Survey (English Version)

Decisions about care priorities at the final stage of life: Listening to renal dialysis patients and carers in Hong Kong

The main aim of this survey is to explore the decision making process about care priorities at the final stage of life among dialysis patients and carers in Hong Kong. Participants are requested to fill in the demographic data before completing the survey. All the information of this survey will be kept strictly confidential and will be destroyed according to National Health and Medical Research Council (NHMRC), Australia guidelines five years after the completion of the study.

If you are interested in participating in a focus group interview, you can approach the dialysis staff who will pass your details to me or, you can contact me directly by email at clee37@une.edu.au or phone on 96682617.

A) Demographic data

Please fill in the blank or tick ☑ the box most suitable for you at each statement.

Sex: Male ☐ Female ☐	Age: _____
Marital status: Single ☐ Married ☐ Divorced ☐ Widowed ☐	Place of birth: Hong Kong ☐ Mainland China ☐ Other: _____
Working: Yes ☐ No ☐	Education: Illiterate ☐ Primary ☐ Secondary ☐ University or above ☐
First language: Chinese ☐ English ☐ Others _____	Type of treatment: (Patient is receiving) Haemodialysis ☐ Peritoneal dialysis ☐
Patient's months on dialysis: _____	Relationship with patient: Parent ☐ Spouse ☐ Offspring ☐ Employee ☐ Other _____
Do you have: (can tick more than one) Hypertension ☐ Diabetes Mellitus ☐ Chronic lung disease ☐ Chronic liver disease ☐ Coronary heart disease ☐ Cancer ☐ Other _____	
Religions: Nil ☐ Buddhist ☐ Catholic ☐ Christian ☐ Taoism ☐ Muslim ☐ Other _____	

B) Carer survey

Please fill in the blank or tick ☑ the box most suitable for you at each statement.

1. Have you heard about the End-of-life care?

   Yes ☐ No ☐

2. Have you heard about the Advance Directives?

   Yes ☐ No ☐

3. Whom do you rely on for social and emotional support for your illness and treatment? (can tick more than one)

   Family ☐ Friend ☐ Doctor ☐ Nurse ☐ Social worker ☐ Spiritual advisor ☐
   Other _____

4. If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your medical care? (can tick more than one)

   Family ☐ Friend ☐ Doctor ☐ Nurse ☐ Social worker ☐ Spiritual advisor ☐
   Other _____

5. How do you normally obtain information that will help you make a personal decision regarding your health / well-being? (can tick more than one)

   Doctor ☐ Nurse ☐ Family☐ Friend ☐ Social worker ☐ Spiritual advisor ☐
   Paper resources ☐ Internet ☐ Television / media ☐
   Other _____

6. Why did your relative choose dialysis over conservative care? (can tick more than one)

   Doctor's advice ☐ His/her own will ☐ Your advice ☐ Friend's advice

7. Do you regret the decision to start on dialysis for your relative (patient)?

   Yes ☐ No ☐

8. Have you thought about what might happen to your relative regarding his/her illness in the future?

   Yes ☐ No ☐

9. Has the renal doctor told you about your relative's life span?

   Yes ☐ No ☐

10. Has your relative completed any of the following?

    Will ☐ Enduring power of attorney ☐ Advance directives ☐ None ☐ Do not know ☐

11. How comfortable are you in discussing the end-of-life issues with your relative?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

12. How comfortable are you in discussing the end-of-life issues with the renal doctor?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

13. How comfortable are you in discussing the end-of-life issues with the renal nurse?

    Very comfortable ☐ Comfortable ☐ Neutral ☐ Uncomfortable ☐
    Very uncomfortable ☐

14. What do you want to be done when your heart stops beating?

    We will try to restart your heart beat if possible (resuscitation) ☐
    We will not try to restart your heart (no resuscitation) ☐
    Do not know ☐

15. There are a number of things doctors can do to try to revive someone whose heart has stopped beating. This usually includes a machine to help you breathe. Based on your current condition, what would you want your doctor to do if your heart stopped beating?

