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**THE EFFECTS OF A NURSE-LED CASE MANAGEMENT  
PROGRAMME ON PATIENTS UNDERGOING PERITONEAL DIALYSIS:  
A RANDOMIZED CONTROLLED TRIAL**

**BY**

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**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE  
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**SCHOOL OF NURSING**

**THE HONG KONG POLYTECHNIC UNIVERSITY**

**DECEMBER, 2005**



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## CERTIFICATION OF ORIGINALITY

I hereby declare that this thesis entitled, “The effects of a nurse-led case management programme on patients undergoing peritoneal dialysis: a randomized controlled trial” is my own work and that, to the best of my knowledge and belief, it reproduces no material previously published or written, nor material that has been accepted for the award of any other degree or diploma, except where due acknowledgements have been made in the text.

\_\_\_\_\_ (Signed)

**Susan Ka-Yee CHOW**

Abstract of thesis entitled, “The effects of a nurse-led case management programme on patients undergoing peritoneal dialysis: a randomized controlled trial”, submitted by Susan Ka Yee Chow for the degree of Doctor of Philosophy at the Hong Kong Polytechnic University in December 2005.

**Background:** The treatment of hospitalized patients receiving peritoneal dialysis is often critical. These patients need integrated health and social care in order to maintain a desirable quality of life and to decrease morbidity during the course of the disease. Nurse-led case management programmes have been tested on selected groups of chronically ill patients, such as those with coronary heart disease or diabetes mellitus. The health of patients receiving peritoneal dialysis is clearly an important issue; it is crucial to develop a nurse-led case management programme and test its effects upon patients undergoing peritoneal dialysis.

**Aim:** This study aimed to develop an innovative nurse-led case management model and test its effectiveness within a sample of patients receiving peritoneal dialysis in Hong Kong.

**Design:** The study used a randomized, controlled trial, in which seventy nine patients were recruited and assigned to two groups; the study group and the control group. The patients in the study group received a comprehensive pre-discharge assessment and individual education programme prior to leaving the hospital, with a weekly telephone follow-up service by the case manager for six weeks after discharge. The education programme covered health knowledge, possible complications and clinical procedure techniques related to peritoneal dialysis. The telephone follow-ups provided ongoing physiological and psychological support. The study protocols were developed from the literature and the expert input of the renal physicians and nurses.

**Outcome measures:** The outcome indicators include amelioration of symptoms and complication control, utilization of health care services, non-adherence behaviours, quality of life and patient satisfaction. Data were collected before discharge, then at six weeks and 12 weeks after discharge.

**Results:** Repeated measures analysis of variance, General Linear Model was performed for the main outcome variables. Patients randomized to the study group showed a significantly higher level of patient satisfaction. There was a statistically significant difference in the between-group ( $F=4.41$ ,  $p<0.05$ ) and within-group ( $F=2.98$ ,  $p=0.05$ ) analyses, as well as in the interaction effects ( $F=6.89$ ,  $p<0.01$ ) in the repeated measures. With regard to adherence behaviours, a statistically significant difference in the within-group measure ( $F=4.09$ ,  $p<0.05$ ) was observed in diet non-adherence behaviour across time. For medication non-adherence, a significant interaction effect ( $F=4.60$ ,  $p<0.01$ ) was noted. For quality of life, the parameters demonstrated significant within-group effects ( $p<0.05$ ) including effects on the impact of kidney disease on daily life, emotional well-being, physical roles, symptoms, pain and social function. The dimensions showed significant positive interaction effects ( $p<0.05$ ) including encouragement from dialysis staff, patient satisfaction, improved sleep and social function. There was, however, no significant difference ( $p>0.05$ ) revealed in the blood chemistry results and utilization of health care services. Multivariate analysis was conducted using regression models to identify the significant predictors for medication non-adherence, dietary non-adherence and patient self-reported health status, respectively. Age and gender were found to be the significant predictors for diet non-adherence; educational attainment, comorbidities and patient group were the significant predictors for medication non-adherence, whilst emotional wellbeing, quality of sleep and effects of kidney disease contributed significantly to self-reported health status. This study also tested the overall psychometric properties of the research instruments with their validity and reliability established with evidence.

**Conclusion:** This was a pioneer study on the effects of a nurse-led case management programme on renal patients, conducted by nurses in Hong Kong. The empirical findings provide useful direction for continuity of care from hospital to community. The study results showed that a nurse-led case

management programme improved patients' quality of life and medication non-adherence behaviours to treatment regimens. The outcomes also revealed a high level of patient satisfaction with the service and nursing care received. Further research, using a larger sample size is required to demonstrate the effects on blood chemistry results and utilization of health care services. The predictors for non-adherence behaviours and self-reported health status provided understanding and insights into the potential contributory factors for non-adherence behaviours. The information is able to facilitate nurses to address any medical, social, and demographic factors that undermine the patient's will to adhere to health related behaviours. The findings show that this proactive programme has been effective and culturally appropriate in guiding future nursing practice in the Hong Kong Chinese patient population.

### **Conference presentations:**

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Chow, SKY. & Wong, FKY. (2005). Post-discharge care to end stage renal failure patients during trajectory phases. *Proceedings of the 27<sup>th</sup> International Conference, International Association for Human Caring, California*. 15-18 June 2005, 29.

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## **CHAPTER 1**

### **INTRODUCTION**

This chapter begins with a general introduction, which is followed by the background of the study. The hypotheses and research questions are presented, followed by a discussion of the significance of the study. The chapter concludes with an outline of the organizational structure of the thesis.

#### **1.1 General introduction**

End-stage renal failure (ESRF) patients face life-long physical, psychological and social problems related to their illness and its treatment. Dialysis is the major method of treatment to sustain the lives of these patients. Health care figures in Hong Kong show that ESRF is becoming a major health problem, causing a high morbidity and hospitalization rate. This chronic and irreversible failure of kidney function poses a challenge to nurses and practitioners of related disciplines in the health care system.

Having a chronic condition such as end-stage renal disease is likely to have an impact on patients' everyday life. Whilst essential for survival, treatment of the condition can also have negative effects on the patient's physical, psychological and social well-being. Patients living on peritoneal dialysis suffer from various degrees of physical discomfort such as fatigue, shortness of breath, headache and body pain. These symptoms are caused by both the effects of ESRF and the dialysis treatment itself (Burrows-Hudson,

1995). Physiological symptoms such as inability to concentrate, depression and anxiety, withdrawal and irritability are common in ESRF patients. Other than these symptoms, ESRF patients also experience various forms of emotional distress, depending on their age, family support system and lifestyle. In addition to coping with the physical manifestations of their illness and treatment, ESRF patients also face financial and employment problems, difficulties in sexual relationships and dilemmas in the choice of treatment that best suits their individual lifestyles and situations (Thomas, 2002). Employed patients' earning potential is reduced, whilst the unemployed and retired may have limited means to fund their health-care. Patients who, previously, had been active sexually may have to deal with varying degrees of sexual dysfunction and all patients may find themselves experiencing unwanted role changes and a disruption in their overall life plan.

For the majority of patients with end-stage renal failure, dialysis is the major treatment modality to sustain their lives while waiting for kidney transplantation. However, patients may not accept the treatment regimen, or the initiation of renal dialysis therapy may not be feasible. End-stage renal disease is a major health problem, posing challenges for both patients and health care professionals.

In 2005, out of the total number of patients on renal replacement therapy (RRT), 50.1% were receiving peritoneal dialysis (PD), 11.3% were receiving haemodialysis and the remaining 38.6% had undergone renal transplantation. Among the RRT patients receiving dialysis treatment, 81.6% were on peritoneal dialysis (Hong Kong Renal Registry Report, 2005). The percentage of patients on PD has outnumbered that of patients on haemodialysis in recent years. A relatively simple and effective dialysis technique, PD has been successfully developed as the preferred method of home dialysis and has since been refined into the preferred treatment choice for ESRF patients. As the therapy is performed by the patients themselves or by informal caregivers, such as family members, the patients and families should be provided with adequate knowledge and continuous psychosocial support by health care professionals to ensure success in the home environment. Peritoneal dialysis patients are one of the most vulnerable patient groups due to the gradual decline of their physical health and their sense of uncertainty about the future.

According to the Statistical Report of the Hospital Authority, Hong Kong, ESRF is classified as one of the six major diseases that have high morbidity figures. The number of discharges and deaths from ESRF cases for 2003-2004 was 69,224. Compared to the six priority disease groups of the Hospital Authority, ESRF patients have the highest hospitalization rate among the five other selected diseases, which include cancer,

cerebrovascular disease, chronic lung disease, diabetes mellitus and ischaemic heart disease (Hospital Authority, 2005).

The inseparable nature of health and social care should be emphasized continually in the community in the management of dialysis patients and their families. Most modern hospitals provide holistic care, including comprehensive patient education and psychosocial support, to renal disease patients prior to discharge. The effective nursing care that has helped restore hospitalized patients' health generally ceases on discharge, although patients' symptoms often continue, to a greater or lesser degree after they have left these institutions (Polaschek, 2003a). The continuity of care provided by the health care staff highlights the importance of continuous holistic support to patients during hospitalization and after discharge.

Patients with ESRF need integrated health and social care to maintain a desirable quality of life and to decrease morbidity during the course of the disease. The patient and the entire health care team all play critical roles in the delivery of care. A supportive social and interpersonal environment is important for patients and their families, both as a preventive agent and as a protective buffer against the impact of ESRF-related stress (Burton, Kline, Lindsay & Heidenheim, 1990). As a result, a multi-disciplinary approach providing a collaborative process that assesses, plans, coordinates and evaluates options and services to meet an individual's health needs through communication and available resources is deemed necessary. The use of

the case management approach typically represents this collaborative process of care delivery.

Case management (CM) has gone through several evolutions. According to the definition adopted by the Case Management Society of America, “Case management is a collaborative process which involves assessment, planning, implementation, coordination, monitoring and evaluation of the options of services required to meet an individual’s health needs, using communications and available resources to promote quality, cost-effective outcomes” (Case Management Society of America, 2005). Case management in most health care settings is comprised of the identification of high-risk or high-cost patients, and the implementation of individualized care plans for quality improvement and better patient care (Radzwill, 2002). Patients with one or more chronic conditions involving potentially high-cost diseases such as cancer, end-stage renal failure or Human Immunodeficiency Virus (HIV) are key targets of case management services (Birmingham, 2003a).

The majority of discharge planning and decision making seldom involves the patients and their families’ participation. Their actual health service needs are often ignored, as the service providers devise plans without an extensive understanding of the actual health requirements of the patients. Discharge planning and continuity of care are in fact the crucial components of case management in the delivery of quality health care services. The

nurse-led case management model can be adapted to fit the ESRF programme, and can be effective in collaboration with the patients and families within the nursing team. Nurses are the most appropriate health care professionals to assist patients within the family system. With the use of a protocol and guidelines for the provision of appropriate services, nurse-led case management is able to maintain a desirable and attainable outcome, a multidisciplinary collaboration and a continuum of care (Wong, Wong & Chan, 2005).

## **1.2 Background of the study**

In the new millennium, the main challenge to our health care system is to develop new services that can best manage the prevalence of chronic disease and promote health and wellness. The vision of Hong Kong's health care services is to create a system that promotes health, provides lifelong, holistic care, enhances the quality of life and enables human development (Health & Welfare Bureau, 2005). The Hong Kong Hospital Authority has stepped up the development of such a system and has proceeded along this route in recent years.

On the international front, because of the long-term care needs of the chronically ill, the trend has focused on the development of ambulatory and community care programmes to replace in-patient treatment whenever appropriate. These programmes pose new challenges to health care

providers to explore ways to improve patient health outcomes and ultimately promote quality cost-effective results.

It is no longer considered sufficient for healthcare professionals to focus solely on keeping their patients alive for as long as possible; they also have to consider their patients' quality of life. Quality refers to the overall well-being that encompasses patients' functioning, and general health perception in the physical, psychological and social domains (Bakewell, Higgins & Edmunds, 2002). The condition of each ESRF patient will deteriorate as a natural course of the disease. However, the rate of deterioration can be slowed down if the patients receive extra support from nurses in different areas, including education and reinforcement of PD treatment compliance, diet, pain management, and aseptic techniques for infection control. Therefore, nurse-led case management with discharge planning may offer great potential and applicability in improving the quality of care given to ESRF patients.

There are several behavioural requirements for ESRF patients undergoing peritoneal dialysis. These include adherence to the dialysis regimen, strict fluid and dietary restrictions, and medication compliance. The variables that predict non-adherence behaviours include socio-demographic factors and psychosocial variables (Hailey & Moss, 2000). The Hong Kong Hospital Authority has been working on initiatives to develop a



patient-centred health service that offers a greater appreciation of socio-economic, environmental, and psychosocial factors that influence health (Health & Welfare Bureau, 2005). By developing new healthcare models, applying the knowledge gained through research and investing in the professional, continuous education of healthcare staff, the new strategy aims to provide continuity of health care over an individual's lifetime.

Some overseas studies have demonstrated that effective nurse-led case management programmes and discharge planning have enabled significant improvements in health-related quality of life (QoL), resulting in fewer hospital readmissions. Other studies, however, reported no difference in outcomes after nurse-led case management intervention. In practice, some of the nurse-led case management programmes have evolved into a focus that is both economic and clinical. The programmes, which focused primarily on the economic aspect, have paid less attention to understanding the patient-focused outcomes, thus resulting in failure (Egan, Clavarino, Burridge, Teuwen & White, 2002). For patients who require peritoneal dialysis, long-term follow-up care is needed, due to both the nature and the treatment of the disease. Nursing is not only about extending care but should also teach people how to care for themselves. The theory of empowerment strengthens the philosophy of helping individuals manage their own health at their own level of capacity. Perhaps more important is the need for patients to feel that they are participating in their own care and are included in the decision-making process, thus enabling them to better

cope with the disease (Summerton, 1995). Hence, the challenge involved in caring for ESRF patients is not just to sustain life but to improve the quality of life and to strengthen self-care adherence. The reduction of symptoms and the control of complications are also dimensions of the contemporary model of professional nursing care. In summary, it is evident that an appropriate, well-designed nurse-led case management programme is likely to bring about effective and positive patient and clinical outcomes. However, to date, there has been no study conducted in Hong Kong using the nurse-led case management model for renal patients. Focusing on continuity of care, patient empowerment, mutually agreed goals and use of renal nurses as the case managers are special features of the present study.

### **1.3 Statement of purpose**

The purpose of this study is to examine the effectiveness of a nurse-led case management programme, based on the outcomes of patient care. The outcome variables include patient-related outcomes (self-care adherence, quality of life, client satisfaction) and clinical outcomes (symptom and complication control, health service utilization) for patients undergoing peritoneal dialysis. The measure of the patients' quality of life is the primary outcome in the study.

#### **1.4 Objectives of the study**

1. To explore whether nurse-led case management care (study group) results in greater self-care adherence, quality of life and patient satisfaction than conventional care (control group);
2. To explore whether nurse-led case management care (study group) results in better symptom and complication control and reduction in health service utilization than conventional care (control group); and
3. To identify the predictive factors of the target patient-related outcome variables.

#### **1.5 Research hypotheses**

1. There is no significant difference in the quality of life measures within and between the study and control group at baseline and over the course of the study.
2. There is no significant difference in self-care adherence within and between the study and control group at baseline and over the course of the study.
3. There is no significant difference in symptom and complication control within and between the study and control group at baseline and over the course of the study.
4. There is no significant difference in health service utilization within and between the study and control group at baseline and over the course of the study.

5. There is no significant difference in patient satisfaction in patients within and between the study and control group at baseline and over the course of the study.

## **1.6 Significance of the study**

The corporate vision of the Hong Kong Hospital Authority is to create a seamless health care environment that will maximize health care benefits. This study is one of the first randomized controlled trials to investigate the effect of a nurse-led case management programme for renal patients in Hong Kong. This study aims, not just to implement a programme, but to cultivate the development of nurse-led case management for chronic renal patients, thereby reducing complications and ensuring a better quality of life. The new model developed in this study aims to ensure a smooth transition from hospital to home and to provide continuous supportive care on self-management for peritoneal dialysis patients. The model encompasses the theory of health promotion, case management and multidisciplinary collaboration with advanced nursing practices. This study provides empirical findings on the new model of care and supplies new evidence for nurse-led case management intervention. The empirical findings should provide frontline hospital nurses with evidence-based approaches to conduct nurse-led case management programmes with renal patients. Consequently, the results should offer useful direction for continuity of care from hospital to community.

## **1.7 Organization of the thesis**

This thesis contains seven chapters. Following this introductory chapter, the thesis is organized as follows. Chapter 2 presents the literature review of the underlying theories of case management in nursing practice and the gaps in knowledge identified in previous researches. Chapter 3 describes the detailed research method and the procedures in the randomized controlled trial. Chapter 4 delineates the results of the pilot study and the results of the validation of research instruments in the study. Chapter 5 analyses the results generated from the main study and reports the psychometric tests of the measurement scales. Chapter 6 provides the overall conclusion of this research study, whilst Chapter 7 reports the limitations and the various implications of the study.

## **CHAPTER 2**

### **LITERATURE REVIEW**

This chapter presents a literature review aiming to address, first, the concepts of end-stage renal failure (ESRF) and peritoneal dialysis (PD). It is followed by discussions on the concept of quality of life (QoL), patient satisfaction, adherence to treatment regimen, utilization of health care services and research evidence in relation to nurse-led case management programmes overseas and in Hong Kong.

#### **2.1 Database search**

A comprehensive literature review was conducted using the Index Medicus (MEDLINE), the Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Library (1990 -2005), the statistical report of the Hong Kong Hospital Authority, the annual reports of Hong Kong Renal Registry, Department of Health, Hong Kong Hospital Authority and unpublished dissertations from overseas and in Hong Kong (2000-2005).

#### **2.2 Introduction**

Self-care, active patient participation and a multidisciplinary approach to care make up the cornerstone for management of patients undergoing peritoneal dialysis (PD). The aim of dialysis management should be to achieve the maximum quality of life, control dialysis side effects and prevent complications. Summerton (1995) stated that it is important for

patients to feel that they are involved and are directly participating in treatment to cope with their chronic illness. The role of a renal nurse case manager is therefore to promote an individual patient's involvement in health care provisions and to concomitantly provide quality and cost-effective outcomes.

### **2.3 End-stage renal failure**

Chronic renal failure is the end stage of many forms of renal disorders, including chronic nephritis; chronic pyelonephritis; hypertensive kidney disease; chronic obstruction of the renal tract; polycystic kidney and kidney disease due to constitutional disorders such as diabetes, gout and myelomatosis (Edwards & Bouchier, 1992).

Chronic renal failure refers to irreversible deterioration in renal function. The impairment of the excretory, metabolic and endocrine functions of the kidney leads to the development of the clinical syndrome of uraemia. In the early stages of the disease, some patients may be asymptomatic, with the only indications of renal insufficiency being proteinuria, anaemia, hypertension, or as a rise in blood urea during routine physical examination. The primary features of chronic renal failure are general fatigue and exhaustion, usually accompanied by anaemia. Although chronic renal failure often progresses to end-stage renal failure, the function will not deteriorate quickly and may remain stable for several years in some patients

(Edwards & Bouchier, 1992). The rate of progression in end-stage renal failure varies as the disease advances. The patient may become severely ill as renal function deteriorates and uraemia increases. Symptoms such as oedema, dyspnoea, deep respiration, pruritus, muscle twitching, fits, drowsiness and coma may occur if the disease is left untreated (Pounder & Hamilton, 1995).

The treatments for end-stage renal failure aim to restore quality of life and prolong life expectancy. The major treatments for the disease are renal transplant, haemodialysis and peritoneal dialysis. In Hong Kong, the average waiting time for renal transplant in the public hospital sector varies from 55-124 months. Renal replacement therapy, such as haemodialysis (HD) and peritoneal dialysis (PD) are the major treatment modalities for patients suffering from ESRF. In March 2005, the data supplied by the Hospital Authority Renal Registry reported that the total number of patients who received HD was 731, whereas for PD, it was 3,237 (Hong Kong Renal Registry Report, 2005).

#### **2.4 Peritoneal Dialysis (PD)**

PD was introduced in the late 1970s and developed into an adaptable treatment choice for many patients. It is used to temporarily relieve symptoms of renal failure until the patient regains kidney function, or to sustain the lives of patients with irreversible kidney disease (Black &



Matassarini-Jacobs, 1997). Peritoneal dialysis is a relatively simple and effective technique that can be successfully carried out by the patient at home. As the treatment allows considerable independence and greater flexibility, it has been successfully developed as the preferred first option for home dialysis (Thomas, 2002).

During PD, the sterile dialysis fluid is instilled into the peritoneal cavity via an indwelling catheter through the use of gravity. The semi-permeable peritoneal membrane allows the passage of both water and solutes. Through the process of diffusion, the uraemic toxins and solutes move across the membrane from the blood stream into the dialysis fluid. Fluid removal takes place by osmosis; the dialyzing fluid is made hypertonic to plasma, usually with the addition of glucose, to achieve the osmotic effects. Dialysis fluid is infused into the peritoneal cavity and left to dwell there for between 3 and 10 hours, according to each individual patient's needs. The dose and dwell time of PD can be increased or decreased depending on the patient's membrane characteristics and his/her lifestyle needs. A permanent Silastic catheter is surgically inserted into the peritoneal cavity via the abdominal wall, and exits on the side of the abdomen. The access facilitates the infusion and drainage of dialysis fluid (Thomas, 2002).

The three types of peritoneal dialysis are: continuous ambulatory peritoneal dialysis (CAPD), continuous cycle peritoneal dialysis (CCPD) and

intermittent peritoneal dialysis (IPD). CAPD is carried out manually, by the patients themselves or with the help of a caregiver. The dialysis fluid is left in the peritoneal cavity for between 3 and 10 hours. Afterwards, the dialysis fluid is drained from the peritoneal cavity, a fresh solution infused, and the whole process starts again. Each exchange takes about 20-30 minutes to complete, with patients usually performing three to four exchanges of PD fluid each day, depending on their prescriptions. Continuous cycle peritoneal dialysis gives the patients more flexibility than CAPD and is performed overnight by a peritoneal cycling machine while the patient is asleep. There are five to seven exchanges of fluid with a relatively short dwell time. Alternatively, the treatment can be programmed to complete a few cycles at night and one cycle in the morning, with an eight-hour dwell time, to retain the dialysis solution in the peritoneal cavity during daytime. The treatment maximises the filtration and clearance capabilities and provides better quality of life (Thomas, 2002). Unlike CAPD or CCPD, intermittent peritoneal dialysis (IPD) is not a continuous dialysis procedure. It is generally carried out in the hospital in sessions of between 12 and 20 hours, two or three times each week. The treatment is particularly suitable for the elderly who are unable to dialyse at home. However, IPD is not suitable for patients with little or no residual renal function as it fails to provide adequate dialysis in the long run.