    Restart my heart, if possible, including using a breathing machine ☐
    Let me die, do not try to restart my heart or use a breathing machine ☐
    Do not know ☐

16. If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort; or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?

    Relieve pain or discomfort and improve quality of life as much as possible ☐
    Live as long as possible, indifferent to prolonged pain and discomfort ☐
    Do not know ☐

17. Where would you prefer your dialysis patient relative to die?

    Home ☐ Hospital ☐ Nursing home ☐ Hospice care centre ☐
    Other _____

18. During the past 12 months, have you had a discussion with any of the following people about your relative's choice concerning his/her end-of -life care? (can tick more than one)

I have not had a discussion with anybody ☐
Family member ☐ Friend ☐ Renal doctor ☐ Family doctor ☐ Renal nurse ☐
Social worker ☐ Spiritual advisor ☐ Other _____

19. If you were the patient, who would you like to involve when discussing about the end-of-life issues? (can tick more than one)

Family member ☐ Friend ☐ Renal doctor ☐ Family doctor ☐ Renal nurse ☐
Social worker ☐ Spiritual advisor ☐ Other _____

20. If you were the patient, when would you like to have these end-of-life conversations?

Before I start dialysis ☐
After I start dialysis but before becoming ill ☐
When I become seriously ill ☐
When the need arises as defined by my medical team ☐
When I specifically request it ☐

21. If you were the patient, how often would you like to have your end-of-life care plan reviewed?

Whenever need arises ☐
Whenever I ask for this plan to be reviewed ☐
On a regular basis (i.e., yearly, half-yearly) ☐
Other _____

22. If you were the patient, where would you like to have these end-of-life discussions?

During dialysis session ☐ During dialysis session but in a private room ☐
During follow-up ☐ At home ☐ Anywhere when needed ☐

23. If you were the patient, would you like to make an advance directive if it is available?

Yes ☐ No ☐

END OF SURVEY

THANK YOU

Appendix N: Carer Survey (Chinese Version)

生命末端時之優先護理決策：聆聽香港透析病人和照顧者的心聲

是次調查的主要目的，是探討香港透析病人和照顧者，對在生命最後階段時之優先護理決策過程的看法。參加者首先填寫一些統計資料，然後回答一些調查問題。是次調查的所有資料是絕對保密的。並在研究完畢之五年後，根據澳洲國家衛生和醫學研究理事會指引全部銷毀。

此外，如果你有興趣參與焦點小組訪談，你可聯絡腎科職員或直接透過電子郵件 clee37@une.edu.au 或致電 96682617 與本人聯絡。

一）統計資料

請在每句最適合你的方塊中加上剔號或在空白處填寫最適合你的答案。

性別： 男 ☐　女 ☐	年齡：_____
婚姻狀況： 單身 ☐　已婚 ☐　離婚 ☐ 喪偶 ☐	出生地點： 香港 ☐　中國內地 ☐ 其他：_____
在職： 是 ☐　否 ☐	教育程度： 從未受教育 ☐　小學 ☐　中學 ☐ 大學或以上 ☐
慣常用語： 中文 ☐　英文 ☐ 其他：_____	病人的治療類型： 血液透析 ☐　腹膜透析 ☐
病人接受透析月數：_____	與病人的關係： 父母親 ☐　配偶 ☐　子女 ☐ 僱員 ☐　其他：_____
你有否患上以下疾病：（可選多項） 高血壓 ☐　糖尿病 ☐　慢性肺病 ☐　慢性肝病 ☐　冠心病 ☐ 癌症 ☐　中風 ☐　其他：_____	
宗教信仰： 無 ☐　佛教 ☐　天主教 ☐　基督教 ☐　道教 ☐　回教 ☐ 其他：_____	