Whichever method of PD is chosen for the patients, health professionals should take into account their lifestyle patterns as well as their clinical needs,

choosing a regimen that provides a balance between the two. This remains a challenge for nurses, whose job requires balancing the care of large numbers of patients, at the same time having to consider the cost concerns of treating patients who are chronically sick (Summerton, 1995).

## **2.5 Problems encountered by ESRF patients on PD**

Patients with ESRF who receive complicated dialysis treatments experience a wide range of multiple and radical lifestyle changes that affect their social and psychological well-being (Tsay & Hung, 2004).

While PD is able to replace most kidney functions, it interferes with daily life. It may be a stressor that impacts patients' psychosocial health and leads them to perform PD less smoothly, thus diminishing their quality of life (Cheng, Tian, Zhang, Huang & Gu, 2002). White and Grenyer's report in 1999 illustrated the negative impacts dialysis can have on couples. Anger, depression and hopelessness were evident in the patients, while a pervasive sadness, resentment, guilt and loss were prevalent in their partners. The study on coping strategies and quality of life among patients on CAPD by Lindqvist and Sjoden (1998) presented the quality of life data. Compared with the general population, CAPD patients have a lower health-related physical quality of life than individuals in the same age group. Women scored significantly lower than men on general health perception.

For reasons other than their emotional and psychological needs, renal patients need further knowledge to improve the therapeutic outcome of their treatments and to avoid disease complications. The rate of peritonitis is high, with frequent readmissions if patients are not adequately prepared, both physically and psychologically, for dialysis treatment (Cook, 1995).

The findings mentioned above suggest that nurses need to recognize and respond to the tremendous physiological and emotional impact that PD and its treatment can have on patients and their families. Holistic care, a well-planned discharge arrangement and continuous quality improvement are the key elements in maintaining the provision of quality care to dialysis patients.

## **2.6 Nurse-led case management programme and models**

Case management is described as the new emerging health care system that facilitates the linking of quality and cost-effective care. The responsibilities of a case manager are therefore to assess, monitor, mutually plan, coordinate and evaluate health care services to respond to the individualized needs of patients and their families.

Because case management and nursing practice focus on individual and family needs, nurses with extensive clinical experience and expertise are in the appropriate position to collaborate, coordinate and make referrals in the system (Lee, Mackenzie, Dudley-Brown & Chin, 1998). Case management

is a system of care that is client-centred, coordinated and resource-efficient. It is the needs of the client that are the focus of care rather than the needs of the institution or the professional. Programmes designed merely to cut costs are not considered to be true case management models (Radzwill, 2002). Since a large segment of the population continues to age and technology increases the life span of people with chronic illness, the integration of acute and long-term services needs to be refocused onto case management programmes. The new type of nurse should be responsive to clients' needs, accountable, interdependent, collaborative and outcome-focused (Cohen, 1996).

The roles of hospital-based case managers work on three levels: clinical coordination and facilitation, utilization management and discharge planning. The case manager coordinates the patient's care plan with all involved disciplines. The case management plans are outcome-oriented, inclusive of clinical and cost outcomes. In addition, the case manager advocates for the patients and (in some Western countries) negotiates patient benefits with the insuring agencies (Cesta & Falter, 1999). Case managers are accountable for the various case management outcomes, namely: clinical, financial, humanistic, quality and system (Powell, 2000).

Different case management models are presented by various authors in the literature. Huber (2002) stated that nursing models of case management

tend to focus on the management of disease or health needs of an individual or population. These models are mainly the medical, medical-social and disease management models in nursing literature. Lamb (1992) categorized the three models of case management as hospital-based, hospital-to-community-based and community-based models, according to the settings in which they are practised. Weiss (1999) referred to case management models as “within-the-walls” and “outside-the-walls”. The within-the-wall model involves management of care during hospitalization. The outside-the-wall model emphasizes supportive interventions on the continuity of care in the community or out-patient service. Taylor (1999) loosely classified the existing models into patient-focused, system-focused and social service models. This author suggests that a comprehensive case management model should include cultural competency, consumer empowerment, clinical framework and multidisciplinary practice. Lee et al. (1998) revealed that the case management model promoted a seamless, integrated transition for clients when they returned to the community from the hospital. In actual nursing practice, case management is aimed at achieving a balance between quality and cost regardless of the different models.

Beilman et al. (1998) emphasized holistic health care, continuity of care and the treatment of patients as health partners. They posited that cost containment and episodic management of diseases should not be the major focus of case management. Since case management is considered a core

strategy for providing cost-effective and quality care to patients, the implementation of sound clinical, fiscal and operational strategies is critical to the continued delivery of quality services and the maximization of revenue (Carr, 2000).

However, despite the diversity of the case management models in the literature and research, there are limitations in the existing case management models. A multidisciplinary approach and continuity of care are the keys to promoting patient care; the advanced-practice nurse supporting patient-centred care using the comprehensive case management model is able to provide the best quality of service. A comprehensive model focusing on clinical and cost outcomes needs to be developed to challenge the limitations of the existing models. From the literature review above, it is expected that more case management models will continue to be developed by various scholars. There is no clear agreement about the definition and component activities of nurse-led case management. Moreover, there are no clear guidelines or suggestions on the applicability of these models to any of the specific patient or disease groups. The utilization of the models should therefore refer to patients' practical needs and responses to environmental changes, rather than to any specific disease.

## **Studies related to the various attributes of nurse-led case management programmes**

This section will critically review current studies and researches of the various attributes of nurse-led case management programmes. The discussions focus specifically on the key areas of the new model of care in this study.

### **2.7 Seamless care**

#### **2.7.1 Problem identification and needs assessment**

Needs assessment prior to discharge is considered crucial from the point of seamless care as nurses can use the data to improve the care outcomes for an in-patient's transition from the hospital to home care (Blaylock & Cason, 1992).

Jewell's study (1993) reported that discharge planning is represented by a careful and accurate assessment of patients' home circumstances, their ability to care for themselves, the carers' ability to manage and the assessment of their health care needs. Evans and Hendricks (1993) noted that the lower hospital admission rates were attributed to an earlier assessment of needs. Some social factors, such as family support and age, predict the likelihood of readmission. The discharge planning should be individualized to cater for each patient's post-hospital needs. Mamon, Steinwachs, Fahey, Bone, Oktay and Klein's (1992) study further substantiated that patients with unmet treatment needs were more likely to



be experiencing complications three weeks post-discharge, and those with unmet activity needs were more likely to be re-hospitalized within three months post-discharge.

Successful outcomes normally occurred when there was concurrence between nurses' assessment and patients' perception of their own needs. A challenge to the hospital staff was to ensure that the planning process both respected the patient's choice and that the choice was made without coercion (Jackson, 1994).

The literature review above described the complex care involved in patients' needs assessment. The above theories are also in line with the nursing process, whereby needs assessment is carried out prior to planning and implementing the nursing activities. It is therefore essential for the case manager to assess the patient's and his/her family's resources and their specific needs in the initial stage of the discharge planning. It is only through a detailed needs assessment that a desirable patient outcome will result.

### **2.7.2 Discharge planning**

Discharge planning is defined as the process of activities that involve the patient and a team of individuals from various disciplines working together to facilitate the transition of a patient from one environment to another.

All patients need some professional support in making the transition from hospital to home.

Discharge planning should begin on admission and should include the patient's participation with an adequate support system outside the institution (Lynne, 1996). Holistic discharge planning bridges the gap between the hospital and the community to ensure the continuity of care (O'Hare, 1996; Naylor, Bowles, Campbell & McCauley, 2001). Birmingham's paper (2003a) indicated that patients diagnosed with potentially high-cost diseases such as cancer, end-stage renal disease and AIDS need case management most. In another paper, Birmingham (2003b) stated that discharge planning is needed throughout the course of an episode of illness. The new wave of discharge planning includes patient identification and selection, problem identification, planning, monitoring, evaluating and outcome-oriented planning. The discharge plans are made available to both the patient and the family so that they can choose between the various options given. Successful discharge planning starts early, with a comprehensive nursing assessment on admission and effective communication among all health professionals involved, to ensure the continuity of care from the hospital to the community (Jackson, 1994; Armitage & Kavanagh, 1996; McKenna, Kenney, Glenn & Gordon, 2000). Discharge planning and patient education are interrelated. Patient education includes teaching about physical care and how to perform self-care at home (Rankin & Stalling, 2001). The four phases of discharge

planning include patient assessment, development of a discharge plan, education and service referrals, follow-up and evaluation (Mamon et al., 1992).

Lastly, a discharge plan is more acceptable to the patient and his/her family when he/she is involved in the planning process. Having patients and their families actively participate with the case manager enhances adherence to the discharge plan (Bristow & Herrick, 2002). A characteristic of the Hong Kong health care system is the lack of any organized discharge planning for chronically ill individuals and their families. The purpose of this study is to implement a nurse-led case management programme on discharge planning, focusing on patients' and families' participation, to examine the effectiveness of the new model of care.

### **2.7.3 Nurse-initiated telephone follow-up**

Nurse-initiated telephone follow-up care is effective in increasing self-efficacy in symptom management and decreasing the use of health care services. Establishing a telephone follow-up service is the most efficient and economical way of providing follow-up interventions (Car & Sheikh, 2003). Within the case management programme, the telephonic method often involves a nurse calling patients after hospital discharge to ensure that the treatment plan is being followed and care is being continued (Riegel, Carlson, Kopp, LePetri, Glaser & Unger, 2002).

Conventionally, it is the nurses who initiate telephone calls to the patients. Bostrom, Caldwell, McGuire and Everson (1996) conducted research to identify the differences between nurse-initiated phone calls and nurse-run telephone hotlines for newly discharged patients in transition to home. The results suggested that the two groups did not differ in patient satisfaction with health education or readmission rates within 30 days of discharge. Nevertheless, the study concluded that patients who have health education needs after discharge are less likely to actively seek necessary information from the hotline service.

The literature review above suggests that telephone calls are able to provide seamless care to discharged patients in a convenient and cost-effective way. However, a research gap exists because no similar study has been conducted targeting renal patients for intervention showing empirical demonstration. The present study aims at providing evidence to examine whether discharge planning with nurse-initiated telephone follow-up is able to bring about positive outcomes for renal patients in Hong Kong.

## **2.8 Health advocate**

### **2.8.1 Treatment adherence**

Adherence to treatment is a crucial component in the success of treatment administration. There are many factors affecting treatment adherence,

including patients' knowledge about the treatment, patient-provider relationships, social support, positive health beliefs and attitudes and ability of patients to control their own lives (Cameron, 1996).

In PD, the additional challenge is to motivate the patients to follow the given prescription in order to achieve the desirable clinical outcomes and to avoid health deterioration. Renal nurses should seek to accommodate the patients' own perceptions of what is best for them, so that they will adhere to the treatment regimen (Polaschek, 2003a).

The goals of PD are to prolong life and reverse the symptoms of uraemia. To date, investigators in this field have not been able to agree on an index that would serve as the yardstick for compliance. Thomas (2002) suggested using blood chemistry indicators, such as urea and creatinine clearance, and protein nutrition to determine the dialysis adequacy in relation to treatment adherence. Other authors have recommended different strategies to measure the pattern of non-adherence with dialysis exchanges in PD patients. Bernardini, Nagy and Piraino (2000) suggested a simple method to document dialysis compliance through home visits during the first six months of PD using inventory checks. Brown and Fitzpatrick (1988), on the other hand, developed a questionnaire to predict patients' compliance with a dietary regimen through self-reported compliance behaviour. Vlaminck, Maes, Jacobs, Reyntjens and Evers (2001) developed the diet and

fluid non-adherence questionnaire as a self-report instrument for clinical practice. The afore-mentioned studies indicate that there are different methods available to directly and indirectly assess non-compliance behaviour for dialysis patients.

Some authors have attempted to examine the obstacles for patients to achieve adequate doses of dialysis and the factors influencing compliance with dietary restrictions. Kutner, Zhang, McClellan and Cole (2002) stated that approximately one-third of both HD and PD patients were non-compliant. Patients' age and smoking habits had statistically significant effects in the model predicting skipping treatment. In addition, perceived negative effects of kidney disease on daily life and decreased perceptions regarding control over future health shortened the treatments. Latham's study in 1998 revealed that the obstacles to achieving adequate dialysis were within patient and environmental control. Education and quality improvement programmes might result in reducing the prevalence of non-compliance with the dialysis prescription in renal patients. The longer patients have been on dialysis, the less likely they are to report dietary compliance (Brown & Fitzpatrick, 1988).

Dialysis adequacy has a significant impact on the clinical outcome of CAPD patients, in terms of both mortality and morbidity (Sezto, Wong, Chow, Leung, Law, Wang, Lui & Li, 2001). The compliance of PD patients is

multi-factorial and thus poses additional challenges to health professionals. Baines and Jindal's paper (2000) suggested that patient empowerment, reward system, formal counselling and a multidisciplinary approach are treatment strategies to increase compliance in the haemodialysis patient group. Morgan (2000) advised that education, a behavioural approach and primary nursing are able to facilitate patients' adherence to prescribed therapeutic regimens and decrease re-hospitalizations. Friedman (2001) used an orderly and non-confrontational approach to care for those who were too sick to comprehend and consent to therapy. O'Brien (1990) held a similar opinion to Friedman and stated that, although a gold standard for measurement in compliance behaviour has not yet been established, social support has been identified as an important variable to be considered in evaluating ESRD patient compliance with the dialysis regimen. Raj (2002) recommended the consideration of using automated peritoneal dialysis in the management of non-compliance among CAPD patients. Finally, Balint (2001) concluded by reminding us that while noncompliant patients are difficult to care for, the medical staff will always have the duty to treat noncompliant patients under the Hippocratic Oath.

Non-adherence to the treatment protocol is a continuing problem among dialysis patients. Research supports the idea that nephrology nurses should spend time with patients on a regular basis in order to understand the factors that hinder individual patients from adhering to the treatment regimen (Morgan, 2000). The lack of adherence to dialysis treatment regimens is a

common problem in patients with ESRD. Adherence to prescribed dialysis regimens is an important factor in patients' overall management and their general well-being (Challinor & Sedgewick, 1998). During the assessment and discharge of patients, guidelines about keeping the prescribed regimens should be established. Nurses can help patients overcome the problem of non-adherence through the nurse-led case management model of continuity of care.

An exhaustive review of the literature on adherence behaviour has revealed a notable lack of published articles focusing on evaluating the effectiveness of case management and discharge planning on compliance behaviour. Hailey and Moss (2000) further stated that there are few studies in the haemodialysis literature that evaluate interventions in relation to reducing non-adherence behaviours. In addition, how patient adherence is related to patient outcome has yet to be examined in case management studies. An extensive search covering two decades of research was able to identify only one research article, from 1989, which focused on the subject of primary nursing and adherence. The abovementioned study conducted by Molzahn (1989) found no significant differences in the adherence of patients before and after the implementation of primary nursing. Nonetheless, the author concluded that renal nurses were able to reduce disease complications in patients by implementing measures that increase adherence. With continuity of care, nurses are able to assist patients in



achieving adherence to treatment, having fewer complications and reducing the incidence of hospitalizations.

From the literature review, it is known that renal patients have a poor adherence rate, yet it is unclear whether adherence is related to clinical outcomes. Since the role of nurse case managers is to advocate health, the purpose of this study is to provide evidence proving the relationship between self-care adherences in relation to the nurse-led case management programme.

### **2.8.2 Empowerment**

Empowerment has recently become acknowledged as one of the more prominent concepts in health care. The concept has been described in many disciplines, including psychology, social work, education, nursing, and the business community (Pitman & Weiskittel, 1999). Today, renal nursing is an established speciality in which the distinctive role of the nurse case manager is to empower and support the patients to live as fully as possible while living with renal replacement therapy.

There are four defining attributes of empowerment derived from the literature, namely: the helping process, a partnership that values the self and others, mutual decision making using resources, opportunities and authority and the freedom to make choices and accept responsibilities (Rodwell,

1996). Self-management is considered the most important need for ESRF patients, and patient empowerment and facilitation of self-care are comprehensive approaches to encourage patients to actively participate in the self-care management of their long-term illness (Tsay & Hung, 2004). Nurses should develop further skills in areas such as listening and facilitation and revisit values about compliance. The notion of patient empowerment is considered a relatively new concept for nurses, whereby patients are provided with information to assist them on making an informed choice and acting on that choice (Metcalf, 2005)

In chronic disease care, moving from compliance to adherence is not enough; something entirely new is needed as a step toward the new chronic care model for PD patients. The nurse case manager, as an advocate for health, is ideally placed to encourage patients to take control of their situations and to explore the full extent of their needs. This background information sheds light on the motivation of the present study to examine the effectiveness of a proactive nurse-led case management programme targeting PD patients.

## **2.9 Appraiser**

### **2.9.1 Improved quality of life**

According to Woolsey (1989), the term 'quality of life' (QoL) has been in use for over 40 years. It is viewed as either unidimensional or

multidimensional. When viewed as unidimensional, a person's own judgment concerning life satisfaction is used as a proxy measure of a good quality of life. The multidimensional model, on the other hand, identifies an all-encompassing social, psychological, physical and functional factor which is indicative of health and well-being.

A number of studies have been published on the quality of life for renal patients. Bakewell, Higgins and Edmunds (2002) concluded that the quality of life of PD patients declines over time and is associated with poor clinical outcomes. Comorbidity, time of renal replacement, social deprivation and serum albumin were related to some of the health domains in the Kidney Disease and Quality of Life Short Form (KDQOL-SF) instrument. In addition, increased hospital admissions were associated with a poorer QoL. Other variables such as age, associated disease, anaemia, gender and social factors also influence patients' perception of QoL (Kutner, Zhang, McClellan & Hoffart, 2000; Valderrabano, Jofre, & Lopez-Gomez, 2001; Wight, Edwards, Brazier, Walters, Payne & Brown, 1998). Improvement of anaemia and renal transplantation are the most positive strategies in improving QoL of patients with ESRD. However, the study by Merkus et al. concluded that comorbidity, haemoglobin level and residual renal function may only explain the variations in quality of life to a limited extent. Other potential determinants should also be explored (Merkus, Jager, Dekker, Boeschoten, Stevens & Krediet, 1997). Frank, Auslander and Weissgarten (2003) presented different findings and

concluded that the negative effects of the disease on quality of life were due to patients' subjective symptom reports rather than the objective indicators of their health status.

Martin & Thompson (2000) attempted to determine the relationship between quality of life and adequacy of dialysis and depression. The results revealed no significant relationship between urea clearance and any of the quality of life measures, while depression and anxiety are associated with low quality of life. Ira and Cleary (1995) developed the framework to propose a specific causal relationship between clinical variables and health-related quality of life. These variables included not only biological and physiological variables but also symptoms status, functional status and general perceptions. Each level of the clinical variable is integrated and linked to have an impact on the overall quality of life. The findings emphasized the importance of further studies to quantify these relationships.

Regarding health-related quality of life amongst patients on haemodialysis and continuous ambulatory peritoneal dialysis, Lindqvist, Carlsson and Sjoden's findings (1998) revealed that the two groups had similar scores on dissatisfaction with physical health. The patients in the CAPD group were more dissatisfied with their physical health; however, the group experienced better emotional health than their counterparts. Lindqvist and Sjoden's study in 1998 compared the health-related quality of life of CAPD patients

with the general population. The CAPD group reported lower values on most of the subscales, including physical functioning, mobility, pain and role limitation. However, it is interesting to note that the female CAPD patients scored higher than the general population. The study was limited by its small sample size; because of this, the authors suggested that patient reactions should be measured several times to see how they differed in the use of coping strategies over time.

Symptom and complication control is the most significant characteristic associated with quality of life of renal patients, which is also determined by other factors such as age, ethnicity and gender. The majority of these studies concluded that that quality of life strongly correlates with disease morbidity and subsequent clinical outcomes. Although this position is supported by a growing consensus in the published literature, the breadth and comprehensiveness of these narrative reviews are limited by their non-interventional study design. Therefore, these enquiries are unable to ascertain whether the case management approach improves quality of life. In this study, the investigator uses empirical evidence to examine whether case management interventions are able to improve patients' quality of life.

### **2.9.2 Patient satisfaction**

Satisfaction with care is a crucial component for all health professionals in the evaluation of quality services. This is especially true when attempts are

being made to measure or change the quality of health care services in a hospital. Patient satisfaction with nursing care, in particular, has been cited as the most important predictor of patients' overall satisfaction with their hospital care (O'Connell, Young & Twigg, 1999).

Patient satisfaction is considered a key concept in evaluating and improving nursing services. Moreover, the measurement of client satisfaction can be used in the creation of administrative decisions and the formation of professional ethics (Merkouris, Ifantopoulos, Lanara & Lemonidou, 1999). Current evidence-based practice requires nurses to produce evidence to support the continuance of current practices or to justify any changes. Patient satisfaction has frequently been used in past attempts to evaluate major changes in nursing practices, such as the introduction of primary nursing (Walsh & Walsh, 1999). As there is increased focus on learning how to produce desirable patient outcomes, patient satisfaction, has become one of the measures of the quality of nursing care (Jacox, Bausell & Mahrenholz, 1997). Regardless of the different approaches, using quantitative or qualitative methods, health care providers create systems for consumer feedback to comply with standards and to maintain the quality of services (Urden, 2002).

There are two elements in the performance of practitioners, suggested by Donabedian (1988), namely technical performance and interpersonal relationship performance. Technical performance depends on the knowledge and judgment of practitioners to arrive at the appropriate

strategies of care. Successful technical care is implemented through an interpersonal process. The various approaches of assessment include structure, process and outcome. Structure includes material and human resources; process denotes the practitioner's or patient's activities, whilst outcome indicates improvements in the patient's knowledge and changes in his/her behaviours, as well as the degree of his/her satisfaction with care. Urden (2002) stated that satisfaction is the individual's subjective perception and is closely linked to his/her expectations of services. When expectations are not met, satisfaction is low.

The new range of roles for nurses indicates the diverse nature of activities with which nurses are becoming involved and the positive impact they appear to be making on the multidisciplinary working team. Evidence suggests that nurses are more competent and comfortable in taking on the role of advanced nurse practitioners (Spilsbury & Meyer, 2001). The results of Bjorkman and Hansson's (2001) study on patient satisfaction with case management interventions showed that satisfaction with case management was high. However, it cannot be presumed that patients are more satisfied with this new kind of health professional, and there has been little attempt to evaluate the nurse case manager's contribution to patients' satisfaction. This phenomenon indicates an exciting development in nursing but highlights the lack of rigorous research in this area. This significant gap in patients' expectations and how much nursing has achieved thus far warrants

further study on patients' satisfaction to identify the nursing contribution in the new paradigm of nursing care.

## **2.10 Change agent**

### **2.10.1 Cost containment**

Given the increased importance in the economic evaluation of health care interventions, the new role of the nurse case manager has an impact on cost containment and cost-effectiveness analysis, and is one of the outcomes associated with the case management programme for chronic disease.