二）調查問題

請在每句最適合你的方塊中加上剔號或在空白處填寫最適合你的答案。

1. 你有沒有聽說過「臨終護理」這個名詞？

有 □　　沒有 □

2. 你有沒有聽說過「預設醫療指示」？

有 □　　沒有 □

3. 當你在患病及治療過程中，遇到社交和情感問題時，你會依靠誰人？（可選多項）

□ 家人　　朋友 □　　醫生 □　　護士 □　　社工 □

神職人員 □　　其他 _____

4. 如果你在生理上或精神上無法自己做決定時，你會授權誰來助你選擇醫療護理的決定呢？（可選多項）

□ 家人　　朋友 □　　醫生 □　　護士 □　　社工 □

神職人員 □　　其他 _____

5. 你通常從何處取得資訊，來幫助你作出個人健康或治療的決定？（可選多項）

家庭醫生 □　　護士 □　　家人 □　　朋友 □　　社工 □　　神職人員 □

報章雜誌 □　　互聯網 □　　影視/媒體 □　　其他 _____

6. 為什麼他(病者)會選擇透析治療，而沒有選擇保守性治療？（可選多項）

醫生建議 □　　他的意願 □　　你的建議 □　　朋友建議 □

7. 你有否後悔當初讓病者作出開始透析治療的決定？

有 □　　沒有 □

8. 你有沒有想過，病者未來的病情是怎樣的呢？

有 □　　沒有 □

9. 病者的醫生有沒有告訴過你關於病者的壽命？

有 □　　沒有 □

10. 病者有沒有安排以下任何各項？（可選多項）

遺囑 ☐　持久授權書 ☐　預設醫療指示 ☐　沒有 ☐

11. 當你與病者討論臨終問題時的感覺如何？

非常舒服 ☐　舒服 ☐　一般 ☐　不舒服 ☐　非常不舒服 ☐

12. 當你與腎科醫生討論臨終問題時的感覺如何？

非常舒服 ☐　舒服 ☐　一般 ☐　不舒服 ☐　非常不舒服 ☐

13. 當你與腎科護士討論臨終問題時的感覺如何？

非常舒服 ☐　舒服 ☐　一般 ☐　不舒服 ☐　非常不舒服 ☐

14. 當你的心臟停止跳動時，你願意接受什麼急救方案？

我們盡能力恢復你的心跳（心肺復甦）　☐

我們不會嘗試恢復你的心跳（不進行心肺復甦）　☐

不知道　☐

15. 當病人的心臟已停止跳動時，醫生可以做一些事情，用以恢復他的心跳，這包括用一台人工呼吸機幫助呼吸。根據你目前的身體狀況，如果你的心臟停止了跳動，你願意你的醫生做些什麼？

如果可能的話，恢復我的心跳，包括使用人工呼吸機 ☐

讓我辭世，不要試圖恢復我的心跳或使用人工呼吸機 ☐

不知道　☐

16. 當你的身體健康狀況正在惡化及在壽命有限的狀態下，如果你必須作出決定，你會選擇一個盡可能延長壽命的療程，但可能意味著延長疼痛和不適；或你會選擇一個盡可能減輕疼痛和不適為重點的護理計劃，即使這意味著活得不久？

減輕疼痛或不適，但盡可能提高生活質素　☐

盡可能延長生命，即使要忍受長期疼痛和不適 ☐

不知道　☐

17. 你寧願病者在哪裡過世？

在家裡 □　在醫院 □　在護老院 □　在臨終關懷中心 □

其他 _____

18. 在過去十二個月，你有沒有與下列人士討論任何有關病者對「臨終護理」的選擇？(可選多項)

我還沒有與任何人討論 □

家庭成員 □　朋友 □　腎科醫生 □　家庭醫生 □　腎科護士 □

社會工作者 □　神職人員 □　其他 _____

19. 假如你是病者，當進行討論任何有關臨終問題時，你願意與下列哪類人士討論？(可選多項)