A study conducted by O'Hare, Yost and McCorkle (1993) reported that repeated hospitalizations have been estimated to account for half of all admissions and 60% of hospital charges. It is therefore necessary to identify patients at a high risk of hospital readmission and target interventions for these patients. Weinberger, Smith, Katz & Moore, (1998) stated that the hospital readmission rate within a three-month follow-up period was significantly higher for patients with at least one unmet need as compared to those with no unmet needs. Therefore, increasing ambulatory care resources after hospital discharge for high-risk patients may reduce health care costs associated with hospital readmission.

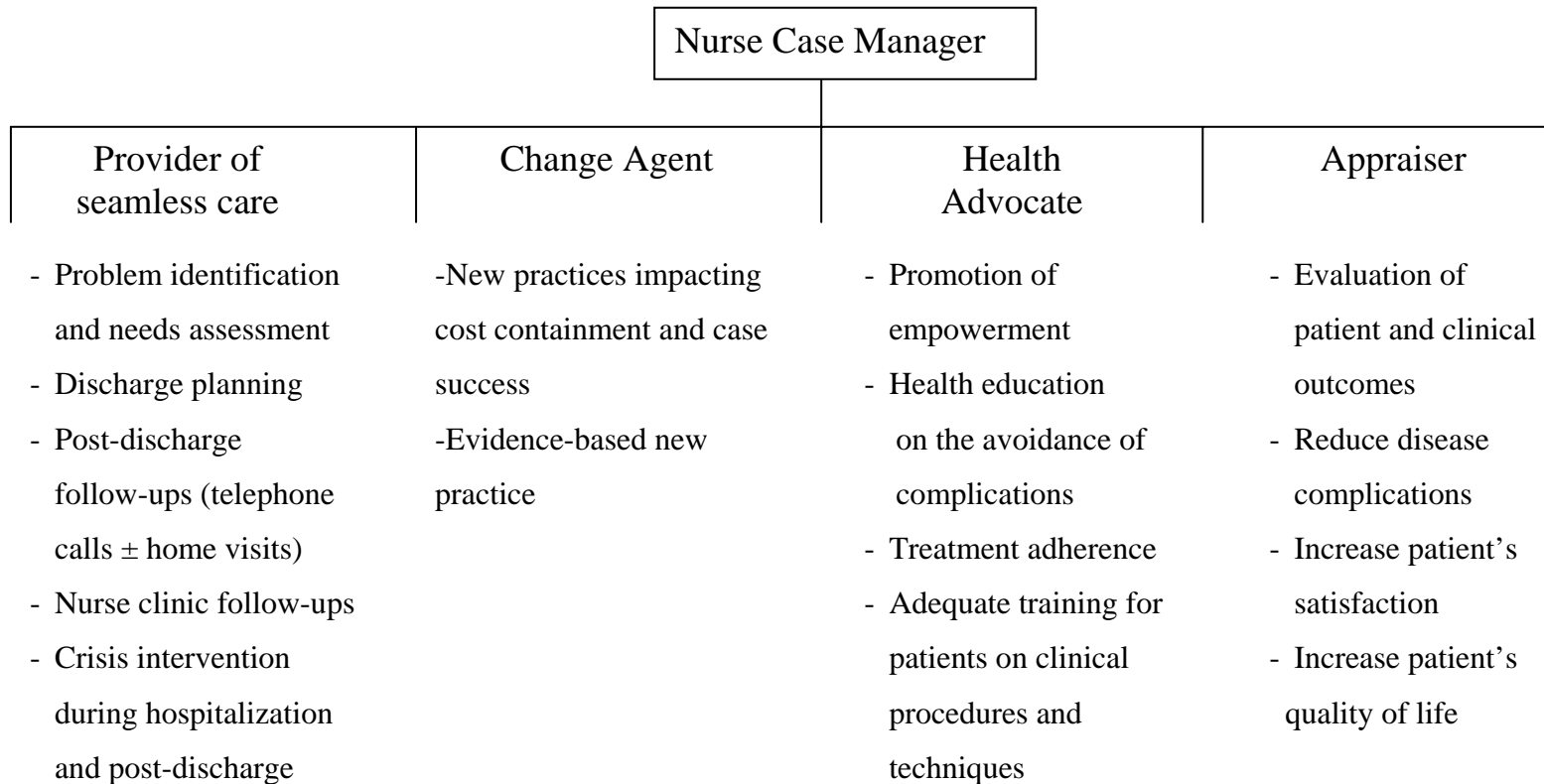
Telephone intervention, patient education and ambulatory care are valuable resources for high-risk patients after hospital discharge. These interventions may reduce health care costs associated with hospital readmission. If a



case management programme is able to reduce the total number of readmission and emergency room visits, the new practices could not only bring positive patient outcomes but at the same time reduce health care costs.

Figure 2.1 shows the various attributes of the nurse case manager.

**Figure 2.1 Various attributes of the nurse case manager**



## **2.11 Review of literature on nurse-led case management programmes**

This section reviews current local and overseas literature and research studies examining the effectiveness of nurse-led case management programmes for patients suffering chronic disease and highlights the potential for developing such programmes for the renal patient group.

### **2.11.1 Case management programme for end-stage renal failure patients**

Patients on dialysis experience multiple physical, social and psychological changes (Luk, 2001). Chronic diseases like ESRF are characterized by readmission for complications of the disease, the need for long-term follow-up and medication and multidisciplinary clinical management. Moreover, renal replacement therapy provokes changes in the patient's lifestyle and affects his/her quality of life (Chau, Chak, Wong, Choi, Wong, Chan, Wong, Cheung & Li, 2003).

The care needs of patients having ESRF appear complex. The goal of nursing management at this stage is to maintain the stability of illness and improve everyday life activities. The health care needs also include improved treatment outcomes, reduction of anxiety and increased opportunities for intervention to delay disease progression (Golper, 2001). Health care delivery to renal patients aims to reduce stress on the family and to evolve with the individual and the family to focus on the patient's special

needs. With the growth of scientific knowledge, the nurse becomes a counsellor, teacher, resource person, leader and advocate, as well as an expert practitioner. The goal of care, therefore, is to control symptoms, to prevent complications and to enhance seamless health care (Challinor & Sedgewick, 1998).

An exploratory work in identifying the needs of patients with end-stage renal disease illustrated that this specific group of patients requires very special care management to achieve desirable clinical outcomes. Nurses are capable of delivering care in some of the perspectives that develop quality care initiatives for patients in the programme (Nissenson, 2002). Brandley (1995) suggested that the end-stage renal disease cohort is a logical beginning for case management efforts. Through close monitoring of patients and adequate patient education by the renal nurse case manager, health outcomes could be maximized in relation to the reduction of the catastrophic onset of dialysis. Holland's paper (1998) argued that the benefits of renal case management have been shown to affect not only improved clinical outcomes, but also decrease fragmentation and repetition of services. However, Harris, Luft, Rudy, Kesterson and Tierney's study (1998) on patients with chronic renal insufficiency asserts that an intensive and expensive case management intervention with a renal nurse as part of the team has little effect on the processes of care and has no effect on important health care outcomes. This case management programme was led by physicians and focused mostly on medication review.

The results of the studies mentioned showed little consistency with the benefits of nurse-led case management in a renal patient group. Some of the studies appeared to have a positive impact on patient care in relation to the case management programme but there is often a lack of coherence in definitions of roles and in the tools used in such studies. With the exception of Harris, these studies failed to describe the structure and processes of care that contribute to the outcomes. The major flaw in these papers is that most of them do not focus on the intervention strategies to establish the evidence for success. They are limited by a non-interventional study design, leaving a significant gap in the research-based literature. Studies on nurse-led case management programmes for end-stage renal failure patients using an empirical design are therefore warranted to build a picture of the evolving nature of the new concept of care.

### **2.11.2 Case management for other chronically ill patients**

This section reviews the evidence of researches conducted on nurse-led case management studies on various chronic patient groups. The methodological difficulties associated with these studies are highlighted. The majority of these studies have demonstrated that the interventions are able to achieve desirable outcomes for chronically ill patients.

A study conducted by Egan, Clavarino, Burridge, Teuwen and White in 2002 provided evidence to suggest that case management is an effective model of care for patients suffering from chronic obstructive pulmonary

disease. The intervention group reported a significant improvement in the level of anxiety between hospitalization and one-month post-discharge. Another study on respiratory disease management demonstrated that, through the use of intensive case management interventions, asthma patients who inappropriately used medication were able to maintain the medication dose to achieve long-term control of the disorder (Delaronde, 2002).

Case management programmes have also been applied to non-specific general medical patients. Following patient triage, the high-risk group that received discharge planning benefited from case management through a shortened length of hospital stay (Hickey, Cook, Rossi, Connor, Dutkiewicz, McCabe Hassan, Fay, Lee & Fairchild, 2000). The study conducted by Einstadtler, Cebul & Franta (1996) also demonstrated positive results, in that the intervention group patients were more likely than the control group patients to have definite follow-up appointments through the use of a nurse case manager to coordinate discharge planning and to arrange for post-discharge out-patient follow-up in a general medical service. However, intervention and control group patients did not differ in the rates of emergency department utilization or unplanned readmissions within 30 days of discharge. On the contrary, Fitzgerald et al's work (1994) detected no significant difference among groups in non-elective readmissions, readmission days, or total readmissions through a randomized controlled trial of patients discharged from general medical in-patient services.

Brooten, Brown, Munro, York, Cohen, Roncoli and Hollinsworth (1988) designed the first model to discharge patients early from hospital with a comprehensive programme of transitional home follow-up by nurses. The model was initially tested on very low birth weight infants and provided a framework to examine other patient groups. Brooten, Naylor, York, Brown, Roncoli, Hollingsworth, Cohen, Arnold, Finkler, Munro and Jacobsen's study (1995) revealed that comprehensive discharge planning plus transitional care provided by nurse specialists reduced the number of re-hospitalizations and acute care visits in four out of five heterogeneous groups of patients. With the exception of the elderly, the patients were more satisfied with their care. The financial cost of hospitalization was reduced in four groups of patients.

Naylor's pilot study (1990) examining the effects of a comprehensive discharge planning protocol implemented by a nurse specialist to the hospitalized elderly, found that the experimental group experienced fewer readmissions than the control group. The report by Naylor (1994) stated that a comprehensive, individualized discharge planning protocol developed specifically for elderly patients and implemented by a gerontological nurse specialist had its greatest effect in delaying or preventing the hospitalization of patients in the intervention group during the first six weeks after discharge. Moreover, a 1999 study by the same author further confirmed that nurse-led discharge planning intervention with home follow-up for at-risk hospitalized seniors reduced readmissions, lengthened the time

between discharge and readmission and decreased health care costs (Naylor, Brooten, Cambell, Jacobsen, Mezey, Pauly & Schwartz, 1999). A similar study conducted recently to examine the effectiveness of a transitional care programme delivered to seniors hospitalized with heart failure demonstrated the short-term improvements in quality of life, patient satisfaction and fewer readmissions (Naylor, Brooten, Campbell, Maislin, McCauley & Schwartz, 2004).

In chronic conditions, such as HIV infection, patients are faced with fears about the treatment and compliance with medication regimens. Case management can help patients overcome their fears of treatment and improve medication adherence (Katz, Cunningham, Fleishman, Andersen, Kellogg, Bozzette & Shapiro, 2001).

Studies involving patients with heart failure demonstrated that case management could save costs and reduce hospitalization. A standardized, nurse-led case management telephone intervention showed that the approach could achieve cost savings, reduce resource use and increase patient satisfaction (Riegel, Carlson, Kopp, LePetri, Glaser & Unger, 2002). Similarly, Harrison and colleagues showed that discharge planning with detailed transition care demonstrated significant improvements in health-related quality of life and a decreased use of emergency rooms in individuals with a history of heart failure (Harrison, Browne, Roberts,



Tugwell, Gafni, & Graham, 2002). For the congestive heart failure population, the nurse case managers delivered phone calls to patients and their family members, resulting in better adherence to treatment plans and medication and increased satisfaction. However, the above study showed no difference in total readmissions and out-patient resource utilization (Laramee, Levinsky, Sargent, Ross & Callas, 2003).

Mamon et al. (1992) stated that formal interdisciplinary discharge planning appeared to have a significant effect on reducing the unmet treatment needs of clients from a wide range of socioeconomic backgrounds. This finding is important as unmet treatment needs are more likely to result in complications within two to four weeks post-discharge.

A study conducted in China on discharge planning and a follow-up programme reported that elderly patients with chronic heart disease benefited by enhancing their related knowledge and health behaviour. The study further suggested that a coordinated discharge plan and follow-up programme is needed for patients during the transitional period from hospital to home (Zhao, 2004).

### **Telephone follow-up within case management programmes**

Many studies have been published on the relationship between discharge planning and various outcome measures, such as the length of hospital stay,

complication rate, readmission rate, mortality rate, patient satisfaction, patient health status and quality of life. Brooten, Naylor, Brown, York, Hollingsworth, Cohen, Roncoli and Jacobsen (1996) suggested that telephone follow-up by a nurse during the first two weeks following discharge can provide support to patients and their families and lead to early problem-solving interventions. Even though patients are no longer hospitalized, the telephone follow-up is able to provide continuing care.

A home-based disease management programme using telephone calls and home visits could improve quality of life and symptom status in heart failure patients after discharge from the hospital (Toderò, LaFramboise & Zimmermann, 2002). Research by DeBusk et al. (1994) on a nurse-led case management care model for post acute myocardial infarction patients showed that the model was able to provide continued nursing care after discharge through nurse-initiated telephone contacts on exercise and drug therapy. The results showed a decrease in the smoking prevalence rate and lipid profile was near normal after six months. Riegel et al.'s study (2002) using a randomized controlled trial demonstrated that standardized, nurse-led case management telephone intervention could achieve significant cost savings, reduction in resource use and increased patient satisfaction for heart failure patients in the study group.

Grant, Elliott, Weaver, Bartolucci and Giger (2002) used telephone interventions with the family caregivers of stroke survivors after rehabilitation. This method was seen to be effective, as the caregivers were able to identify and address the unique concerns of each patient through initial and subsequent telephone contacts with the nurse. Similarly, the results of a post-discharge follow-up telephone project conducted by Garland in 1992 also suggested that telephone calls to patients and their families after discharge are an effective and efficient means of delivering a wide range of follow-up assistance and an effective method for evaluating the success of the discharge plans. Cline, Israelsson, Willenheimer, Broms & Erhardt (1998) supported the theory that a programme consisting of telephone follow-ups and education was able to reduce the number of days patients spent in hospital and thus contributed toward a mean, per patient reduction in annual health care costs

Kim and Oh (2003) used a randomized design to explore the effects of nurse telephone calls on glycosylated haemoglobin levels and adherence to diabetes control. The intervention group had a better diet and blood glucose testing adherence, and showed a greater reduction in glycosylated haemoglobin level than the control group. Piette, Weinberger, McPhee, Mah, Kraemer and Crapo (2000) studied the effectiveness of automated telephone assessment and self-care education calls with nurse follow-up on the management of diabetes. Compared to the standard care patients, the intervention group patients reported more frequent glucose monitoring, foot

inspection, weight monitoring and fewer problems with medication adherence.

### **Summary of reviews from overseas studies**

The overseas studies showed mixed results. The review reflects the different study populations and the different ways the interventions were implemented. The results showed that some discharge planning strategies were successful in reducing hospital length of stay and may have reduced the hospital readmission rate. Discharge planning was also observed to improve the physiological and psychological health of patients, hence increasing patients' satisfaction in nursing services. Lastly, the development of a high level of communication between the health care providers and patients was demonstrated in a few of the outcomes.

The studies used a range of methodological approaches in order to capture the complexity of nurse-led case management interventions. Most of the researches used randomized controlled trials with a control group as the gold standard for research rigour and were able to provide valid information on the outcome of interventions. Despite the positive results that were presented in most studies, detailed examination revealed some obvious gaps. Most of the studies indicated that nurses contributed to patient outcome in the following areas: patient education, anxiety reduction, improvement in quality of life, increased adherence and higher patient satisfaction. For

chronically ill patients, it should be noted that at times it is neither easy, nor in some cases possible, for nurses to contribute to certain patient outcomes, such as reducing morbidity; nevertheless, it is the responsibility of nurses to control symptoms during the stable phase after hospitalization. This raises the question of which are the most important outcome measures for these groups of patients suffering from chronic diseases. Symptom control and complication management therefore remain important outcomes attributable to nurse-led case management intervention and this offers insight into the nursing contribution. There are very few studies discussing symptom management that also have validation from biochemical measures. Harris, Naylor, Toderro, DeBusk and Kim have focused on this area to assess nursing interventions in the management of symptom and complications control. The variables included renal function, functional status, symptom occurrence, plasma cholesterol and blood glucose level. These studies have concentrated on measuring nursing outcomes in terms of improvements in clinical condition and maintaining stability during the course of disease.

With regards to education and adherence behaviours, most of the research has attempted to evaluate the contribution that these new, extended roles make to patient care. Studies have confirmed that such roles have a positive impact on patients' knowledge and behaviours. However, it is suggested that these benefits should be incorporated with the blood chemistry results and other objective clinical signs to determine the

association between behavioural changes and specific health outcomes. The clinical signs should include body weight change, level of oedema, swelling, wound condition and other signs and symptoms related to the disease. It is unlikely that any scale could capture patient outcome adequately unless complemented by these objective data. A study to examine the interface between subjective and objective outcomes is critical to ensure the expansion of the nursing role and to provide evidence-based practice for nurse-led case management research.

Despite the increasing popularity of nurse-led case management as a strategy for health care professionals, Lamb (1992) critically pointed out the flaws in nurse-led case management research. The research insufficiencies include the sampling criteria, research design, instrumentation, selection of outcome indicators and absence of theoretical base. Although the studies have focused mostly on patients with chronic diseases, the effectiveness of nurse-led case management programmes and telephone follow-ups for patients receiving peritoneal dialysis has not been studied. Therefore, the development of a body of knowledge on nurse-led case management for PD patient care and outcomes should fill the knowledge gap and define the nursing contribution in this area.

### **2.11.3 Nurse-led case management programmes in Hong Kong**

Case management care in Hong Kong is still considered to be in its infancy, despite the increasing body of knowledge accumulated in local studies,

which has added strength to support this model of care. The new dynamic model of care needs enormous support from researchers, hospital management and frontline nursing staffs. It is worthwhile to highlight the findings of some local researches as differentiated from overseas studies.

A local study used a two-tiered case management model in post-hospital community nursing care for elderly patients and family carers. The results revealed that the patients had lower scores in the sickness impact profile, reduced readmission and emergency room attendance rates and a higher satisfaction score following the case management programme than the comparison group (MacKenzie, Lee, Dudley-Brown & Chin, 1998a). The same study also demonstrated that through the process of case management, there was an improved relationship between patients and the community nurse, resulting in better assessment and improved continuity of care (MacKenzie, Lee, Dudley-Brown & Chin, 1998b). Chan, Mackenzie, Fu and Leung (2000) used a matched, pre-post, case-control group design to compare case management and the conventional care group in a community psychiatric nursing service. The case management group was more satisfied with the service and had better outcomes in terms of their mental status and functional level.

Research conducted by Wong, Mok, Chan and Tsang (2005) used a randomized, controlled trial to compare the outcomes of diabetic patients undergoing early discharge with patients who were discharged routinely.

The early discharge group, after receiving a follow-up programme from the case manager, demonstrated effective glycaemic control and enhanced adherence to health behaviours. There was no significant difference in health service utilization. Wong, Wong and Chan (2005) examined the effects of nurse-initiated telephone follow-up among patients with chronic obstructive pulmonary disease. The results revealed a substantial increase in self-efficacy in managing dyspnoea for patients in the study group. No significant difference was found in total service use and hospitalization rate.

The most recent study conducted by Leung, Yau, Liu, Yeoh, Chui, Chi and Chow (2004) evaluated the process of nurse-led case management by a randomized, controlled trial on a group of post-discharge, frail, elderly patients. The new paradigm of care was effective in significantly reducing the utilization of hospital services and resulted in a high level of patient satisfaction.

The literature review above provides evidence to show that case management interventions have brought about effective health outcomes for elderly patients and those with chronic conditions in Hong Kong. Most of the studies have demonstrated research rigour and used a control or comparison group to delineate the effectiveness of nurse-led case management interventions. The combined positive results, based on a variety of researches, indicate an improved relationship between patients and nurses; better clinical outcomes, reduction in utilization of hospital



services, higher patient satisfaction and improved continuity of care. However, the studies present conflicting arguments on the value of case management in reducing readmission and utilization of health services. Moreover, programmes that produced positive results generally appeared to be limiting their efforts to one element of the model but not extending them to encompass comprehensive system change. The utilization of a comprehensive model of nurse-led case management in future studies will ensure that all critical areas are addressed.

Lastly, there is very little documentation in Hong Kong about the effectiveness of nurse-led case management programmes and telephone follow-ups for patients receiving peritoneal dialysis. Likewise, there has been no research in this area from overseas. The original case management model proved to be useful in improving the patient outcomes, as seen in previous successful research studies. An improved and revised model attempts to include new elements, as enriching the general features in chronic illness care is crucial to guide the specific practice (please refer to Figure 2.1). This study uses a randomized controlled trial with the enhanced model to examine the effectiveness of a nurse-led case management programme in Hong Kong. It is only through this type of systematic effort that nursing knowledge is developed by means of best scientific evidence.

Table 2.1 summarizes the research methods and results of nurse-led case management and discharge planning from local and overseas studies.

**Table 2.1 Review of research methods on case management and discharge planning from local and overseas studies**

<b>Study</b>	<b>Sample</b>	<b>Design</b>	<b>Intervention</b>	<b>Measurement</b>	<b>Outcome</b>
Harris et al (1998)	437 (chronic renal insufficiency)	Randomized controlled trial (RCT)	Multidisciplinary case management clinic by doctors, nurses and social workers	Renal function Health service use Mortality rate	No effect on all outcomes.
Egan et al (2002)	66 (chronic obstructive pulmonary disease based on FEV <sub>1</sub> )	RCT	Nursing assessment and review Education to patient and caregivers Discharge planning Phone call on regular basis for 6 weeks	Anxiety Depression Symptoms Support and subjective well-being	Little difference was found between the control and intervention groups in terms of the key outcome variables. There was a positive impact on the intervention group's psychological well-being but effect diminished over time. Both groups reported improvement in symptoms between admission and one month post discharge but improvement was not sustained after interventions.
Delaronde (2002)	249 (asthma)	Comparative study	Single-contact vs intensive, multiple-contact telephone contact intervention	Increase intake of anti-inflammatory prescriptions Decrease in short-acting prescriptions	Subjects receiving intensive telephone interview were four times more likely to increase the number of anti-inflammatory medications in the 12 months after intervention.
Hickey et al (2000)	302 (general medical service)	Prospective controlled study	Coordinated discharge planning for case management group: Pre-discharge education Telephone follow-up within 48 hours after discharge	Hospital length of stay Patient satisfaction Non-acute medical service utilization	Case management group patients discharged earlier than standard care group. Utilization of services was slightly higher among study group patients. No significant difference in patient satisfaction between groups

Fitzgerald et al (1994)	668 (general medicine)	RCT	Mailed education materials Telephone call within 5 days post discharge Contact the patients if they made no visits for 30 days	Readmissions Readmission days Total readmissions	Study group had more frequent visits to clinic. No significant differences between groups in non-elective readmissions, readmission days, or total readmissions.
Einstadter et al (1996)	478 (general medical service)	Prospective cohort trial	Discharge planning before hospital discharge Arrange post-discharge out-patient follow-up	Out-patient follow-up Unexpected readmission within 30 days Emergency room utilization Hospital length of stay	A significantly greater proportion of study group patients had appointments scheduled before discharge (63% vs 46%) and made scheduled visits (32% vs 23%). No significant difference in readmission, emergency room visit and hospital length of stay.
Brooten et al (1995)	679 (very low-birthweight infants; women with caesarean section; DM pregnant women; hysterectomy, elderly patients)	RCT	comprehensive discharge planning, instruction, counselling, home visits, telephone outreach by a nurse specialist	Length of initial hospital stay Rehospitalization Acute care visits Satisfaction	Except of the elderly, patients were more satisfied with care. Charges for hospitalization were reduced. Reduced number of rehospitalizations and acute care visits.
Naylor et al (1994)	276 patients and 125 caregivers. (elderly patients with medical or surgical cardiac diagnostic related group)	RCT	Comprehensive discharge plan plus gerontological nurse specialist services and protocol developed specifically for elderly patients	Length of initial hospital stay Re-hospitalization Cost of care	Patients in the medical intervention group had fewer readmissions, fewer total days of re-hospitalization, lower readmission charges and lower charges for health care services after discharge. No differences in the above outcomes were found between the surgical intervention group and control group.

Naylor et al (1999)	363(elders at risk of readmission)	RCT	Comprehensive discharge planning and home follow-up with protocol designed specially for elderly patients at risk after discharge	Readmission Time to first readmission Acute care visits Cost Functional status Depression Patient satisfaction	Control group patients more likely to be readmitted at least once. Intervention group had fewer multiple readmissions and fewer hospital days/patient. Reimbursement for health services was less in intervention group. No difference in acute care visits, functional status, depression or patient satisfaction.
Naylor et al (2004)	239 (elderly hospitalized with heart failure)	RCT	3-month APN-directed discharge planning and home follow-up protocol	Time to first re-hospitalization or death Number of re-hospitalizations Cost Quality of life Functional status Satisfaction with care	Time to first readmission or death was longer in intervention group. Intervention group had fewer readmissions, lower mean total cost. Short-term improvements in quality of life, functional status and patient satisfaction in intervention group.
Katz et al (2001)	2437 (HIV-infected adults)	National probability sample	Case managers to address on unmet needs	Unmet need for supportive services Medical care utilization Use of HIV medications	Decrease in unmet needs for income assistance, home health care, health insurance and emotional counselling. Not significantly associated with decrease medical care utilization. Higher utilization of some drugs.

Riegel et al (2002)	358 (hospitalized patients with chronic heart failure)	RCT	Telephonic case management	Hospitalization rates Readmission Hospital days Cost Patient satisfaction	Hospitalization rates, hospital days and multiple readmissions were lower in the intervention group. Cost saving in intervention group. High patient satisfaction in intervention group.
Harrison et al (2002)	Number of subjects not stated (congestive heart failure)	Prospective randomized trial	Transitional care Education programme Phone outreach Community nurse visit	Quality of life Readmission Emergency room use	Study group had better quality of life. Fewer presentations at emergency room and fewer readmission of study group patients.
Laramee et al (2003)	287 (congestive heart failure)	RCT	Early discharge planning Education Telephone follow-up	Readmission Cost Treatment adherence	No difference in total readmissions. Intervention group adherence to treatment plan greater than control group. Patients in intervention group were more satisfied. The intervention did not increase cost; no significant difference found in outpatient and inpatient resource utilization.
Mammon et al (1992)	919 (surgical and medical patients age 60 and over)	Random sample, non-experimental study	Interdisciplinary hospital discharge planning	Needs for care related to treatment, activity limitation, self-sufficiency limitations	Patients with unmet treatment needs more likely to experience complications and re-hospitalization Presence of case manager reduced number of unmet treatment needs.

Todero et al (2002)	102 (heart failure)	Prospective, repeated measures study	One of four strategies randomly assigned: telephone calls, home visits, telephonic communication device, combined home visits and telephonic communication device	Symptom occurrence Symptom characteristics Quality of life	Patients experienced less angina, fatigue, depression and swelling. Improvement in the subscales of physical role, pain, mental status and vitality.
Zhao (2004)	200 (Myocardial infarction)	RCT	Discharge planning programme Health education Home visits and telephone contacts	Self-reported knowledge Adherence behaviours Readmission rates	Higher self-reported knowledge and adherence behaviours in the study group. No difference in readmission rate among the two groups.
DeBusk et al (1994)	585 (Acute myocardial infarction)	RCT	In-patient interventions for healthy lifestyle Nurse-initiated telephone contacts after discharge Progress reports mailed to patients Treadmill exercise test, lipid-lowering drug therapy	Patient self-report of non-smoking Plasma cholesterol Treadmill exercise testing	The intervention group had higher smoking cessation rates, lower plasma cholesterol levels and better functional capacities.

Cline et al (1998)	190 (heart failure)	Prospective randomized trail	Education on heart failure and self management Follow-up in nurse directed outpatient clinic	Time to readmission Days in hospital Health care cost	Mean time to readmission was longer in intervention group, with fewer hospital days. Annual reduction in health care cost in the intervention group.
Kim & Oh (2003)	50 (Diabetes Mellitus)	RCT	Education on adherence Telephone follow-up Medication adjustment based on blood glucose log	Self-reported adherence Blood glucose level	Study group had a mean decrease in blood glucose level and greater diet and blood glucose testing adherence.
Piette et al (2000)	248 (Diabetes Mellitus)	RCT	Automated telephone disease management calls with telephone nurse follow-up	Mental health Self-efficacy Satisfaction Quality of life	Intervention group had fewer symptoms of depression, greater self-efficacy, fewer days in bed and higher satisfaction. No measurable effects on anxiety and health related quality of life.
MacKenzie et al (1998a)	55 patients and 40 family carers (elderly people in community)	Descriptive correlation design	Care co-ordinator before discharge Case managers in the community Community nurse visits	Sickness Impact profile (SIP) Cost Patient satisfaction Readmission	Case management group had lower scores in the SIP and therefore less sickness. High patient satisfaction. Emergency room visits and readmission rates reduced. No difference in cost of care among two groups

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Chan et al (2000)	146 (chronic schizophrenia)	Matched, pre-post, case-control group design	Comprehensive needs assessment Home visits Coordinating community resources	Brief Psychiatric Rating Scale Specific Level of Functioning Scale Satisfaction	The study group had higher scores in BPRS & SLOF, showing better functional and mental condition. High patient satisfaction in the study group.
Wong et al (2005)	101 (Diabetes Mellitus)	RCT	Early discharge Telephone follow-up	Blood glucose level Adherence behaviour Hospital stay	The study group had a greater decrease in blood glucose level, higher monitoring adherence scores and shorter hospital stay.
Wong, KW et al (2005)	60 (Chronic obstructive pulmonary disease)	RCT	Telephone follow-up	Self-efficacy Emergency room use Readmission	The study group had better self-efficacy scores. No significant difference in total service use and hospitalization rate.
Leung et al (2004)	92 (home-dwelling, elderly patients)	RCT	Regular monitoring Availability for phone assistance Home visits if needed Referral to community resources	Utilization of hospital services	Reduction in mean total number of hospital bed-days, hospital admissions, attendance at outpatient department in the study group.

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## **2.12 A framework of the nurse-led case management programme**

The nurse-led case management programme is a multidimensional programme that focuses on improving and integrating nursing care. Nurses are in the best position to facilitate the transformation of health care services along a continuum of care from birth to death (Cohen, 1996). The various components of a successful case management programme include understanding the course of the disease, targeting patients who will benefit from intervention, focusing on prevention and resolution, increasing patient compliance through education, providing full care continuity and establishing integrated data management systems for outcome measurements (Powell, 2000). The various roles of the case manager include those of leader, appraiser, health advocate, seamless care provider and agent of change.

The nurse-led case management model in this study was developed according to the analysis of the previous models and the various methodological issues involved in the research of this area. The literature review of the different case management models provides direction and sheds light for the conceptualization of the present study. The study sample was end stage renal failure patients receiving peritoneal dialysis. The study adopts the randomized controlled trial which is considered the gold standard for true experimental design. A true experiment is theoretically able to exert control over most threats to internal validity than

other design such as the quasi-experimental designs. The interventions in the new model of care encompassed discharge planning, patient and family education, comprehensive assessment and continue telephone follow-up. The utilization of a comprehensive model of nurse-led case management ensures that all critical areas are addressed. The outcome measures reported in the previous studies mainly addressed provider-evaluated outcomes and cost. The unique contribution of this study is the original effort in examining the interface between subjective and objective outcomes in relation to the new intervention and defines the nursing contribution in this area. The objective outcomes such as blood chemistry results and symptom occurrence provided substantial evidence on measuring nursing interventions in maintaining the stability of condition during the course of the disease. At the same time, we measured the subjective measures of quality of life and the reported health behaviour adherence of the renal patients. This comprehensive model of nurse-led case management ensures that all essential features of nurse-led case management are addressed as defined by Wong et al (2005). The various dimensions which form the basis of the comprehensive case management protocol included comprehensiveness, continuity, collaboration and coordination.

### **2.13 Summary of literature review**

Ideally, discharge planning begins shortly after admission. ESRF patients requiring PD, in particular, also require special education about the disease,

its effect on lifestyle, possible complications, instructions for home care, dietary and activity instructions, adverse effects and schedule of drug treatment. This literature review illustrates that case management programmes relying on specially trained case managers to implement detailed clinical protocols have shown efficacy in managing chronic medical conditions.

Even though much of the evidence produced in previous studies has demonstrated that the use of case management in hospitalized and post-hospital care brings about positive effects on improved patient health outcomes, patient satisfaction and reduced health care utilization, these studies were unable to show the relationships of the outcome variables. It has not yet been determined whether adherence to treatment is related to improvement in clinical outcomes, or if improved symptom and complication control reduces service utilizations. This literature search has revealed the paucity of studies examining the effectiveness of the nurse case management programmes and identifying the relationship of the outcomes of such approaches for patients with ESRF. To rectify this situation, a comprehensive study quantifying the effectiveness of a nurse-led case management programme in Hong Kong is essential.

This study has targeted several concrete outcomes, which it hopes to achieve. First, through the implementation of a nurse-led case management model in the two selected renal units, the investigator aims to develop a model suitable for local use. The new model will serve as a demonstration project to stir the interest of local researchers, educators and clinicians in exploring how current practice can be changed. The ultimate goal is to improve the long-term quality of care for ESRF patients.

This chapter reviewed literature related to patients with end-stage renal failure who are undergoing peritoneal dialysis, nurse-led case management, and discharge planning. The investigator was able to gain a deeper understanding of, and insights into the various dimensions that have arisen from the case management studies and research methodologies described in the reviewed literature. The literature review enabled the investigator to reflect on the new paradigm of nursing care, providing new insights for developing the design of the current study.

## **CHAPTER 3**

### **METHODS**

This chapter describes the research methods used and includes the following sections: research design, protection of human subjects, study setting, study sample, sampling method, randomization, training of nurse case managers, intervention for each study group, data collection tools, data collection, reliability of case management intervention and data analysis.

#### **3.1 Study design**

The study adopted a randomized control trial (RCT) with a pre-test and post-test study and control group to assess the effectiveness of the nurse-led case management programme for PD patients. The use of a control group, against which any new intervention can be compared, is a prerequisite of sound scientific clinical investigation, with randomization being the preferred method of assigning subjects to control and study groups (Friedman, Furberg & DeMets, 1998). The randomization of subjects acts as a control over most threats to internal validity, providing more conclusive data than non-randomized designs and the strongest evidence for causal relationships (Portney & Watkins, 2000; Chan, Lee, Tsang-Li & Lam, 1999). The RCT is a powerful tool in clinical research, and the sample population tends to be a normal distribution for statistical analysis (Polit & Hungler, 1999). In a randomized controlled trial, a control group is required to ensure that the performance of the study group is the result, solely of the

intervention provided. The control group can either be a placebo trial or a standard treatment group.

In this study, patients in the study group received comprehensive discharge planning and standardized six-week nurse-initiated telephone follow-ups. In contrast, patients in the control group received routine discharge care offered by the renal units in which the study was conducted. The control group patients were informed of the patient-initiated telephone hotline service, given a set of self-help printed materials and reminded to attend the out-patient clinic as scheduled. All subjects received the same routine care during hospitalization as other patients in the unit.

The study was single-blinded. The investigator was not involved in the patients' group assignments. Although this study also intended to blind the patients, the single-blinded method was adopted due to the risk of information exchange between patients in the hospital setting and participation in social functions outside hospital that could affect the blinding process. Random assignment of the subjects was completed by a research assistant, who facilitated the correct intervention for each subject in a specific group. In order to protect the integrity of the trial and its implementation, case managers and ward nurses did not have access to the randomization schedule or the research questionnaires for data collection. The nurse case manager implemented the whole intervention for each of

his/her allocated subjects receiving experimental intervention, including pre-discharge patient education, assessment using the Omaha system (please refer to section 3.82 for details of the Omaha system) and post-discharge telephone interviews. The study group patients alone received pre-discharge assessment and patient education, from which the control group was excluded. The telephone interviews were solely handled by the case manager after the patients were discharged from the hospital. Although this study also intended to blind the patients, this was not possible due to information exchange between patients in the hospital setting and participation in social functions outside the hospital. To help prevent socially biased responses, the investigator responsible for the outcome data collection had no clinical association with the patients, did not belong to the therapeutic team and was blind to the group assignment.

### **3.2 Study setting**

The renal units of two regional general hospitals, the United Christian Hospital, located in Kowloon East, and the Queen Elizabeth Hospital in Central Kowloon, participated in the study. These two hospitals were chosen because of the similarities in their mission of care. The two hospitals are operated by a large corporation, the Hong Kong Hospital Authority, and provide comprehensive services to the regions they each serve. Most importantly for this study, both hospitals are driven by excellence in patient care and were willing to work with the research team to establish evidence for the adoption of the case management approach.

### 3.3 Study sample

The subjects were patients admitted to the renal units of the study hospitals between April 2004 and July 2005.

Inclusion criteria:

- patients on Continuous Ambulatory Peritoneal Dialysis (CAPD) or Continuous Cycle Peritoneal Dialysis (CCPD) with unplanned admissions
- patients who are alert and oriented when admitted
- patients who are able to communicate with the case manager
- patients who have access to a telephone after discharge from the hospital
- patients who live in the hospital service area

Note: Subjects were excluded if they lived outside the hospital service area, as community nursing services would not be available in these areas.

Exclusion Criteria:

Subjects excluded from the study:

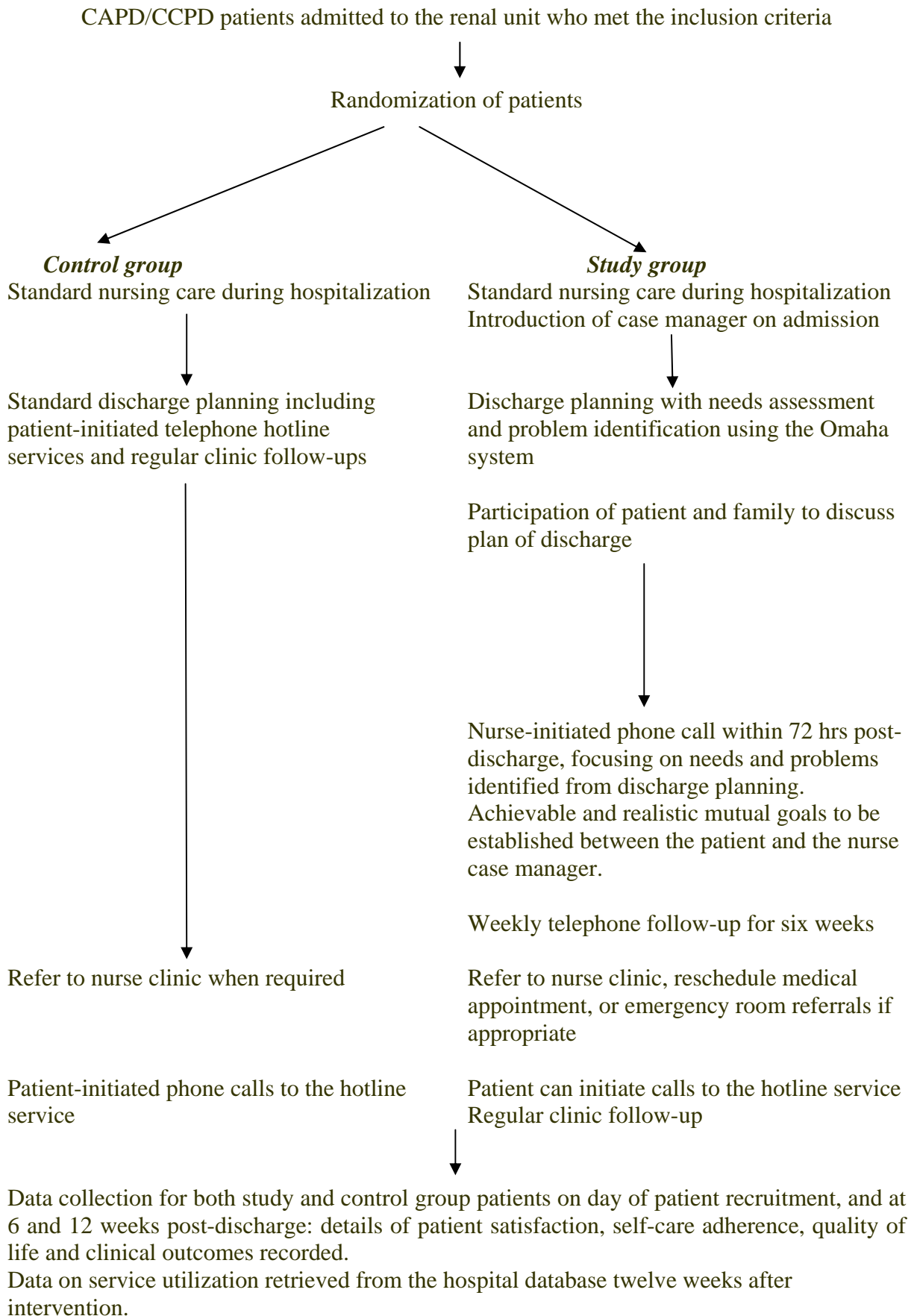
- patients on Intermittent Peritoneal Dialysis or haemodialysis
- patients with planned admissions (e.g., for renal biopsy, blood transfusion, CCPD training, intermittent PD, surgical operation, insertion/change of Tenckhoff catheter)
- patients who could not be contacted by phone at home



- patients who could not communicate effectively with the case manager
- patients residing in elderly-care homes
- patients who lived outside the hospital service area (see note above)

Patients who were admitted to the renal unit of the study hospitals were sequentially recruited for the study. The subjects who met the inclusion criteria and agreed to participate were randomized to the study or control groups. The assignment of patients into the study and control groups was based on a simple randomization method. Fifty sets of random numbers ('0' and '1') were generated from a computer. When a patient arrived and met the inclusion criteria, the recruited patient with a computer number '0' was assigned to the control group, and the patient with a computer number '1' was assigned to the study group. This was done sequentially, producing groups of approximately equal size throughout the study. The flow chart of the study plan is presented in Figure 3.1.

**Figure 3.1 Flow chart of Study Plan**



### **3.4 Protection of human subjects**

Prior to the commencement of data collection, the study was approved by the Hong Kong Polytechnic University, the research ethics committee of the United Christian Hospital and the research ethics committee of Queen Elizabeth Hospital.

Participation in the study was voluntary. The potential subjects were provided with detailed information about the study, including an explanation of the ethical issues (Appendix 3.1), after which, those subjects who were prepared to join the study were asked to sign a consent form (Appendix 3.2). All participants were informed and assured of their right to refuse or withdraw from the study at any time, and that their decisions would not impact medical and nursing care in any way. In addition, the participants were furnished with the name and contact telephone numbers of the investigator and the ward in-charge, to facilitate any subsequent enquiries about the research.

A strict level of patient confidentiality and anonymity was maintained throughout, with access to personal information and data restricted to the research assistant, the investigator, and the supervisor.

### **3.5 Sample size**

When planning for a study, the desired power, acceptable significance level, and expected effect size are determined (Munro, 2005). The effect size is a

measure of the magnitude of difference or correlation amongst the different tests. The larger the effect size, the more likely that it will result in a significant statistical test. As research data were not available at the initial phase, the author used several previous studies to provide reasonable estimates for the mean differences in the calculation of effect size (Portney & Watkins, 2000). Since research data on the quality of life were not available in previous case management studies, the data on disease complications and health-related behaviours in PD patients in Wong, Chung, and Chan's study (2003) were used for effect size estimation. The study showed that renal patients had a 21% improvement rate in terms of symptoms and complications between two renal nurse clinic visits. There was no previous study using case management intervention on end-stage patients undergoing PD; hence, the investigator used the minimal effect size to calculate the sample size in this study. When the mean differences could not be computed directly, the following conventions were used to assign value to the effect size index: small  $d=.20$ , medium  $d=.50$ , and large  $d=0.80$  (Portney & Wilkins, 2000, p.708). Although it was mentioned from the previous literature review that case management programmes had some moderate to strong effects on biophysical outcomes, the effect size of the estimates was set at small (0.30) as this was a new area of enquiry in investigating the efficacy of the nurse-led case management programme for end-stage renal failure patients and, as such, there were only a few researches focused on this area. Moreover, it is usually more prudent to be

conservative in effect size estimates so that a large sample might be recruited.

According to this finding and based on one-way repeated measures, an estimated sample size of 94 (47 case and 47 control), which was derived using the computer software, nQuery Advisor (Elashoff, 2000), was considered adequate to demonstrate the effects of the experimental interventions. This design achieved 81% power to test between-group (study and control) effect with a 5% significance level and 0.29 effect size. For within-group (repeated measures, three times) effects, the design achieved 79% power with a 5% significance level and 0.32 effect size. For the interaction (group x time) effect, it achieved 79% power with a 5% significance level and 0.32 effect size. The study estimated a 20% drop out rate, the sample size of 112 subjects (56 study and 56 control) was needed for the study. This sample size is realistic for data collection, since the average number of emergency admissions is approximately 30 patients per month for each of the hospitals included in the study.