家庭成員 □　朋友 □　腎科醫生 □　家庭醫生 □　腎科護士 □

社會工作者 □　神職人員 □　其他 _____

20. 假如你是病者，你覺得何時是適當的時候談及有關臨終的問題？

在我開始接受透析之前 □

在我接受透析之後，但在病情轉差前 □

當我的病情轉為嚴重時 □

在我的醫療團隊認為有需要時 □

當我特別要求時 □

21. 假如你是病者，你希望你的「臨終護理計劃」檢討頻密次數是？

每當有需要時 □

每當我要求這個計劃進行檢討時 □

定期進行，例如每年或每半年 □

其他 _____

22. 假如你是病者，你願意在何處進行這些臨終問題探討？

在進行透析過程中 □　　在一個私人房間進行透析的過程中 □

在覆診時 □　　在家裡 □　　有需要時，任何地方都可以 □

23. 假如你是病者，你是否願意設立一個「預設醫療指示」？

願意 □　　不願意 □

問卷完畢

謝謝

Appendix O: Characteristics of Dialysis Patients

N = 121	Frequency	Percentage	Mean
Gender			
Male	65	53.7	
Female	56	46.3	
Marital status			
Single	24	19.8	
Married	73	60.3	
Divorced	12	9.9	
Widowed	12	9.9	
Age range			
Younger than 50	23	19	
50–59	28	23.1	
60–69	46	38.1	
70–79	18	14.8	
80–89	6	5	
Mean			59.6
Place of birth			
Hong Kong	84	69.4	
Mainland China	33	27.3	
Japan	1	0.8	
USA	1	0.8	
Vietnam	1	0.8	
Thailand	1	0.8	
Employment status			
Employed	11	9.1	
Unemployed	110	90.9	
Educational status			
Illiterate	9	7.4	
Primary	35	28.9	
Secondary	63	52.1	
University or above	14	11.6	
First language			
Chinese	119	98.3	
English	1	0.8	
Others	1	0.8	
Dialysis mode			
Haemodialysis	37	30.6	
Peritoneal dialysis	84	69.4	
Time on dialysis			44.56 (SD 43.91)
0–6 months	18	14.9	
7–12 months	15	12.4	
1–2 years	20	16.5	
3–5 years	37	30.6	

6–10 years	23	19
> 11 years	8	6.6
Dialysis done by		
Self	67	55.4
Family member	15	12.4
Domestic worker	3	2.5
Elderly home staff	4	3.3
Renal centre staff	32	26.4
Comorbid chronic illness		
Nil	13	10.7
Hypertension	96	79.3
DM	53	43.8
Chronic lung disease	3	2.5
Chronic liver disease	3	2.5
Coronary heart disease	16	13.2
Cancer	9	7.4
Stroke	6	5
Religion		
Nil	79	65.3
Buddhist	20	16.5
Catholic	7	5.8
Protestant Christian	11	9.1
Taoist	3	2.5
Islam	1	0.8

Appendix P: Dialysis Patients' End-of-Life Preferences

Questions	Frequency	Percentage
Whom do you rely on for social and emotional support for your illness and treatment?		
Family	95	78.5
Friends	27	22.3
Doctor	23	19
Nurse	16	13.2
Social worker	12	9.9
Spiritual advisor	7	5.8
If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your medical care?		
Family	104	86
Friends	4	3.3
Doctor	40	33.1
Nurse	17	14
Social worker	5	4.1
Spiritual advisor	2	1.7
How do you normally obtain information that will help you make a personal decision regarding your health / wellbeing?		
Renal doctor	89	73.6
Family doctor	11	9.1
Nurse	54	44.6
Family	42	34.7
Friends	12	9.9
Social worker	6	5
Spiritual advisor	2	1.7
Paper resources	20	16.5
Internet	12	9.9
TV/media	17	14
Why did you choose dialysis over conservative care?		
Doctor's advice	100	82.6
Own wish	30	24.8
Family's advice	27	22.3
Friend's advice	3	2.5
Do you regret the decision to start on dialysis?		
Yes	14	11.6
No	107	88.4
Have you completed any of the following?		
Will	12	9.9
Enduring of power	6	5
Advance directives	1	0.8
Nil	103	85.1
How comfortable are you in discussing the end-of-life issues with family members?		
Very comfortable	9	7.4
Comfortable	20	16.5

Neutral	71	58.7
Uncomfortable	15	12.4
Very uncomfortable	6	5
How comfortable are you in discussing the end-of-life issues with your renal doctor?		
Very comfortable	5	4.1
Comfortable	28	23.1
Neutral	64	52.9
Uncomfortable	18	14.9
Very uncomfortable	6	5
How comfortable are you in discussing the end-of-life issues with renal nurse?		
Very comfortable	3	2.5
Comfortable	30	24.8
Neutral	66	54.5
Uncomfortable	15	12.4
Very uncomfortable	7	5.8
What do you want to be done when your heart stops beating?		
Resuscitation	46	38
No resuscitation	35	28.9
Don't know	40	33.1
There are a number of things doctors can do to try to revive someone whose heart has stopped beating. This usually includes a machine to help you breathe. Based on your current condition, what would you want your doctor to do if your heart stopped beating?		
Restart my heart, if possible, including using a breathing machine	40	33.1
Let me die, do not try to restart my heart or use a breathing machine	45	37.2
Do not know	36	29.8
If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort; or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?		
Relieve pain or discomfort and improve quality of life as much as possible	66	54.5
Live as long as possible, indifferent to prolonged pain and discomfort	15	12.4
Do not know	40	33.1
Where would you prefer to die?		
Home	25	20.7
Hospital	87	71.9
Hospice care centre	5	4.1
other	4	3.3
During the past 12 months, have you had a discussion with any of the following people about your choice concerning your end-of-life care?		
I have not had a discussion with anybody	94	77.7
Family member	24	19.8
Friend	4	3.3
Renal doctor	2	1.7
Renal nurse	2	1.7