### **3.6 Interventions**

The design of interventions was based on a comprehensive framework involving both the patients and their families. The interventions for the study group included the participation of patients and family members to discuss the discharge plan, a pre-discharge needs assessment using the Omaha system (please refer to section 3.82), and an individualized

education programme conducted by the case manager. The involvement of the family highlighted the need for family members to be fully prepared to support the patient and perform their role as caregivers in the recovery process.

In the advanced care model, the case manager is pivotal in identifying and evaluating patient and family preparedness for the successful discharge of a patient (Lowenstein & Hoff, 1994). An individualized and comprehensive education programme was provided to the patients and their families close to the day of discharge (please refer to section 3.9.1). Lauver, Gross, Ruff & Wells (2004) classified the above intervention as ‘patient-centred interventions’, since a patient is assessed on selected characteristics; the approach is chosen to address characteristics of the patient’s experiences, and the process is responsive to the patient’s characteristics. Each study group patient received the first phone call within 72 hours post discharge and a weekly phone call for six weeks (please refer to section 3.7.2). During the telephone interviews, the case manager engaged with the patient to establish achievable and realistic mutual goals for best patient and clinical outcomes. The ultimate goal of the intervention was to provide formal, supportive, patient-centred care in the post-acute phase after hospitalization. The mutual objectives established between the case manager and the patient worked as a mechanism for monitoring behavioural change and a method to evaluate individual change in response to intervention (Stuifbergen, Becker, Timmerman & Kullberg, 2003). The patient could also be referred to

community nurses, the emergency room, ward follow-up and the nurse clinic when unmet health needs were identified in the telephone follow-ups. The effective and successful discharges, as described by Anthony & Hudson-Barr (1998), consisted of continuity of care and common understanding of the agreed objectives. These two components are crucial and essential to differentiate standardized care and case management intervention.

To ensure consistency of practices among the case managers, the case managers received special training prior to commencement of the study (please refer to section 3.6.2).

### **3.6.1 Protocol development**

The importance of protocols and guidelines in case management cannot be underestimated. A comprehensive protocol is necessary to avoid confusion among staff involved and to support the collaborative nature of the case management system. Protocol reduces variations in practice, assists in staff decision making and eliminates inappropriate procedures (Flarey & Blancett, 1996). A set of protocols and guidelines was developed for the study. The protocol development was based on a review of current published literature and expert inputs contributed by the renal nurses and the investigator. The essential four components, derived from case management, encompassed continuity, collaboration,

comprehensiveness and coordination (Wong, Mok, Chan & Tsang 2005), (Appendix 3.3). The complete sets of protocols were then validated with the help of nurses and physicians specializing in renal care. The various protocols used included a checklist for patient and family education before discharge, initial and subsequent telephone interview guides, criteria for referral to community nurses or medical social workers, guidelines to determine follow-up at the nurse's or doctor's clinic and documentation of telephone interviews (Appendices 3.4, 3.5, and 3.6). A series of training sessions was organized for the nursing staff who assumed the role of case managers to ensure familiarization and consistency whilst working with the newly developed study protocols.

### **3.6.2 Selection and training of nurse case managers**

In preparation for the introduction of the case management programme, it was essential to select and train nurse case managers and to develop the case management protocols that were crucial components of the intervention programme.

#### **3.6.2.1 Specific qualifications for case managers**

To ensure quality service for patients involved in the study, only skilled nurses with an average of 10 years' experience working in the renal unit were recruited as case managers for the study. In addition, the case managers gain qualifications at graduate or post-graduate level in order to



deal with the complex patients' problems and the demand of the health care system. The case manager selection criteria were as follows:

- Sound clinical knowledge in the renal field
- Experience in health and nursing assessment – able to conduct a comprehensive and holistic health assessment whilst focusing on a patient's particular medical and health concerns
- Well-developed health education skills
- Well-developed communication and negotiation skills
- Ability to work as a member of a multidisciplinary team
- Ability to act as the patient's advocate
- Knowledge of outcomes management

(Egan, Clavarino, Burrige, Teuwen & White, 2002).

### **3.6.2.2 Training of case managers**

All the case managers were required to undergo a series of training programmes, covering case management theories and models, discharge planning and continuity of care, telephone communication and interview skills and the key elements of the case management approach, i.e., continuity, coordination, collaboration and comprehensiveness (Wong et al., 2005) (Appendix 3.7). The initial training series included self-directed learning, group discussions and briefing sessions organized by the investigator.

The second phase of the training focused on the specific nursing skills required in providing a holistic health assessment. A case management programme intervention addresses the continuity of care through pre-discharge assessment. In this instant, the Omaha system was chosen to assess patients' specific needs after discharge. The system was originally derived inductively from the practice of community health nurses in the USA in 1975. The system is a research-based, comprehensive classification scheme designed to generate meaningful data following the documentation of client care. The classification scheme has been extensively field-tested and is able to meet the needs of a variety of health care disciplines. It encompasses four dimensions, including environmental, psychosocial, physiological and health-related behaviours (Martins, 2005). For this study, the tool was revised to include a subscale, addressing items that were specifically related to renal patients receiving PD (Appendix 3.8). The revised tool was validated by nurse case managers, unit managers and nurse specialists in terms of the relevance and representativeness on the newly developed items in the subscale. In order to ensure the effective and competent use of the scale by the case managers, a training session on how to use the Omaha system was provided by the investigator.

The third phase involved discussions with the case managers on the proper use of clinical protocols and guidelines. The case managers were briefed and invited to provide feedback on the different types of research protocols. It was important to have a group of well-motivated renal nurses, working

together in the production of the working guidelines, to enable their active participation and to cultivate their sense of 'ownership' of the research project. The implementation of telephone interviews with detailed clinical protocols was shown to be efficient in dealing with patients with chronic medical conditions (DeBusk, West, Miller & Taylor, 1999).

The final phase of the training focused mostly on telephone interview skills. The protocol-driven phone call ensured that the patients' needs and concerns were well addressed. The content of communication included telephone triage, checking on adherence to diet, fluid intake, medication and PD regimen, care of exit site, self-monitoring of symptoms and complications, assessment of psychosocial status, health teaching and counselling and referral to appropriate health care professionals when necessary. Although the guidelines were developed to monitor clinical practice, their effectiveness ultimately depended on how well they were implemented and how the clinicians utilized them (Ramsay, Campbell, Cantarovich, Catto, Cody, Daly, Delcroix, Edward, Grimshaw, vanHamersvelt, Henderson, Khan, Koene, Papadimitrou, Ritz, Tsakiris & MacLeod, 2000). Given these expectations, various measures were taken to ensure safe and reliable advice and management options were provided by the case managers. First, the case managers were trained by the investigator, renal unit nurse managers, and nurse specialist using pilot cases to ensure that the protocols were applied appropriately and consistently. The audiotapes of the telephone interviews and written

documentation were reviewed independently by the investigator, nurse specialists and unit managers. The reviewers assessed the appropriateness of the advice and decided whether the nurse-patient interaction would bring about positive health outcomes. Individual written and verbal feedback was provided to the case managers for improvement. Review meetings were organized with sample cases selected for discussions among the case managers, unit managers and the investigators. During the meetings, team members sought clarification and raised questions on patients' conditions and the related care provided. The criteria used for clinical decision making were clarified and discussed in cases of discrepancy. At least 90% agreement amongst the team members had to be reached before the main study could be launched.

### **3.6.2.3 Reliability of case managers**

To ensure that the advice and intervention quality given by the case managers to the patients was consistent and reliable, the following measures were taken.

First, as mentioned in the previous section, the case managers were required to undergo special training using pseudo patients for telephone counselling skills and execution of the case management protocols. Second, the intervention protocol was tested in the pilot study using 5% of the intended sample size (i.e., six cases). The telephone conversations between the

patients and the case managers were audiotaped. In the pilot study, the investigator, nurse unit manager, and renal physicians reviewed the tapes to ensure the quality and effectiveness of the nurse-patient interaction. The inter-rater reliability (at least 80% agreement) was established in the pilot study before the commencement of the main study. Thirdly, the audiotapes were selected randomly for quality assurance by the investigator during the course of the main study. The documentations on interventions including the telephone interview records, Omaha system, pre-discharge education and referrals to the health care professionals were inspected by the investigator at regular intervals to determine the reliability of the interventions. Feedback and comments were provided to individual case managers when required. Lastly, the case managers and invited members of the multidisciplinary team, including the physician and social worker, met periodically to discuss the cases. In the case conferences, team members sought clarification and discussed patients' conditions and the related care being provided. These strategies served as the process evaluation to monitor the operation of the case management interventions.

### **3.7 Features of the nurse-led case management programme**

#### **3.7.1 Pre-discharge assessment and patient education**

The intervention period started at hospital admission and continued until six weeks after discharge. Following the patient's admission, he/she would be introduced to his/her own case manager. All patients in the renal unit

received standard hospital care services during hospitalization. Prior to discharge, the case manager conducted a comprehensive assessment of the patient's physical, social, cognitive and emotional needs, based on the Omaha system. The information collected included the patient's health history and any recently acquired medical conditions, social support, social functioning and mental health. The case manager discussed the discharge plan with the patient and family, according to the assessment results and the patient's existing difficulties in self-care. Throughout the discharge process, psychosocial health assessment ran parallel with the medical diagnosis to enable a holistic approach and to ensure that appropriate referrals were made. Moreover, the case manager was required to collaborate with physicians to design an individualized patient management plan within the protocol.

The comprehensive education programme for patients and families consisted of an exercise regimen, medication, fluid and diet adherence behaviours, technical procedures for CAPD, avoidance of infection and ordering of medical equipment and supplies. Although all the patients had received intensive training prior to commencement of the regimen, the pre-discharge education programme was provided to strengthen and consolidate the past learning experiences, clarify misconceptions and to optimize health outcomes.

### **3.7.2 Post-discharge, nurse-initiated telephone calls**

The main responsibility of the case manager was to ensure a smooth transition from hospital to home and to anticipate problems that may arise upon a patient's discharge. The nurse case manager contacted the patients by telephone within 72 hours after discharge to assess their status and provided advice during the critical period of transition from hospital to home. Young's study (1990) stated that telephone calls to patients within two days post-discharge were able to answer questions, provide reassurance and help relieve anxiety in patients, their families and other caregivers. Subsequent telephone follow-ups were conducted once every week over the next five to six weeks. Brooten and Naylor (1995) revealed that telephone follow-ups were very effective up to six weeks post-discharge, but that their effectiveness diminished over the subsequent 6-12 weeks after discharge. This study used the research of Young and Brooten to guide the design of the intervention scheme.

#### **Protocol driven telephone contacts**

The content of the telephone call was guided by the protocol and the specific problems identified in the Omaha system. In addition, the case manager identified possible problems that could have arisen in the areas of environmental, physiological, psychosocial and health-related behaviours. The case manager and the patient then developed mutual objectives with a realistic action plan incorporating the patient's preferences. Within the

chronic health care context, negotiated care has the potential to humanize contemporary medical technologies by responding to clients' experiences of illness and integrating the demands of therapeutic regimens into their own lifestyles (Polaschek, 2003b). To develop patient empowerment, case management intervention concerns patients' autonomy and responding to their needs as persons living on dialysis. The patients were reassured that they could contact the case manager as needed, should they require further assistance, or could call the hotline service when the case manager was not available at any particular time. In the follow-up call, the nurse checked and reinforced the patient's behaviours in achieving the objectives, identified new and potential complications and needs and maintained a sustained relationship with the patient. During each telephone call, the case manager would discuss with the patient, the problems the latter encountered after returning home, and if necessary, the case manager would make an appropriate referral. The initial call required more time as the nurse was required to focus on the specific problems and the health behaviour changes in the patient. The nurse normally spent 20-30 minutes in the initial telephone contact with the patient. The duration of the follow-up calls varied, depending on the special needs of the patients. Each of the follow-up calls lasted for 7-15 minutes and typically focused on the achievement of mutual objectives and the reinforcement of health-related behaviours. The overall duration of the phone call was based on the comprehensive fulfilment of the protocol.



### **Management options**

There were several possible management disposal options after the telephone calls by the case manager. Decisions on management options were underpinned by the nurse's professional judgement and the developed objective referral criteria. The options included referral to the community nurse for home visit; referral to the renal nurse clinics or wards for follow-up; referral to the renal doctor's clinic for advanced assessment, investigation, and medical treatment; and lastly, referral to the emergency department for urgent treatments.

#### **3.7.3 Home visits**

Patients were referred to the Community Nursing Services (CNS) when they required physical assessment, instruction on techniques in providing self-peritoneal dialysis, and drug compliance monitoring where the telephone interviews did little to resolve the situation. Scheduled home visits were conducted by the community nurses on referrals received from the case managers for the study group patients. The control group patients did not receive community nursing services. The case manager completed the physical, environmental, emotional and psychosocial assessment, and identified the critical items on which the visiting nurse should focus. The community nurse provided related education and consultation according to the assessment and referral documents. The community nurses then used their judgement to define the frequency, intensity, and focus of contacts to

meet the patients' and caregivers' needs. The community nurses reported to the case manager on the conditions of the referred clients after each home visit.

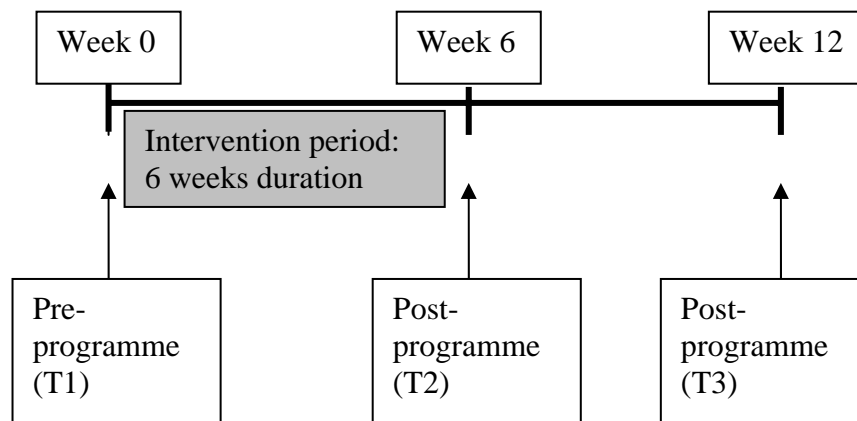
### **3.8 Data collection**

Data were collected at three time intervals. The outcome data collected at T1 (upon discharge), which provided the baseline for comparison. The data collected at T2 (6 weeks post-discharge, after the completion of case management intervention) was used for comparison with T1 data to determine the immediate intervention effects, and T3 data (12 weeks post-discharge) were used to detect the sustaining effects of the case management intervention (Figure 3.2). The six-week telephone intervention was based on Brooten's model of telephone follow-up on discharged patients (please refer to section 3.7.2). Other than the outcome data, information, including patients' demographic characteristics, comorbidities, existing complications, duration of PD regimen, financial situation and availability of family and social support were collected at T1 (Appendix 4.7).

**Figure 3.2**

Diagram showing the six-week programme and assessment schedule of the clinical trial

**The Case Management Programme for the study group**



‘ T ‘ represents the clinical observation/data collection schedule.

There were two major sources of outcome data: subjective and objective. Clinical outcomes classified as objective data included blood chemistry results, utilization of health care services and symptom control. Patient-related data were subjective data that included the quality of life, level of adherence to treatment and patient satisfaction. These two approaches complemented each other in providing a comprehensive assessment of the case management programme in improving patients’ well-being. Patient records, chart review, and patient interviews were the means of data collection in the study. Two major categories of outcomes were evaluated after the implementation of the case management programme.

### **3.8.1 Patient-related outcomes**

#### **3.8.1.1 Self-care adherence**

Patients' adherence to their fluid, diet, and dialysis regimen was measured. The dialysis, diet and fluid non-adherence questionnaire (DDFQ) was used to evaluate the effectiveness of the nurse-led case management programme in improving patients' level of adherence to the regimen (Vlaminck, Maes, Jacobs, Reyntjens & Evers, 2001). The DDFQ questionnaire was created in Belgium and is a self-report instrument designed to measure non-adherence behaviour to diet and fluid guidelines among patients treated with hospital-based haemodialysis. Construct and criterion validity were established using the score results, which were compared with the biochemical data for the measure of non-adherence. The study showed a weak to moderate, positive, significant correlation between diet non-adherence behaviour and the serum levels of potassium, phosphate, and serum albumin in the scale.

In order to capture a comprehensive assessment on treatment adherence of PD patients, two additional domains were included in the existing questionnaire, namely non-adherence to medications and PD regimen. To better facilitate the choice of answers that would best represent the patients' health care behaviour, a protocol was developed, explaining in detail the various definitions in relation to the different levels of non-adherence to diet, fluid, medication and PD regimen (Appendix 3.9). The patients were

asked to choose the correct answers with reference to the protocol. The subjects were advised to read the protocol, and the data collector explained the definitions to them and answered any queries.

The instrument was translated and validated for relevance in the local context and was tested for reliability. The details on instrument validation will be discussed in Chapters 4 and 5.

### **3.8.1.2 Quality of life**

The literature review of published studies on the quality of life of end-stage renal disease patients indicates that, although a variety of generic and disease-specific instruments have been developed and applied to the assessment of the quality of life of renal patients, few have been adequately tested. The short form of the Kidney Disease Quality of Life (KDQOL-SF), which is comprised of 80 items, was used in this study. The instrument is a self-report questionnaire that was developed in the USA specifically for individuals with kidney disease who are receiving dialysis (Hays, Kallich, Mapes, Coons & Carter, 1994). It includes a short-form 36-item, general health survey and a range of scales targets the particular concerns of patients on dialysis. Except for quality of social interaction, all kidney disease targeted measures exceeded 0.70 for internal consistency reliability estimates (Martin & Thompson, 2000). The instrument was chosen because it provides a comprehensive assessment of both generic and

kidney-disease targeted areas of quality of life for dialysis patients. Its internal consistency reliability exceeded 0.8 for 20 subscales, except for the scale of quality of social interaction (Hays, Kallich, Mapes, Coons & Carter, 1994). Cagney, Wu, Fink, Jenckes, Meyer, Bass and Powe (2000) carried out a formal literature review of Quality of Life instruments used in ESRF patients, from which it was concluded that a disease-specific measure was essential, as generic measures lack the specificity to examine the quality of life among renal patients. The KDQOL-SF offers a well-tested alternative and is considered the most reliable instrument for measuring the quality of life in the ESRF population. Other authors rated KDQOL as valid and reliable, and this rating has been supported by various studies in America and Europe (Valderrabano, Jofre & Lopez-Gomez, 2001).

The instrument was translated into Chinese and was found to be valid for Chinese patients. The internal consistency ranged from 0.71-0.95 for each of the 11 kidney disease targeted scales, and from 0.72-0.94 for the eight general health scales of the SF-36. The translated version also indicated that the level of difficulty in completing the questionnaire was acceptable, as 79% of the sample patients were able to complete the questionnaire on their own (Li, 1998). Please refer to section 4.2.1.1 for details of translation and validation process of the Chinese version of the scale.

### **3.8.1.3 Patient satisfaction**

Regarding the tools for measurement of patients' experiences and satisfaction, Thomas and Bond (1996) completed the literature review on studies measuring patients' satisfaction with their nursing care. The findings revealed that most studies were lacking in conceptual and methodological rigour. No study in their review examined the test-retest reliability of an instrument. The authors suggested that some valid and reliable measures were needed to assess patients' experience and satisfaction with nursing in an acute hospital. Urden (2002) argued that published reports on patient satisfaction with nursing care were in huge variation and were without standardization. An extensive literature review conducted by Merkouris, Ifantopoulos, Lanara and Lemonidou (1999) on patient satisfaction and nursing care revealed that there were only three instruments that gave a satisfactory description or which included an evaluation of the psychometric properties. These were the Abdellah-Levine instrument which was developed in 1964, the Risser Patient Satisfaction Instrument (PSI) in 1975 and the La Monica-Oberst Patient Satisfaction Scale (LOPSS) in 1986.

The La Monica-Oberst Patient Satisfaction Scale was developed to measure hospitalized patients' satisfaction with nursing care (LaMonica, Oberst, Madea & Wolf, 1986). The scale was developed, based on three dimensions, namely technical, trusting relationship, and education relationship. The items were revised and expanded from the Risser scale (Risser, 1975) to

reflect nursing behaviours expected in an acute care setting. The testing procedure included content validation involving both clinicians and patients. A three-factor matrix explaining 93.7% of the total variance was derived from the factor analysis procedures. The high internal consistency has a reported Cronbach's alpha of 0.92 for the total instrument in successive testing, and for the three subscales was more than 0.89.

The LOPSS was further revised by Munro, Jacobsen and Brooten in 1994. The modified version of the LOPSS was used in this study because of its simplicity, and the scale items focused on interpersonal support of nurses to patients rather than on the technical procedures. The revised scale was shortened to 28 items, of which 14 were negatively phrased. The scale also measures the satisfaction of patients toward accessibility of care, information giving, and professional competence of nursing services. The instrument has been tested and used in a number of studies with different client groups, and has a reported high internal consistency with coefficient alpha of  $>0.94$  for the subscales. The instrument was translated into Chinese, validated for relevance in the local context, and tested for reliability. The details of the instrument validation are discussed in Chapters 4 and 5.



### **3.8.2 Clinical outcomes**

#### **3.8.2.1 Symptom and complication control**

The use of blood chemistry results can serve as a means of validation for self-reporting adherence in health behaviours. This includes examination of blood for urea, creatinine, sodium, potassium, phosphate, calcium, haemoglobin and albumin. Among these biomarkers, creatinine serves as a measure of dialysis adequacy (Thomas, 2002). The information was retrieved from the hospital computer system at the three time intervals, for comparison. Other than blood chemistry results, clinical information on symptom control, such as self-reported exit site condition, peritonitis, percentage body weight gain and visual examination of oedema, using a rating scale, was collected by the interviewer during the interviews with patients. The items were developed from literature review and the expert inputs from a panel consisted of ten renal nurses and a physician. The data served as objective information for improved physical health. The documentation of clinical data was standardized with the inter-rater reliability established at a minimum of 0.8.

#### **3.8.2.2 Health service utilization**

The recorded health service utilization included the number of hospitalizations, length of stay, and number of unscheduled acute care visits to emergency departments. The data were extracted from the hospital

computer systems 12 weeks before and 12 weeks after intervention from the two groups of subjects.