Social worker	1	0.8
Who would you like to involve when discussing about the end-of-life issues?		
Family member	104	86
Friend	22	18.2
Renal doctor	46	38
Family doctor	3	2.5
Renal nurse	29	24
Social worker	5	4.1
Spiritual advisor	4	3.3
When would you like to have these end-of-life conversations?		
Before I start dialysis	11	9.1
After I start dialysis but before becoming ill	29	24
When I become seriously ill	44	36.4
When the need arises as defined by my medical team	16	13.2
When I specifically request it	21	17.4
How often would you like to have your end-of-life care plan reviewed?		
Whenever need arises	79	65.3
Whenever I ask for this plan to be reviewed	17	14
On a regular basis (i.e., yearly, half-yearly)	18	14.9
Other	7	5.8
Where would you like to have these end-of-life discussions?		
During dialysis session	3	2.5
During dialysis but in private room	10	8.3
During follow up	19	15.7
At home	17	14
Anywhere when needed	72	59.5
Would you like to make an advance directive if it is available?		
Yes	101	83.5
No	20	16.5

Appendix Q: Characteristics of Dialysis Patient Carers

N = 61	Frequency	Percentage	Mean
Gender			
Male	17	27.9	
Female	44	72.1	
Marital status			
Single	17	27.9	
Married	43	70.5	
Divorced	1	1.6	
Age range			
Younger than 50	26	59	
50-59	11	18	
60-69	12	19.7	
70-79	2	3.3	
80-89	0	0	
Mean			48.03
Place of birth			
Hong Kong	37	60.7	
Mainland China	13	21.3	
Others	11	18	
Employment status			
Employed	39	63.9	
Unemployed	22	36.1	
Educational status			
Illiterate	0	0	
Primary	7	11.5	
Secondary	35	57.4	
University or above	19	31.1	
First language			
Chinese	55	90.2	
English	3	4.9	
Others	3	4.9	
Patient dialysis mode			
Haemodialysis	13	21.3	
Peritoneal dialysis	48	78.7	
Patient time on dialysis			44.25 (*SD* 39.37)
0-6 months	5	8.2	
7-12 months	12	19.7	
1-2 years	10	16.4	
3-5 years	20	32.7	
6-10 years	11	18.1	
>11 years	3	4.9	
Relationship with patient			
Parent	12	19.7	

Spouse	22	36.1
Offspring	12	19.7
Employee	9	14.8
Other	6	9.8
Comorbid chronic illness		
Nil	44	72.1
Hypertension	14	23
DM	7	11.5
Chronic lung disease	0	0
Chronic liver disease	1	1.6
Coronary heart disease	2	3.3
Cancer	0	0
Stroke	0	0
Religion		
Nil	32	52.5
Buddhist	8	13.1
Catholic	7	11.5
Christian	9	14.8
Islam	5	8.2

Appendix R: Carers' End-of-Life Preferences

Questions	Frequency	Percentage
Whom do you rely on for social and emotional support for your illness and treatment?		
Family	42	68.9
Friends	33	54.1
Doctor	19	31.1
Nurse	12	19.7
Social worker	6	9.8
Spiritual advisor	6	9.8
If you are physically or mentally unable to make a decision yourself, who would you choose to make decisions on your medical care?		
Family	49	80.3
Friends	6	9.8
Doctor	30	49.2
Nurse	8	13.1
Social worker	1	1.6
Spiritual advisor	2	3.3
How do you normally obtain information that will help you make a personal decision regarding your health / wellbeing?		
Renal doctor	36	59
Family doctor	20	32.8
Nurse	31	50.8
Family	25	41
Friends	4	6.6
Social worker	1	1.6
Spiritual advisor	16	26.2
Paper resources	13	21.3
Internet	9	14.8
TV/media	36	59
Why did your relative choose dialysis over conservative care?		
Doctor's advice	53	86.9
His/her own wish	21	34.4
Your advice	10	16.4
Friend's advice	1	1.6
Do you regret the decision to start on dialysis for your relative (patient)?		
Yes	4	6.6
No	56	91.8
Has your relative (patient) completed any of the following?		
Will	5	8.2
Enduring of power	1	1.6
Advance directives	1	1.6
Nil	54	88.5
How comfortable are you in discussing the end-of-life issues with your relative (patient)?		
Very comfortable	0	0
Comfortable	4	6.6