### **3.9 Data analysis**

Information collected from the instruments were coded and entered into a central database. Standard procedures to check coding and data entry error were implemented. The analyses were divided into two phases. In phase one, descriptive statistics were generated for the demographic variables (e.g., age, gender, social support and comorbid conditions) and were categorized, compared and reported. In phase two, a parametric test, such as the General Linear Model (GLM) with repeated measures, was employed to determine between-group (study vs. control), within-group (time), and interaction (group x time) effects. If the data were heavily skewed and not normally distributed, a non-parametric test, the Friedman test, was used to address the within-group effects. When significant ( $p < 0.05$ ) differences were found, a post-hoc test was used to determine which of the pairs (T1 vs. T2, T1 vs. T3) indicated the differences. A paired sample t-test and Wilcoxon signed rank test were used in the pairwise comparisons for continuous and ordinal data, respectively. The correlations were used to quantify the relationship among all continuous/ordinal data and the Chi-square test was used to examine the associations between the demographic data and the categorical data. For binary data, the McNemar test ( $\chi^2$ ) and Cochran's Q test were used to test the differences for two or three related groups, respectively. The regression model was used to

associate the nurse-led case management interventions (independent variables) with the different dependent variables. The missing values in the data set were replaced, either through the last observation carried forward technique, or through group means. To avoid type 1 error, the statistical significance was set at two-tailed  $p < 0.05$ .

All the data were analysed using the Statistical Package for Social Sciences (SPSS) 12.0 for Windows (SPSS Inc, Chicago, IL).

### **3.10 Summary**

This chapter described the design of the study, the interventions, the selection and training of case managers and the quality control procedures. The origins of the samples and the justifications for the sample size were explained. An introduction to the original instruments used in this study and their corresponding contents were also presented.

## **CHAPTER 4**

### **THE PILOT STUDY**

This chapter details the results of the pilot study and is divided into two parts. The first part describes the methods used to validate the research instruments, which include the procedures, study sample, criteria for psychometric evaluation and results of the field tests. The second part of the chapter reports the pilot test results for the main study.

#### **4.1 Aims of the pilot study**

The aims of the pilot study were:

1. To test the reproducibility and feasibility of all instruments used in the study;
2. To estimate the validity and reliability of the research instruments;
3. To test the feasibility of the data collection procedure;
4. To note possible problems in the administration of the questionnaires.

#### **4.2 Psychometric properties of questionnaires**

The questions and constructs adopted for use in the outcome measures have been tested for validity and reliability in various studies and populations, as described previously in Chapter 3. However, the psychometric properties of the newly developed or revised instruments required further testing in the

pilot study to ensure their validity and reliability before commencing the main study.

Five research instruments were tested for the measurement of quality of life, treatment adherence, patient satisfaction, personal demographic information and symptoms and complications control. The first three instruments, developed overseas, include the Kidney Disease Quality-of-Life Short Form (KDQOL-SF), the Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ) and the revised version of the La Monica-Oberst Patient Satisfaction Scale (LOPSS). The instrument used to measure symptoms and complication control was developed by the investigator. The validation study mainly collected evidence for content validity. Criterion and construct validation were also conducted for the DDFQ. The results of these evaluations provided recommendations for the necessary modification and refinement of the instruments.

#### **4.2.1 The Kidney Disease Quality of Life**

The Kidney Disease Quality-of-Life Questionnaire (KDQOL) was developed by Hays, Kallich, Mapes, Coons and Carter in 1994 (Appendix 4.1). The instrument provides a comprehensive assessment of both generic and kidney-disease targeted areas of quality of life for dialysis patients. Its internal consistency reliability exceeded 0.8 for 20 subscales, except for the scale of quality of social interaction. Cagney, Wu, Fink, Jenckes, Meyer,

Bass and Powe (2000) carried out a formal literature review of Quality of Life instruments used in ESRF patients, from which it was concluded that a disease-specific measure was essential because generic measures lack the specificity to examine the quality of life among renal patients. The KDQOL offers well-tested alternatives and is considered as the most reliable instrument for measuring the quality of life in the ESRF population. Other authors rated KDQOL as valid and reliable, and have been supported by various studies in America and Europe (Valderrabano, Jofre & Lopez-Gomez, 2001).

#### **4.2.1.1 Validity test**

The present study used the short form (version 1.3) of the KDQOL instrument (KDQOL-SF) and is comprised of 80 items. The KDQOL-SF was translated from English into Chinese by Li (1998) (Appendix 4.2). Specifically, the questionnaire was first translated into Chinese and was then back-translated into English by independent translators. The original and the back-translated versions were compared to examine their equivalence in terms of meaning and concepts. Content validation of the Chinese version was conducted by both the group of patients and the expert review panel, comprised of health care professionals. The results of the content analysis revealed that the majority of the participants agreed that the kidney disease targeted scales and items in the original version were comprehensive and culturally relevant in measuring the quality of life of Hong Kong Chinese ESRF patients. Some of the Chinese expressions and wordings were

revised to improve understanding, following suggestions by the professional panel members and the renal patients, themselves. The Content Validity Index (CVI) for item relevance ranged from 0.63 to 1.00 for the patients group, and from 0.58 to 1.00 for the health care professionals. The CVI for item comprehensiveness ranged from 0.86 to 1.00 for the patients group, and from 0.79 to 1.00 for the health care professionals (Li, 1998). These indices met the required average minimum index of 0.80 (Grant & Davis, 1997) for a new content valid instrument.

During the content validation process, some patients reported that “swelling of ankles”, “aching bones” and “abnormal blood pressure” were frequent symptoms, which should be included in the existing list under the category, “The extent of symptoms that bothered the patients”. Other items, such as “your ability to participate in leisure activities or hobbies” were added to the subscale, “Effects of Kidney Disease on Daily Life”. Lastly, some health professionals commented on the subscale on social support and stated that a good relationship with one’s family does not necessarily imply a good relationship with friends, so they suggested splitting the term “family and friends” into two separate statements under the subscale (Li, 1998). Overall, the Chinese version of the KDQOL-SF consisted of 86 items instead of 80 items on the original English short form version.

#### **4.2.1.2 Reliability test**

A reliable test is one that is consistent and free from error. Reliability can be conceptualized as reproducibility or dependability (Portney & Watkins, 2000). A reliable instrument performs with consistency under set conditions.

##### *Internal consistency*

The internal consistency of the constructs in the questionnaire was determined using Cronbach's alpha coefficient. Through this, all the multi-item scales in KDQOL-SF were found to be acceptable for each measure (range was from 0.71-0.95). Further research was carried out to examine the test-retest and inter-rater reliability and provide a comprehensive testing of the scale (Li, 1998).

##### *Test-retest reliability*

The test-retest reliability was conducted by the investigator. The reliability test employed the Intra-class Correlation (ICC) for multiple categorical responses. Among the 15 patients who participated in the pilot study, 14 were called back after one week to complete the questionnaire. The responses given by the patients in the two tests were used to establish the test-retest reliability of the questionnaire. The one week interval was chosen because the time span was far apart enough to avoid the memory effects, but close enough to avoid changes in patients' quality of life over



time. The ICC form (2,  $k$ ) was calculated to be 0.81 to 0.96 for the different domains in the scale. Model 2 of ICC assumes that the ‘test’ and ‘retest’ occasions are representatives of other testing occasions within the same population, with more than one rater (Rankin & Strokes, 1998). All the results were considered significantly correlated ( $p < 0.001$ ). Table 4.1 shows the test-retest reliability of the scale.

**Table 4.1 Test-retest reliability of KDQOL-SF**

	Intra-class correlation coefficient		
	ICC	95% CI	p
<b>Kidney disease-targeted scales</b>			
Symptoms/problems	0.85	0.83-0.90	<0.001
Effects of kidney disease on life	0.91	0.86-0.95	<0.001
Burden of kidney disease	0.88	0.80-0.92	<0.001
Work status	0.89	0.82-0.93	<0.001
Cognitive function	0.95	0.92-0.87	<0.001
Quality of social interaction	0.81	0.75-0.85	<0.001
Sexual function	0.96	0.91-0.98	<0.001
Sleep	0.92	0.88-0.95	<0.001
Social support	0.87	0.82-0.90	<0.001
Dialysis staff encouragement	0.95	0.92-0.97	<0.001
Patient satisfaction	0.93	0.90-0.97	<0.001
<b>SF36 health survey scales</b>			
Physical functioning	0.83	0.78-0.86	<0.001
Role -physical	0.81	0.75-0.84	<0.001
Pain	0.85	0.80-0.91	<0.001
General health perceptions	0.90	0.85-0.93	<0.001
Emotional well-being	0.82	0.76-0.88	<0.001
Role-emotional	0.91	0.85-0.96	<0.001
Social function	0.86	0.80-0.91	<0.001
Energy/fatigue	0.82	0.78-0.84	<0.001
<b>Overall health rating</b>	0.88	0.82-0.91	<0.001

### *Inter-rater reliability*

Inter-rater reliability concerns variation among different raters who measured the same group of subjects. The test was to establish the stability of the measurement and to ensure consistency of measurement between raters. The ICC form (2,  $k$ ) was selected to generalize the results so that they could be interpreted and applied in other studies using a number of raters (Rankin & Strokes, 1998). The inter-rater reliability test was conducted among 10 raters, inclusive of the investigator and nine hospital nurses. The results showed significant agreement among the 10 raters, with ICC=0.94 (95% C.I. 0.90-0.97),  $p<0.001$ .

The psychometric test provided a comprehensive assessment of the clinical outcome when measuring the quality of life for dialysis patients. The revised KDQOL-SF Chinese version, after content validation and estimates of internal consistency, inter-rater and test-retest reliability, was recommended for use in Hong Kong as a Quality of Life outcome measure.

#### **4.2.2 La Monica-Oberst Patient Satisfaction Scale (LOPSS revised version)**

The La Monica-Oberst Patient Satisfaction Scale (revised version) was revised by Munro, Jacobsen, and Brooten in 1994 (Appendix 4.3). The revised scale consisted of 28 items with 14 items reversely phrased.

#### **4.2.2.1 Validity test**

The instrument was translated and back-translated following the techniques described by Bracken and Barona (1991), making sure that the major ideas of the original scale were retained (Appendix 4.4). The twenty-eight item scale was first translated by the investigator from English to Chinese then another translator was asked to blindly complete the back translation. The original English version and the retranslated English version were compared to determine the equivalence of meaning of each item. The identified discrepancies were discussed and negotiated by the investigator and the back-translator. The expert panel was established to review the translated scale and examine the content validity.

The panel consisted of five members (two renal nurse specialists, one university teaching staff, one renal unit nurse manager, and one physician) who were invited to make direct comparison between the original version and the translated version of the scale. The panel members indicated that a few items in the translated Chinese version need further refinement. Examples of translated phrases that needed further revision are: ‘neglects to be sure I understand the importance of my treatments’ and ‘acts like I cannot understand the medical explanation of my illnesses’. As such, these translated phrases were further revised and reviewed by the panel members to ensure that the Chinese version was accurate and true to the original thought.

In addition, they were required to determine the content-related evidence of the scale, including the relevance and representativeness of the instrument in relation to the study's objectives (Chan & Lee, 1999). The panel members were requested to indicate the relevance of each item in the questionnaire to their respective theoretical domain on a 4-point Likert Scale (ranging from 'irrelevant' to 'relevant'), and to provide additional comments if they found an item irrelevant. Agreement among the five experts on the constructs in the questionnaire was assessed using the CVI.

The five panel members determined that the scale is relevant and appropriately measures patients' satisfaction in various aspects. The first domain consisted of 14 items on interpersonal support, and good impression yielded the CVI of 0.92. The second domain contained 14 items which determine the level of dissatisfaction by the clients with regard to hospital nurses. The CVI of the second domain was 0.84. There were a few items in the scale that the panel members considered irrelevant to the local context of nurse-led case management. These items include, 'the nurse is impatient', 'the nurse is not attentive as he/she should be', 'the nurse does not return to do things for me as he/she promised', and 'the nurse talks down to me'. Most of the panel members considered these items as being solely measures of evaluating the personality of the nurse and not aimed at examining the overall case management services. These items were therefore suggested to be removed from the subscale. Since some of the items were deleted from the original version, further validity testing of the

revised scale was conducted after the main study. The results of this are discussed in Chapter 5.

#### **4.2.2.2 Reliability tests**

##### *Internal consistency*

The internal consistency of the two constructs in the questionnaire was likewise examined using Cronbach's alpha coefficients. The coefficient alpha for the entire scale was high (0.91). The alphas for the subscale 'interpersonal support/good impression' and 'dissatisfaction' were 0.94 and 0.76, respectively. The Cronbach's alpha for these subscales demonstrated an acceptable measure of internal consistency reliability of the scale.

##### *Test-retest reliability*

The test-retest reliability was calculated using the ICC form (2,  $k$ ). Eleven renal patients were recruited for the test-retest reliability check. The patients were requested to complete the same questionnaire seven days after the first trial to determine the consistency of the scale over time. The responses given by the patients in the two tests were used to establish the test-retest reliability of the questionnaire. The ICC between days was 0.97 (95% C.I. 0.89-0.99). All the results were considered significantly correlated ( $p < 0.001$ ).

### *Inter-rater reliability*

The ICC form (2,  $k$ ) was selected to determine the inter-rater reliability because the purpose was to generalize the results so that they may be interpreted and applied in other studies (Portney & Watkins, 2000). The inter-rater reliability test was conducted among 10 raters, inclusive of the investigator and nine hospital nurses. The results showed significant agreement among the 10 raters with ICC=0.94 (95% C.I. 0.89-0.99) and  $p<0.001$ .

The psychometric tests provided a comprehensive assessment of the outcome measures of patients' satisfaction in relation to the performance of the case managers and the facilities. After content validation and estimates of internal consistency, inter-rater, and test-retest reliability, the revised Chinese version of the LOPSS was recommended for use in this study as a tool for the measurement of quality of care.

### **4.2.3 Dialysis diet and fluid non-adherence questionnaire**

The dialysis diet and fluid non-adherence questionnaire (DDFQ) was developed by Vlaminck, Maes, Jacobs, Reyntjens and Evers (2003) (Appendix 4.5). The original scale consisted of four questions measuring the number of days and levels of non-adherence to the diet and fluid regimen based on patients' reports in the last 14 days.

#### **4.2.3.1 Validity test**

The instrument was translated into Chinese for local use. A panel of five experts was invited to examine the relevance and representativeness of the items with reference to the study's aims and objectives. All five experts considered the constructs appropriate and relevant. The original scale examined the non-adherence behaviours of dialysis patients on diet and fluid restriction at a 14-day interval. After due consideration, the panel members reduced the interval to 7 days, in view of their concerns that 14 days was too long a period for patients to accurately recall health-related behaviours. The seven-day recall scale ensured that the most accurate information was obtained. Apart from examining the adherence behaviour on fluids and diet, the panel members further suggested that two additional items, medication and PD regimen, be included to provide a comprehensive assessment of the health-related behaviours. The revised questionnaire consisted of four domains that included eight questions measuring the intensity and severity of the patients' behaviour on non-adherence from four different perspectives (Appendix 4.6). The revised scale yielded good content validity with CVI=1.

#### **4.2.3.2 Reliability tests**

##### *Internal consistency*

Sixteen renal patients were invited to establish the reliability test of the revised scale. The internal consistency of the four subscales in the questionnaire was examined using Cronbach's alpha coefficients. The

alpha coefficient for the subscale, 'diet' was 0.94, and for "fluids", it was 0.76. The alpha values demonstrated a good measure of internal consistency reliability of the two subscales. However, the alpha value of the two new subscales on 'medication' and 'PD regimen' were not successfully computed at the initial phase because both domains had zero variance as derived from the item scores. Due to the small sample size in the pilot study, the investigator decided to carry out further work on the internal consistency during the main study. The detailed results are discussed in Chapter 5.

#### *Test-retest reliability*

On two different occasions and with a three-day interval, 16 renal patients were invited to establish the test-retest reliability of the questionnaires. The minimal time interval in administering the two questionnaires was to reduce the possibility of changes in patients' health-related behaviour occurring. The test-retest reliability was calculated using the ICC form (2,  $k$ ). The ICCs between days were 0.98 and 1.00 for the subscales on 'diet' and 'fluid' non-adherence, respectively. The very high test-retest reliability showed that the items in the domains were stable and reproducible. Again, the two new domains developed on 'medication' and 'PD regimen' were not successfully estimated, due to zero variance as derived from the scores. Table 4.3 shows the test-retest reliability scores.



**Table 4.2 Test-retest reliability of DDFQ**

	<b>Intra-class correlation</b>		
	<b>ICC</b>	<b>95% CI</b>	<b>p value</b>
<b>Treatment non-adherence</b>			
Number of days of not following diet guidelines	0.98	0.97-0.99	<0.001
Degree of deviation from diet guidelines	1.00	1.00-1.00	<0.001
Number of days of not following fluid guidelines	1.00	1.00-1.00	<0.001
Degree of deviation from fluid	1.00	1.00-1.00	<0.001

*Inter-rater reliability test*

The ICC model form (2, *k*) was selected to determine inter-rater reliability. The results showed significant agreement among the raters, with ICC=0.94(95% C.I. 0.89-0.99),  $p<0.001$ .

The psychometric tests showed that the subscales on ‘diet’ and ‘fluid’ non-adherence were valid, stable, and reproducible. The two new domains developed by the investigator required further validation with a larger sample to assess their internal consistency and test-retest reliability. The detailed results of the reliability test are further discussed in Chapter 5.

**4.2.4 Personal information**

The questionnaire on demographic data was designed by the investigator (Appendix 4.7). Personal information, including sex, age, educational attainment, marital status, occupation, number of years on PD treatment,

comorbidity, economic status, whether or not a recipient of social security, living environment and level of social and community support was collected at baseline measurement (T1).

#### **4.2.5 Symptom and complication control**

The questionnaire on collection of blood chemistry results and symptom control was also designed by the investigator (Appendix 4.8). The items on symptom control included the level of oedema, existence of peritonitis, exit site condition and percentage weight gain (existing body weight minus baseline body weight divided by the baseline weight X 100%). The data on the blood results were retrieved from the hospital computer system, whilst the information on symptom control was collected by the investigator during the interviews.

##### *Inter-rater reliability test*

The scales on symptom and complication control, and personal information were designed specifically for the study. The ICC form (3, 1) was selected to determine inter-rater reliability as the tested raters were considered the only raters of interest for using the scales. The inter-rater reliability test was conducted by the investigator and the research assistant. The results showed significant agreement among the two raters with ICC=0.93 (95% C.I. 0.89-0.95),  $p<0.001$ .

### **4.3 Summary of instrument validation**

The results of the psychometric tests of the instruments provided support for the reliability and validity of the measurement scales used in the study. The high test-retest and inter-rater reliability measures showed that the measurement scales were stable and reproducible for data collection. In addition, the internal consistency of the instruments denoted by Cronbach's alpha coefficient indicated the good intercorrelation of the test items.

### **4.4 Pilot study**

#### **4.4.1 Sampling**

Prior to the main study, a pilot study was conducted, from April to June 2003. The criteria for subject recruitment in the pilot study were exactly the same as in the main study. The case manager used the same protocol and assessment tool for discharge planning and guidelines for telephone interviews as in the main study. A total of seven male and eight female patients were recruited from one of the study hospitals.

#### **4.4.2 Procedure**

Similar to the main study, the subjects were each assigned to either the study or control group as indicated in the random, computer-generated schedule. The investigator collected the baseline and outcome measures in the pilot study to determine the feasibility and effectiveness of the instruments and to identify problems in the data collection procedures as

proposed in the main study. Depending on the results of the pilot study, the investigator revised the research plan for the main study.

#### **4.4.3 Results**

Due to the very small sample size, descriptive statistics and nonparametric tests were used to examine the results of the pilot study. From the limited number of participants involved in the pilot phase, it could not be determined whether the treatment administered to the subjects in the study groups was successful.

##### **4.4.3.1 Demographic characteristics of the participants**

The mean age of the participants was 58.8 years, and the average number of years on PD regimen was 3.91. Most of the participants were married (53.3%) and some were widowed (26.7%). The majority of the subjects (46.7%) had completed secondary school education; 40.0% had attained only primary school education level. Only two of the participants worked fulltime, whilst the rest were retired. The majority of the patients (66.3%) reported that their financial resources were insufficient for their daily expenses; 20.0% declared their financial resources as barely enough, and the remaining 13.7% assessed their financial resource as more than enough.

#### **4.4.3.2 Treatment effects evaluation**

Means and Standard Deviation (SD) were used to compare the treatment effects and outcomes between the two study groups at three time points.

Before commencement of the nurse-led case management programme, the two groups of subjects showed minimal differences in non-adherence health behaviours. After intervention, the study group patients demonstrated gradual improvement in adherence to medication and PD regimen (Table 4.3).

For symptoms and complications control, there was gradual improvement in serum creatinine and haemoglobin levels, and a decrease in the oedema level (Table 4.4).

For quality of life measures, the study group patients showed improvement in physical function, fewer problems affecting physical activities, a reduction in pain, an increased energy/fatigue level, fewer effects of kidney disease and greater social support. A higher score indicated a more desirable health outcome (Table 4.5).

The study group patients showed a high level of satisfaction with the case managers' work (Table 4.6).

Due to the small sample size in the pilot study, the differences in treatment effects were not easily identified by the statistical tests. Further analyses in the main study had to be undertaken to determine whether the improvements were related to the treatment effects.

**Table 4.3 Non-adherence behaviours before and after nurse-led case management programme**

<b>Outcome</b>	<b>Group</b>	<b>T1</b>	<b>T2</b>	<b>T3</b>
		<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>
Frequency of diet non-adherence	Control (8)	2.3 (3.2)	3.13 (3.3)	2.25 (3.2)
	Study (7)	3.00 (3.7)	3.43 (3.4)	2.29 (3.3)
Level of diet non-adherence	Control (8)	1.00 (1.2)	1.50 (1.5)	1.00 (1.5)
	Study (7)	1.43 (1.8)	1.29 (1.3)	1.00 (1.4)
Frequency of fluid non-adherence	Control (8)	0.87 (2.5)	1.13 (2.4)	0.38 (0.7)
	Study (7)	0.00 (0.0)	0.29 (0.8)	0.00 (0.0)
Level of fluid non-adherence	Control (8)	0.38 (1.1)	0.75 (1.4)	0.25 (0.5)
	Study (7)	0.00 (0.0)	0.14 (0.4)	0.00 (0.0)
Frequency of medication non-adherence	Control (8)	0.00 (0.0)	0.88 (1.2)	1.25 (1.4)
	Study (7)	0.86 (1.5)	0.29 (0.5)	0.71 (1.0)
Level of medication non-adherence	Control (8)	0.00 (0.0)	0.38 (0.5)	0.38 (0.5)
	Study (7)	0.71 (1.3)	0.29 (0.5)	0.57 (0.8)
Frequency of PD regimen non-adherence	Control (8)	0.00 (0.0)	0.63 (1.2)	0.63 (1.2)
	Study (7)	0.14 (0.4)	0.43 (0.8)	0.43 (0.5)
Level of regimen non-adherence	Control (8)	0.00 (0.0)	0.25 (0.5)	0.38 (0.5)
	Study (7)	0.14 (0.4)	0.43 (0.8)	0.29 (0.5)

**Table 4.4 Blood chemistry results and physical symptoms before and after nurse-led case management programme**

Outcome	Group	T1		T2		T3	
		Mean	(SD)	Mean	(SD)	Mean	(SD)
Urea	Control (8)	23.60	(7.3)	22.63	(7.0)	22.01	(6.3)
	Study (7)	26.47	(7.6)	26.11	(8.2)	25.35	(8.5)
Creatinine	Control (8)	990.88	(375.8)	985.75	(337.0)	977.25	(362.5)
	Study (7)	1080.43	(235.2)	1047.71	(198.8)	1080.00	(290.7)
Sodium	Control (8)	136.50	(5.2)	137.63	(5.1)	138.88	(6.3)
	Study (7)	133.00	(3.9)	134.43	(4.4)	132.67	(2.5)
Potassium	Control (8)	4.03	(0.8)	3.80	(0.6)	3.94	(0.6)
	Study (7)	3.86	(0.3)	3.89	(0.2)	3.73	(0.5)
Phosphate	Control (8)	1.57	(0.5)	1.79	(0.4)	1.72	(0.4)
	Study (7)	1.63	(0.9)	1.88	(0.6)	1.77	(0.8)
Albumin	Control (8)	33.63	(5.3)	33.13	(5.3)	33.25	(5.7)
	Study (7)	31.43	(4.0)	30.86	(3.0)	31.83	(3.0)
Calcium	Control (8)	2.32	(0.4)	2.28	(0.2)	2.37	(0.2)
	Study (7)	2.47	(0.7)	2.21	(0.1)	2.40	(0.2)
Haemoglobin	Control (8)	8.38	(1.0)	8.25	(1.1)	8.45	(1.3)
	Study (7)	8.09	(1.9)	9.03	(1.7)	9.65	(2.3)
Oedema	Control (8)	0.38	(0.5)	0.25	(0.5)	0.25	(0.5)
	Study (7)	0.57	(1.1)	0.29	(0.5)	0.14	(0.4)
Weight in percentage	Control (8)	1.00	(0.0)	1.00	(0.0)	0.98	(0.1)
	Study (7)	1.00	(0.0)	1.00	(0.0)	0.97	(0.1)



**Table 4.5 Quality of life before and after nurse-led case management programme**

<b>Outcome</b>	<b>Group</b>	<b>T1</b>	<b>T2</b>	<b>T3</b>
		<b>Mean (SD)</b>	<b>Mean (SD)</b>	<b>Mean (SD)</b>
Physical function	Control (8)	44.38 (28.7)	44.38 (24.4)	50.63 (20.1)
	Study (7)	35.71 (20.9)	42.86 (20.0)	34.29 (20.9)
Role-physical	Control (8)	3.13 (8.8)	9.38 (26.5)	18.75 (29.1)
	Study (7)	0.00 (0.0)	21.43 (36.6)	14.29 (19.7)
Pain	Control (8)	57.50 (29.8)	63.44 (25.7)	77.50 (31.8)
	Study (7)	35.00 (37.9)	60.36 (35.5)	71.79 (39.0)
General health	Control (8)	19.38 (19.0)	27.50 (15.8)	25.63 (18.4)
	Study (7)	26.43 (28.1)	29.29 (20.1)	16.43 (17.5)
Emotional well-being	Control (8)	69.00 (21.0)	65.50 (12.6)	71.50 (17.6)
	Study (7)	75.43 (12.1)	78.86 (11.0)	78.29 (15.1)
Role-emotional	Control (8)	45.83 (50.2)	29.17 (37.5)	58.33 (46.3)
	Study (7)	57.14 (46.0)	52.38 (42.4)	66.67 (38.5)
Social function	Control (8)	42.19 (27.5)	29.69 (13.3)	43.75 (25.0)
	Study (7)	28.57 (29.5)	33.92 (37.3)	37.50 (33.9)
Energy/Fatigue	Control (8)	38.75 (16.9)	41.88 (19.1)	46.25 (27.2)
	Study (7)	35.71 (27.0)	46.43 (14.4)	50.71 (19.9)
Symptom/problem list	Control (8)	67.50 (13.8)	70.21 (15.0)	72.29 (16.2)
	Study (7)	65.48 (17.0)	70.24 (14.6)	69.05 (17.4)
Effects of kidney disease	Control (8)	48.26 (17.5)	55.90 (11.5)	55.56 (20.6)
	Study (7)	55.16 (17.2)	65.87 (20.8)	70.63 (14.2)
Burden of kidney disease	Control (8)	25.00 (14.9)	25.00 (14.9)	21.88 (12.9)
	Study (7)	25.00 (25.3)	25.00 (25.3)	35.71 (35.7)
Work status	Control (8)	0.00 (0.0)	12.50 (23.2)	12.50 (23.2)
	Study (7)	21.43 (39.3)	28.57 (39.3)	35.71 (47.6)
Cognitive function	Control (8)	65.00 (25.1)	71.67 (25.6)	65.83 (20.0)
	Study (7)	66.67 (32.2)	73.33 (13.3)	75.24 (23.3)

Table 4.5 Continued

Quality of social interaction	Control (8)	69.17 (20.1)	74.17 (22.1)	67.50 (24.8)
	Study (7)	72.38 (27.9)	80.00 (14.4)	79.05 (22.6)
Sexual function	Control (8)	62.50 ***	31.25 (26.5)	12.50 ***
	Study (7)	*** ***	*** **	*** **
Sleep	Control (8)	55.63 (24.0)	50.00 (24.0)	46.56 (23.6)
	Study (7)	33.93 (22.7)	36.07 (25.0)	34.64 (22.0)
Social support	Control (8)	75.00 (17.8)	75.00 (13.4)	68.75 (29.1)
	Study (7)	71.43 (17.9)	84.52 (14.8)	88.09 (12.6)
Dialysis staff encouragement	Control (8)	82.81 (26.7)	67.19 (20.0)	76.56 (24.5)
	Study (7)	85.71 (15.2)	73.21 (37.1)	91.07 (11.9)
Patient satisfaction	Control (8)	62.50 (24.8)	64.58 (20.8)	62.50 (19.4)
	Study (7)	76.19 (16.3)	64.29 (17.4)	61.90 (18.5)

Table 4.6 Patient satisfaction before and after nurse-led case management programme

Outcome	Group	T1	T2	T3
		Mean (SD)	Mean (SD)	Mean (SD)
Patient satisfaction	Control (8)	88.12 (14.1)	87.00 (9.5)	89.75 (11.3)
	Study (7)	92.00 (5.9)	98.00 (11.8)	89.43 (7.7)

#### **4.5 Implication of the pilot study for the main study**

The pilot study confirmed the feasibility of the data collection process. Some patients had difficulty recalling their answers to the Kidney Disease Quality of Life-Short Form, due to the variation in the number of answer choices in the different subscales. The participants were given an answer sheet containing different answer choices to facilitate the data collection process and to help the patients make the exact choice for their answers (Appendix 4.9).

With regard to the telephone interviews conducted by the case managers, most case managers found no difficulty contacting the patients at home after discharge. The study group patients demonstrated great pleasure in accommodating the proactive phone calls initiated by the nurse case managers. The interview tapes in the pilot study were reviewed by the investigator, the unit manager and the nurse specialist to ensure that safe, valid and consistent advice was given. After the pilot study, a case conference was organized involving each renal unit. The experiences and difficulties encountered during the process were shared by the nurses and the investigator. In addition, the case managers were provided with feedback on their interview techniques. Some outstanding works that demonstrated a good integration of case management theories with practice, as well as effective nurse patient communications which serve as the benchmark for quality work, were shared in the meeting. Finally, the case

managers were reminded to use clear verbal expressions and to always establish mutual objectives with the patients in the telephone interviews.

The preparatory stage and the pilot study lasted over six months. Through the various testing cycles, the protocols of this randomized controlled trial, and the operational logistics of the intervention and control conditions were tested and refined. The pilot study confirmed that the research instruments were feasible for data collection. Moreover, the telephone-based interview after discharge was a convenient way of reaching the patients to provide comprehensive continuity of care during transition from hospital to home. The experience from this pilot study demonstrated the effectiveness of telephone interviews in discharge planning, and feasible data collection for the main study.

## **CHAPTER 5**

### **RESULTS**

This chapter contains two sections. The first section focuses on the results of the main study. The second section discusses the regression analyses of the independent variables and their association with the key dependent variables, and undertakes an examination of the validity results of the research instruments.

The study sample was drawn from a population of adults undergoing continuous ambulatory peritoneal dialysis or continuous cycling peritoneal dialysis who were admitted to the two renal units of the study hospitals between April 2004 and August 2005. A full calendar year data collection period was used to ensure that the study's results were not influenced by seasonal effects. The statistical analysis evaluated the treatment effects between groups, the treatment effect of the individual groups across time and the interaction effects between the groups and time.

The present study was a single-blinded, randomized controlled trial to investigate whether the nurse-led case management programme was more effective than a conventional discharge programme alone for peritoneal dialysis patients. The outcome measures included the immediate and sustained treatment effects.

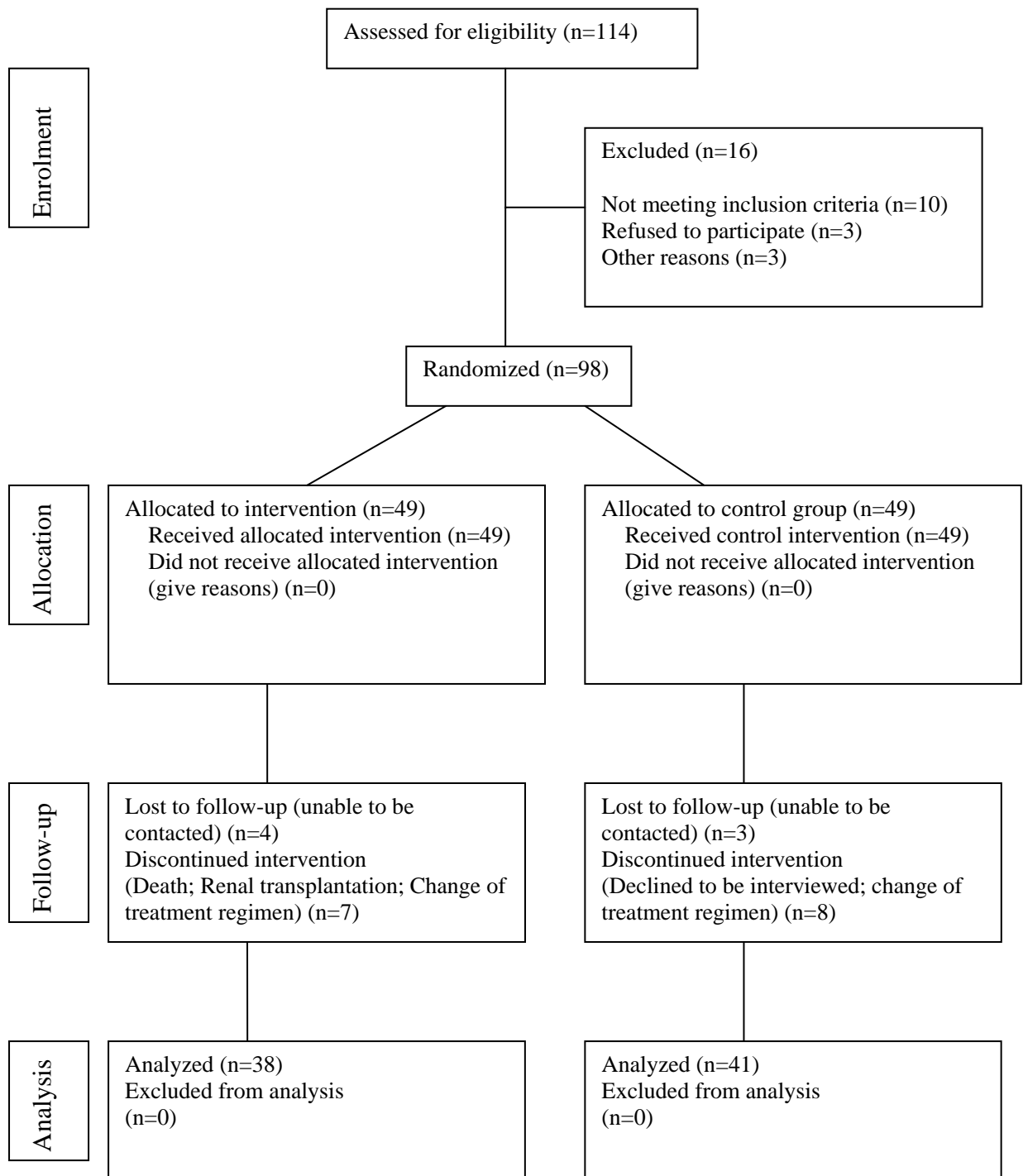
## **Section 1**

### **5.1 Subject recruitment**

During the data collection period, 114 patients met the eligibility criteria and were assessed by the hospital nurse for recruitment in the study. The ward nurses examined the inclusion criteria, briefly discussed the study with the patients and their families and informed the investigator of patients' eligibility and interest in the study. Sixteen patients who failed to meet the inclusion criteria were excluded from the study. Of the 16 patients excluded from the study, 10 were transferred to haemodialysis before discharge. Of the remaining 6 patients, some refused to participate, whilst others were too tired or were in critical condition and therefore unable to complete the study interview. The 98 patients who joined the study were randomly assigned to either the study or control groups. The study and control groups consisted of 49 subjects in each of the treatment arms. At week 12, 38 of the 49 (77.6%) study patients and 41 of the 49 (83.6%) controls had completed the follow-up questionnaires. A total of 79 patients completed the protocol and were included in the analysis. Although an estimated sample size of 94 (47 case and 47 control) is adequate to demonstrate the effects of the experimental interventions, the recruitment process faced an unexpected challenge during the outbreak of an epidemic disease, Avian Flu, in the neighbouring countries. As four months into the data collection process, one of the hospitals barred the research personnel from further access to the hospital ward. To recruit the remaining subjects from a single unit became more difficult than was expected. In

the end, only one to three subjects were recruited per month, with 79 subjects recruited over a 16-month period. Figure 5.1 provides the details of the patient trial profile.

**Figure 5.1 Patient trial profile**



Reference: Moher, Schulz & Altman, (2001). The CONSORT statement.



## **5.2 Data collection**

Data collection included face-to-face interviews and retrieval of the patients' medical records through both the hospital computer system and clinical records. The initial data collection consisted of checking the patients' medical notes before treatment commenced, such as the type of peritoneal dialysis (PD) regimen, comorbid conditions, years on PD, financial status, personal and educational background and types of accommodation.

### **Data screening and cleaning**

To test for outliers and missing data, descriptive statistics were conducted on all study variables for the 79 records in the sample. The z-score, range, mean, standard deviation, and frequency counts of the various outcome variables were examined for the presence of random or systematic missing data and outliers (Polit, 1996). After checking the missing data, the descriptive statistics showed that some missing values were detected in the biochemistry results owing to physicians not routinely performing blood tests for all patients in the clinic follow-ups. The percentage of missing data in the blood chemistry results was 4.2%. For other outcome variables, there were no missing data, as the information was collected by the investigator through face-to-face interviews. It was considered that the exclusion of the missing data could lead to a bias in the clinical trial analysis. Since the overall percentage of the missing value was less than 5%, an alternative approach was to assign a value to replace the treatment response

of the patients. The group mean value of the outcome variables for each respective group was therefore used as a replacement for the missing data in the study (Tabahnick, 2001).

For the detection of outliers, the z-scores were used to differentiate the distorted statistics due to incorrect data entry or extreme values than expected. The cases with the z-scores greater than 3.00, or less than -3.00 were considered as potential outliers. These cases were inspected and investigated for data accuracy. Some of the very extreme outliers, e.g., z-scores of greater than 4.00, or less than -4.00 were replaced with the score corresponding to  $z=3.00$  or  $-3.00$  for the same group. (Carey, Carey, Maisto, Gordon, Schroder & Venable, 2004). Across all variables and assessment occasions, there were 0.04% outliers.

### **5.3 Data Analysis**

#### **5.3.1 Group randomization**

The preliminary analysis compared the groups in terms of basic demographic and social outcome variables to determine whether the random assignment produced equivalent groups. The Chi-square and Fisher Exact tests were used in categorical data, whilst the independent t-test was used for continuous data.

### **5.3.2 Equivalence of groups at baseline**

To determine whether random assignment produced equivalent groups, besides the demographic variables, other outcome variables such as symptom management, blood chemistry results, and kidney disease quality of life were compared before programme intervention at the baseline using t-test and the Chi-square test to substantiate for group equivalence before treatment.

### **5.3.3 Outcome measures**

Outcome measurements were analyzed by means of repeated measures analysis method. This method examined whether intervention could bring about any significant differences in outcome between the groups over time. The design in this study had two factors. The between-group factors were the study and control groups. The within-group factors were measured at three assessment intervals: at baseline before intervention (T1), immediately after intervention at week 6 (T2) and six weeks post- intervention at week 12 (T3). The repeated measures, General Linear Model (GLM), was employed to determine the between-group (intervention) and within-group (times) effects, and the interaction effect to determine (time X group) significant difference on the patterns between groups against time.

The two assumptions for repeated measures ANOVA included the score differences are normally distributed and individual cases represent a random sample from the population (Green & Salkind, 2005). The histogram,

normal probability plot, skewness and kurtosis index were used to determine data normality. The assumptions were fulfilled before statistical tests were executed. Appropriate tests were applied according to nature of the data, Friedman test was used for ordinal data as analogue of repeated measures analysis of variance. Non-parametric tests were used for ordinal, binary and heavily skewed data.

For gathering data following a normal distribution, a parametric test, the repeated measures, GLM, was employed to determine the between-groups and within-group (times) differences, as well as the interaction effect. The level of significance for the above statistical tests is set at 0.05. All statistical tests were set as two-tailed. The assumption of compound symmetry (Mauchly's test of sphericity) was checked. If the Mauchly sphericity test was not significant ( $p > 0.05$ ), the assumption of compound symmetry was met, and the univariate test was appropriate for interpretation. If Mauchly's test of sphericity was not assumed ( $p < 0.05$ ), the assumption of homogeneity of the variance was not met; an adjusted test (e.g., Greenhouse-Geisser) with the epsilon correction was used (Munro, 2005). If the between-group, within-group, or interaction factors showed significant differences, a repeated measures test was performed for each respective group to test for the within-group (times) effect. If significant difference was indicated, the post hoc test with multiple comparisons was performed to examine which pair(s) of time comparison showed differences (T1 vs. T2, and T1 vs. T3). Bonferroni correction was used to adjust the type I error as

the two comparisons were computed simultaneously (Green & Salkind, 2005) and the statistical significance level was set at 0.025 ( $=0.05/2$ ).

For data not following a normal distribution, the Mann-Whitney U test was used to examine the differences between groups at each time point, and the Friedman test was used to examine any differences on the three assessment intervals for each group (Munro, 2005). If the results showed significance, the multiple comparisons with the Wilcoxon sign test were performed to examine which pairs (T1 vs. T2, and T1 vs. T3) showed any differences. Hence, the Bonferroni correction was adopted for such comparisons, and the statistical significance level was set to 0.025 ( $0.05/2$ ).

## **5.4 Results**

### **5.4.1 Socio-demographic characteristics of patients**

This section compares the characteristics of the patients who participated in the randomized controlled trial (RCT). Any differences identified between the groups in the basic characteristics of the patients were included in the covariance when analyzing the outcome measures, and were adjusted to examine the effectiveness of the intervention.

Among the 79 patients who completed the baseline interview, 33 (41.8%) were female and 46 (58.2%) were male. Their ages ranged from 23 to 81 years of age. The mean age of the sample was 56.5 years (standard deviation = 13.6). Most of them were married (72.2%). Some 50.5%

of the subjects attained primary school education or less; about 41.8% was able to attain secondary school education and around 8% had tertiary education or above. The majority of subjects (59.5%) were retired; around 29% were either unemployed or were housewives. Only a minority of the subjects (11.4%) were a part of the work force, either as full- or part-time employees. The mean number of years on PD treatment was 3.2 years, ranging from 0.08 to 12 years. The majority of the subjects were also suffering from diseases other than end-stage renal failure. The percentage of patients without other comorbid conditions was 31.6%. Among those patients who were suffering from other diseases, 41.5% had diabetes mellitus, 35.4% had cardiac diseases and the remaining sample had chronic diseases other than the above disease groups. Table 5.1 displays the details of the sample's characteristics. The Chi-square comparison and t-test showed that there were no significant differences between the control (n=41) and study groups (n=38) in terms of their clinical and demographic variables. Successful randomization was therefore indicated. Tables 5.1 and 5.2 show the demographic and clinical characteristics of the two study groups.