Neutral	33	54.1
Uncomfortable	14	23
Very uncomfortable	10	16.4
How comfortable are you in discussing the end-of-life issues with your renal doctor?		
Very comfortable	2	3.3
Comfortable	7	11.5
Neutral	30	49.2
Uncomfortable	16	26.2
Very uncomfortable	6	9.8
How comfortable are you in discussing the end-of-life issues with renal nurse?		
Very comfortable	1	1.6
Comfortable	5	8.2
Neutral	31	50.8
Uncomfortable	18	29.5
Very uncomfortable	6	9.8
What do you want to be done when your heart stops beating?		
Resuscitation	31	50.8
No resuscitation	15	24.6
Don't know	15	24.6
There are a number of things doctors can do to try to revive someone whose heart has stopped beating. This usually includes a machine to help you breathe. Based on your current condition, what would you want your doctor to do if your heart stopped beating?		
Restart my heart, if possible, including using a breathing machine	26	42.6
Let me die, do not try to restart my heart or use a breathing machine	23	37.7
Do not know	12	19.7
If you had to make a choice at this time, would you prefer a course of treatment that focuses on extending life as much as possible, even if it means prolonging pain and discomfort; or would you want a plan of care that focuses on relieving pain and discomfort as much as possible, even if that means not living as long?		
Relieve pain or discomfort and improve quality of life as much as possible	45	73.8
Live as long as possible, indifferent to prolonged pain and discomfort	10	16.4
Do not know	6	9.8
Where would you prefer your relative (patient) to die?		
Home	13	21.3
Hospital	39	63.9
Hospice care centre	6	9.8
other	3	4.9
During the past 12 months, have you had a discussion with any of the following people about your relative's choice concerning his/her end-of-life care?		
I have not had a discussion with anybody	52	85.2

Family member	8	13.1
Friend	2	3.3
Renal doctor	2	3.3
Renal nurse	2	3.3
Social worker	1	1.6
If you were the patient, who would you like to involve when discussing about the end-of-life issues?		
Family member	58	95.1
Friend	16	26.2
Renal doctor	26	42.6
Family doctor	5	8.2
Renal nurse	9	14.8
Social worker	6	9.8
Spiritual advisor	7	11.5
If you were the patient, when would you like to have these end-of-life conversations?		
Before I start dialysis	5	8.2
After I start dialysis but before becoming ill	17	27.9
When I become seriously ill	16	26.2
When the need arises as defined by my medical team	15	24.6
When I specifically request it	8	13.1
If you were the patient, how often would you like to have your end-of-life care plan reviewed?		
Whenever need arises	44	72.1
Whenever I ask for this plan to be reviewed	5	8.2
On a regular basis (i.e., yearly, half-yearly)	11	18
Other	1	1.6
If you were the patient, where would you like to have these end-of-life discussions?		
During dialysis session	1	1.6
During dialysis but in private room	7	11.5
During follow up	6	9.8
At home	17	27.9
Anywhere when needed	30	49.2
If you were the patient, would you like to make an advance directive if it is available?		
Yes	55	90.2
No	6	9.8

Appendix S: Permission Email to Use the Survey Instrument

Paul Lee

From: sara.davison@ualberta.ca
Sent: 28日十一月2011年星期一 21:55
To: paulleecw@cuhk.edu.hk
Subject: RE: Enquiry of research instrument

Hi Paul Lee,

This was a survey that I developed and validated in my patient group. I'm not sure of the applicability and validity for an ethnically very diverse patient group.

Good luck with your research!

Sara

From: Paul Lee [mailto:paulleecw@cuhk.edu.hk]
Sent: November 28, 2011 2:40 AM
To: Sara Davison
Subject: Enquiry of research instrument

Hi Dr. Davison,
I am Paul, a PhD student studying in University of New England, Australia. My research topic is "Decisions about care priorities at final stage: listen to Chinese dialysis patients and carers." As read your journal article "End-of-life care preferences and needs: Perceptions o patients with chronic kidney disease" in the Clin J Am Soc Nephrol, I am interest in the instrument you used in assessing the patients. Not sure I can borrow the instrument with the results of validity and reliability, any specific points to utilize the questionnaire, so that I can translate into Chinese and modify it if necessary. You are welcome to contact me for any question. Thank you for your attention.

Best regards

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