**Table 5.1 Demographic characteristics of the subjects**

Variable	Total n =79(%)	Control n=41 (%)	Study n=38 (%)	$\chi^2/$ t-test P value
<b>Gender</b>				0.51 <sup>a</sup>
<b>Male</b>	46 (58.2)	22 (53.6)	23 (60.0)	
<b>Female</b>	33 (41.8)	19 (46.3)	15 (41.0)	
<b>Age (years)</b>				0.45 <sup>c</sup>
<b>Mean (SD)</b>	56.59 (13.6)	55.50 (13.2)	42.00 (14.0)	
<b>Median [Range]</b>	56.00 [23-81]	55.00 [25-81]	60.00 [23-76]	
<b>Marital Status</b>				0.52 <sup>a</sup>
<b>Single</b>	8 (10.1)	4 (9.5)	4 (10.8)	
<b>Married</b>	57 (72.2)	33 (78.6)	24 (64.8)	
<b>Divorced</b>	6 (7.6)	2 (4.8)	4 (10.8)	
<b>Widow</b>	8 (10.1)	2 (7.1)	5 (13.5)	
<b>Education</b>				0.58 <sup>a</sup>
<b>No formal education</b>	8 (10.1)	6 (14.3)	2 (5.4)	
<b>Primary</b>	32 (41.5)	15 (35.7)	17 (45.9)	
<b>Secondary</b>	33 (41.8)	17(41.5)	16 (43.2)	
<b>Post-secondary</b>	2 (2.5)	1(2.4)	1(2.7)	
<b>University or above</b>	4 (5.4)	3(7.1)	1(2.7)	
<b>Occupation</b>				0.36 <sup>a</sup>
<b>Full time</b>	7 (8.9)	3(7.1)	4 (10.8)	
<b>Part time</b>	2 (2.5)	1(2.4)	1(2.7)	
<b>Unemployed</b>	13 (16.5)	8 (19.0)	5 (13.5)	
<b>Retired</b>	47 (59.5)	22 (52.4)	25 (67.6)	
<b>Homemaker</b>	10 (12.7)	8 (19.0)	2 (5.4)	
<b>Accommodation</b>				0.43 <sup>b</sup>
<b>A flat</b>	72 (92.3)	38 (95.0)	34 (89.5)	
<b>A room</b>	7 (7.7)	3 (5.0)	4 (10.5)	
<b>Financial Status</b>				0.94 <sup>a</sup>
<b>More than sufficient</b>	7 (8.9)	4 (9.5)	3 (8.1)	
<b>Barely sufficient</b>	45 (57.0)	24 (57.1)	21(56.8)	
<b>Insufficient</b>	22 (27.8)	12 (28.6)	10 (27.0)	
<b>Extremely insufficient</b>	5 (6.3)	2 (4.8)	3 (8.1)	

a. Person  $\chi^2$  Test

b. Fisher's Exact Test

c. Independent Sample t-test

**Table 5.2 Clinical characteristics of the subjects**

<b>Variable</b>	<b>Total n (%)</b>	<b>Control n (%)</b>	<b>Study n (%)</b>	<b><math>\chi^2</math>/ t-test p value</b>
<b>Comorbidity</b>				
No other disease (yes)	25 (31.6)	14 (33.3)	11 (29.7)	0.73 <sup>a</sup>
Cancer (yes)	3 (3.8)	2 (4.8)	1 (2.7)	0.63 <sup>b</sup>
Diabetes (yes)	32 (41.5)	16 (38.1)	16 (43.2)	0.64 <sup>a</sup>
Cardiac related (yes)	27 (35.4)	14 (33.3)	14 (37.8)	0.68 <sup>a</sup>
Systemic Lupus Erythematosus (yes)	1 (1.3)	1 (2.4)	0 (0.0)	1.00 <sup>b</sup>
Respiratory disease (yes)	2 (2.5)	1 (2.4)	1 (2.7)	1.00 <sup>b</sup>
Other (yes)	17 (21.5)	10 (23.8)	7 (18.9)	0.60 <sup>a</sup>
<b>Reason for ESRF</b>				
Unknown (yes)	45 (57.0)	21 (50.0)	24 (64.9)	0.19 <sup>a</sup>
Hypertension (yes)	8 (10.1)	5 (11.9)	3 (8.1)	0.72 <sup>b</sup>
Diabetes (yes)	20 (25.3)	10 (23.8)	10 (27.0)	0.74 <sup>a</sup>
Chronic Glomerular Nephritis (yes)	1 (1.3)	1 (2.4)	0 (0.0)	1.00 <sup>b</sup>
SLE (yes)	1 (1.3)	1 (2.4)	0 (0.0)	1.00 <sup>b</sup>
Others (yes)	5 (6.3)	4 (9.5)	1 (2.7)	0.36 <sup>b</sup>
<b>Years on CAPD</b>				
Mean (SD)	3.17 (2.6)	3.41 (2.7)	2.89 (2.6)	0.38 <sup>c</sup>
Median [Range]	2.00 [0.08-12.0]	2.75 [0.1-10.0]	2.00 [0.08-12.0]	

a. Person  $\chi^2$  Test

b. Fisher's Exact Test

c. Independent sample t-test

\*Some patients have suffered more than one kind of disease causing the number of comorbidity greater than the number of subjects recruited in each group.



#### **5.4.2 Baseline measurements on blood chemistry, symptom control and quality of life**

Table 5.3 shows a comparison of the baseline measurements of the two groups of patients in terms of blood chemistry, symptom control and quality of life before intervention. Categorical data compared by Chi-square showed that there was no significant difference between the study and control groups at the baseline measures on peritonitis, level of oedema and exit site condition. The independent sample t-test was conducted on continuous variables, such as blood chemistry results, and on the different subscales in Kidney Disease Quality of Life-Short Form (KDQOL-SF). No significant difference was identified in the two groups of subjects which indicated that they had very similar characteristics before the treatment interventions. Thus, the two groups were comparable in most baseline clinical characteristics and demographic variables, indicating the adequacy of randomization.

**Table 5.3 Baseline comparisons on blood chemistry, symptom control, and quality of life of the subjects**

<b>Variable</b>	<b>Control group n=41</b>	<b>Study group n=38</b>	<b><math>\chi^2</math> / t-test p value</b>
<b>Symptom and complication control</b>			
Urea	25.07 (7.08)	25.07 (7.85)	0.99
Creatinine	1047.70 (259.05)	1006.65 (274.94)	0.49
Sodium	135.75 (4.76)	135.57 (4.92)	0.87
Potassium	3.75 (0.65)	3.86 (0.61)	0.45
Phosphate	1.93 (0.58)	1.77 (0.64)	0.26
Albumin	32.73 (5.01)	34.27 (4.71)	0.16
Calcium	2.27 (0.25)	2.23 (0.23)	0.62
Haemoglobin	8.91 (1.93)	8.56 (1.96)	0.42
Oedema      Median [range]	0.00 [0-3]	0.00 [0-3]	0.82 <sup>a</sup>
Exit site      Median [range]	0.00 [0-1]	0.00 [0-1]	0.98 <sup>a</sup>
Peritonitis      Median [range]	0.00 [0-1]	0.00 [0-1]	0.81 <sup>a</sup>
<b>Kidney Disease Quality of Life</b>			
Physical functioning	51.46 (26.88)	48.15 (29.04)	0.60
Physical role	4.87 (13.94)	3.94 (12.36)	0.75
Pain	50.00 (30.51)	48.28 (36.76)	0.82
General health	25.60 (20.98)	25.26 (17.70)	0.93
Emotional well-being	62.53 (24.63)	59.05 (19.95)	0.49
Emotional role	37.38 (42.94)	43.85 (43.91)	0.51
Social function	32.01 (27.38)	26.31 (27.49)	0.33
Energy/fatigue	38.26 (21.11)	41.26 (23.33)	0.84
Effects of kidney disease	56.97 (19.54)	51.90 (15.82)	0.21
Burden of kidney disease	22.56 (19.75)	16.67 (18.23)	0.17
Work status	7.31 (17.89)	14.47 (28.25)	0.17
Cognitive function	66.58 (22.55)	72.23 (16.82)	0.22
Social interaction	65.36 (22.56)	58.77 (23.60)	0.20
Sexual function	83.92 (91.66)	15.66 (14.43)	0.48
Sleep	43.78 (35.19)	23.51 (23.74)	0.11
Social support	70.93 (66.22)	25.89 (24.88)	0.41
Dialysis staff support	86.21 (21.97)	79.27 (21.99)	0.16
Patient satisfaction	62.60 (19.28)	60.96 (19.09)	0.70
Symptoms	61.74 (16.35)	62.63 (16.97)	0.81
<b>Overall health rating</b>	41.03 (28.21)	41.03 (27.11)	0.98

<sup>a</sup> Pearson  $\chi^2$  Test was used in categorical data analysis  
P value: NS

### **5.4.3 Patient satisfaction**

The hypothesis on whether patients showed satisfaction with the case management service before and after intervention was tested by the repeated measures, GLM. Because Mauchly's test of sphericity was significant ( $p < 0.05$ ), an epsilon correction with Greenhouse-Geisser as estimates of adjustment was reported. The post hoc test for multiple comparisons, together with the Bonferroni adjustment, was conducted since the F ratio was statistically significant in between group and within group analysis. Tables 5.4, 5.5, and 5.6 show the results of patient satisfaction with the treatment.

**Table 5.4**  
**Comparison of satisfaction scores of the groups of patients at the three time intervals**

	Control Group			Study Group		
	n = 41 Mean (SD)			n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Interpersonal Support	54.03 (6.1)	53.45 (6.3)	52.80 (6.7)	55.29 (5.4)	56.84 (5.9)	55.45 (5.6)
Dissatisfaction	31.73 (4.9)	31.12 (5.0)	31.78 (4.4)	31.37 (5.1)	35.37 (3.7)	34.08 (3.7)
Total score	85.76 (10.3)	84.57 (10.0)	84.58 (10.4)	86.66 (9.2)	92.21 (9.2)	89.53 (8.0)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.5**  
**Results of repeated measures, General Linear Model (GLM)**

Effect	df	F	P
Within group (Time)	1.71 <sup>a</sup>	2.98 <sup>a</sup>	0.05 <sup>a</sup>
Between group (Group)	1	4.41	0.03
Time × Group	1.71 <sup>a</sup>	6.89 <sup>a</sup>	0.001 <sup>a</sup>

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

**Table 5.6**  
**Repeated measures on total score for individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	1.54	0.57	0.56 <sup>a</sup>
Study group	2	7.19	0.001

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, \*p<0.025 is significant.

	Mean difference	P value
T1 & T2	-5.5	0.01*
T1 & T3	-2.87	<0.01*

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

The responses to the questionnaire were scored by first reversing the scaling of the negative items (dissatisfaction) and then adding all of the scores to obtain an overall satisfaction score. This was done based on the criteria set by La Monica et al. (1986).

Referring to Table 5.4, the average total score at T2 of the study group showed a large difference with reference to the T1 score (86.66 vs. 92.21,  $p=0.01$ ). In addition, the average total score at T3 score (89.53) remained consistently high despite the discontinuation of case management intervention ( $p<0.01$ ).

As shown in Tables 5.5 and 5.6, the repeated measures, GLM indicated that there was a significant overall difference between the two groups of patients after case management intervention ( $F(1,76)=4.41$ ,  $p<0.05$ ). For within-group effects, there were significant differences in satisfaction scores at the three time intervals ( $F(1.71, 130.20)=2.98$ ,  $p<0.05$ ). Moreover, the interaction effects between groups and the assessment occasions were also significant, indicating that the increased level of satisfaction between the two groups was highly different for the three time intervals ( $F(2, 154)=6.89$ ,  $p=0.001$ ).

Since the within-group effect was significant in the GLM analysis, each group was also examined for changes in the scores over time using repeated measures with post hoc test (T1 vs. T2, and T1 vs. T3). The results

revealed that the study group showed ( $F(2,74)=7.19, p<0.005$ ) significant different results at the baseline and the two time intervals. A further post hoc test with Bonferroni adjustment with  $p<0.025$  illustrated that there was a significant difference when comparing T1 and T2 ( $p=0.01$ ), and T1 and T3 ( $p=0.009$ ). The results indicated that there was a significant increase in satisfaction among the study group patients after intervention and these effects were retained six weeks post-intervention.

#### **5.4.4 Symptom management and complication control**

The blood chemistry results included for analysis were urea, creatinine, sodium, potassium, phosphate, albumin, calcium and haemoglobin levels. Other than these blood results, the percentage change in body weight, level of oedema, existence of peritonitis and exit site condition were also examined. The repeated measures, GLM was used to examine whether the intervention could bring about significant differences in clinical outcomes between the groups over time. The non-parametric test, the Friedman test, was conducted as analogue of repeated measures GLM for categorical data such as levels of oedema. The Cochran Q test was computed for binary data including the existence of peritonitis and exit site conditions.

The repeated measures, GLM tests showed no significant differences for within-group effects on blood urea, creatinine, phosphate, albumin, calcium, haemoglobin and percentage change in body weight. When grouping was examined for any between-group effects, no significant differences were

found in the variables mentioned above. Also, the interaction effect was insignificant.

For blood sodium and potassium levels, the repeated measures, GLM showed that there was a significant effect over time. The test of between-groups effect indicated no significant difference. There was no significant interaction effect between time and the group assignment. However, since there was a significant effect across time, repeated measures were performed for each group to test for within-group (times) effect; a post hoc pairwise comparison was done to compare the significant differences at the three time intervals for the significant group. The control group demonstrated a wider range of scores at the three time intervals than the study group. Tables 5.7, 5.8, and 5.9 show the analyses of data on blood sodium level. Tables 5.10, 5.11 and 5.12 show the statistics output on serum potassium level.

**Table 5.7**  
**Comparison of blood sodium levels at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n =38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
<b>Sodium</b>	<b>135.44 (4.5)</b>	<b>137.22(5.08)</b>	<b>136.63 (4.63)</b>	<b>135.44 (4.07)</b>	<b>136.76 (4.6)</b>	<b>135.84 (4.14)</b>

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.8**  
**Results of repeated measures, General Linear Model**

Effect	df	F	P
Within group (Time)	2	3.92	0.02
Between group (Group)	1	0.16	0.69
Time × Group	2	0.26	0.78

**Table 5.9**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	3.10	0.05
Study group	2	1.30	0.28

Post hoc pairwise comparisons for the control group.

Bonferroni adjustment for multiple comparisons, \*p<0.025 is significant.

	Mean difference	P value
T1 & T2	-1.78	<0.01*
T1 & T3	-1.19	0.06



The two groups of patients had similar mean blood sodium at the baseline measures. The control group, T2 measure with reference to T1 showed a larger range than the study group, 135.44 vs. 137.22 and 135.44 vs. 136.76, respectively. The T3 scores were centred between the T1 and T2 scores in both groups.

As shown in Tables 5.8 and 5.9, the repeated measures, GLM indicated that the within-group effect was significant. There were significant differences in the scores at the three time intervals ( $F(2,110)=3.92, p=0.02$ ). Each group was therefore examined for changes in the scores over time using repeated measures followed by a post hoc test (T1 vs. T2, and T1 vs. T3). The result showed that the control group yielded significant differences in the three measurements across time ( $F(2,62)=3.10, p=0.05$ ). A further post hoc test with the Bonferroni adjustment illustrated a significant difference when comparing T1 and T2 ( $p=0.007$ ), and no significant difference was found in T1 and T3 comparison ( $p=0.059$ ). The results indicated that there was a gradual increase in the blood sodium level in the control group patients, despite the insignificant intervention. Also, the control group was able to demonstrate some retention effects as indicated in T1 and T3 comparison. For the study group, the effect of test time on the outcome measures was not significant. Since the normal range of sodium lies between 136-148 mmol/L (Longmore, Wilkinson & Torok, 2001), the results above indicated that the two groups of patients had a desirable range of blood sodium level despite the different treatments being received. The

findings can be regarded as clinical significant, though not statistically significant for the study group patients.

*Potassium level*

Tables 5.10, 5.11 and 5.12 show the blood potassium levels of the two groups and the computations generated from the repeated measures.

**Table 5.10**  
**Comparison of blood potassium levels of the groups of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Potassium	3.70 (0.66)	3.90 (0.53)	4.04 (0.51)	3.78 (0.55)	3.96 (0.54)	4.09 (0.65)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.11**  
**Results of repeated measures, General Linear Model**

Effect	df	F	P
Within group (Time)	2	7.63	0.001
Between group (Group)	1	0.28	0.59
Time × Group	2	0.012	0.98

**Table 5.12**  
**Repeated measures comparing individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	5.53	<0.01
Study group	2	2.63	0.08

Post hoc pairwise comparisons for the control group.

Bonferroni adjustment for multiple comparisons, \*p<0.025 is significant.

	Mean difference	P value
T1 & T2	-0.19	0.04
T1 & T3	-0.33	*<0.01

Similar to the sodium level, a significant within-group effect was demonstrated in the GLM statistics on potassium level ( $F(2, 106)=7.63$ ,  $p=0.001$ ). The repeated measures highlighted that the control group demonstrated significant differences across the three time intervals ( $F(2, 62)=5.53$ ,  $p=0.006$ ). The post hoc test, adjusted by Bonferroni for multiple comparisons, substantiated the increase in potassium level over time among the control group. Despite the level of increase being similar in the study group, the results showed no significant time effect, probably due to the relatively large values of the standard deviation. Nonetheless, the potassium level range of was within the normal range of 3.5-5.1 mmol/L during the course of the study among the two groups of subjects. The findings can be regarded as clinical significant, though not statistically significant for the study group patients.

### *Oedema*

For the oedema level measurements, the Friedman and Wilcoxon tests were used as nonparametric analogues of the repeated measures analysis of variance and the paired t-test was used to differentiate between pre-intervention and post-intervention in the two groups. The levels of oedema were classified into four categories indicating the different degrees of severity. The grading of 0 indicates no oedema, 1 for mild oedema, 2 for moderate oedema, 3 for severe oedema, and 4 for deep oedema (Jarvis, 1996).

The Friedman test showed no significant differences in decreased levels of oedema across time for both the study and control groups. Despite the insignificant results derived from the Friedman test, a further analysis using the Wilcoxon test was conducted to determine the differences between each pair of scores at the three time periods. The results indicated that a trend toward decreased oedema was evident during treatment in the study group. For the study group,  $p=0.96$  was recorded in the T1 vs. T2 comparison, whilst a borderline significance of  $p=0.06$  was noted in the T1 vs. T3 comparison. For the control group, the T1 vs. T2 comparison was  $p=0.35$ , whilst T1 vs. T3 was  $p=0.60$ . These results did not reach statistical significance; however, there was evidence to substantiate the claim that the study group demonstrated a greater improvement in terms of decreased levels of oedema as compared to the control group. The findings can be regarded as clinical significant, though not statistically significant for the study group patients.

### *Peritonitis*

The Cochran Q Test was used to examine the differences for three or more related groups for binary data. The value of 1 identified the existence of peritonitis, whilst 0 indicated no peritonitis. Mc Nemar tests were conducted to determine which pair of results had a significant difference at the three time intervals. The results confirmed that the pairwise comparisons (T1 vs. T2, and T1 vs. T3) were significant in the two groups. For the study group,  $p<0.001$  and  $p<0.005$  were noted in the T1 vs. T2, and

the T1 vs. T3 comparisons, respectively. For the control group,  $p < 0.005$  was demonstrated in the T1 vs. T2, and the T1 vs. T3 comparisons in the Mc Nemar tests. These results revealed that the two groups showed similar improvement in reducing the existence of peritonitis across time. The findings can be regarded as clinical significant for all patients regardless of their group assignments.

#### *Exit site condition*

To determine the effects of case management intervention on the improvement of exit site condition, the Cochran's Q and Mc Nemar tests were used. The value of 0 indicated a normal condition, whilst 1 denoted an abnormal exit site. There was no statistically significant difference in exit site condition across time within either the study or the control group. However, a trend toward improvement was evident in the study group during treatment where significance was approached ( $p = 0.097$ , Cochran's Q test). Mc Nemar analysis showed no significant differences in the pairwise comparisons in the two groups at any time point.

#### *Bodyweight change*

The Friedman test was used as the nonparametric tests of the repeated measures analysis of variance to measure on the percentage of bodyweight change. The Wilcoxon signed rank test was used to differentiate the differences between pre-intervention and post-intervention in the two groups. The percentage of body weight change is defined as the existing body

weight (T2 & T3) minus the baseline bodyweight (T1) and then divided by the baseline value. The Friedman test showed no significant differences in percentage body weight change across time for both the study and control groups. The Wilcoxon signed rank test was also conducted to determine whether significant differences occurred between each pair of scores at the three time periods. The results indicated that neither group could demonstrate significant difference in T1 vs T2 and T1 vs T3 comparisons.

#### **5.4.5 Non-adherence to treatment regimen**

One of the key variables for investigation was the measurement of patients' non-adherence to the treatment regimen using the Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ). The aspects of the treatment regimen included diet, fluid, medication and PD regimens. The frequency of non-adherence was measured by the number of days of non-adherence which a patient reported in the last seven days, where the scores ranged from 0-7. The degree of non-adherence was scored on a 5-point Likert scale from, 'no' to 'very severe'. The frequency of non-adherence was computed by repeated measures, GLM, whilst the intensity (level) of non-adherence was determined by the Friedman test. The repeated measures on dietary non-adherence were adjusted by the number of years on the PD regimen.

It has been reported that the longer patients had been on dialysis, the less likely they were to report dietary compliance (Brown & Fitzpatrick, 1988).

Studies have shown that patients' adherence to one aspect of the regimen is generally not correlated with another aspect of the regimen. They may choose to be adherent with one aspect and less adherent with others (McNabb, 1997). To further determine whether the number of years on a PD regimen was an appropriate covariate in the analysis of dietary non-adherence, Munro (2005) suggested that the covariate and the dependent variable must show a linear relationship with  $r > 0.30$ . The stronger the relationship, the more effective the analysis of covariance (ANCOVA) would be. The second consideration would be whether there is an interaction between the independent variable and the covariate. A model is therefore needed to test this interaction before carrying out the ANCOVA.

The Pearson correlation explained a positive linear relationship between years of PD and frequency of dietary non-adherence. The correlation coefficient was 0.40, which was significant at 0.05 level (2-tailed), for the frequency of dietary non-adherence. For interaction between the main effect and the covariate, the F associated with the interaction was 0.21 ( $p=0.64$ ) and there was no significant interaction between the independent variable and the covariate. By referring to the assumptions, the number of years on PD fulfilled the rationale behind the mathematical operations involved in ANCOVA. The effect of the covariate (years on PD regimen) was removed before the means were compared.



The results of the outcome measures on non-adherence behaviours were mixed. The repeated measures, GLM tests showed that the non-significant main effect for intervention (between-groups effect) was observed on all the perspectives, including diet, fluid, medication and PD regimen. There was no significant difference for within-group (time) effect on frequencies of fluid restriction, medication, and PD regimen. The within-group effect on dietary non-adherence was found significant after controlling for the covariance. There was no interaction effect between time and group on diet, fluid intake, and PD regimen; that is, the pattern of mean scores of these variables mentioned seemed to be consistent across groups over time. The only variable that demonstrated a significant interaction effect was medication non-adherence.

Tables 5.13, 5.14 and 5.15 show the results of dietary non-adherence, as computed by repeated measures, GLM. Tables 5.16, 5.17 and 5.18 show the results for medication non-adherence with significant interaction effects.

**Table 5.13**  
**Comparison of the frequencies of diet non-adherence of the groups of patients at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
Diet non-adherence	2.37 (2.5)	2.05 (2.5)	2.12 (2.8)	2.24 (2.8)	1.76 (2.4)	1.82 (2.5)

T1 = Before the intervention programme  
T2 = Immediately after the programme  
T3 = Six weeks after the programme

**Table 5.14**  
**Results of repeated measures, GLM (adjusted for years on PD)**

Effect	df	F	P
Within group (Time)	2	4.09	0.02
Between group (Group)	1	0.18	0.67
Time × Group	2	0.03	0.97

**Table 5.15**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	2.46	0.10
Study group	1.73	2.44 <sup>a</sup>	0.09 <sup>a</sup>

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

The two groups of patients reported having similar frequency of dietary non-adherence at baseline measurement. After the nurse-led case management programme, the study group patients demonstrated a marked decrease in dietary non-adherence as compared to their counterparts. For the control group, there was a slight reduction in the frequency of non-adherence but the reported figures remained relatively high when compared with the study group.

As shown in Tables 5.14 and 5.15, the repeated measures, GLM indicated that the within-group effect was significant. There were significant differences in the scores at the three time intervals ( $F(2,150)=4.09, p=0.02$ ). Since the within-group effect was significant in the GLM analysis, the individual groups were examined for changes over time. The results demonstrated that they approached a significant difference in the three measurements across time in the study group ( $F(1,73, 62.14)=2.44, p=0.09$ ). For the control group, the effect of test time on the outcome measures was not significant.

The results indicated that there was some gradual decrease in the frequency of diet non-adherence in the control group. However, the study group patients were able to achieve greater improvement after the case management interventions in comparison with the control group.

**Table 5.16**  
**Comparison of the frequency of medication non-adherence of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
<b>Medication Non-adherence</b>	<b>0.68 (1.4)</b>	<b>1.02 (1.7)</b>	<b>1.05 (1.7)</b>	<b>1.08 (1.6)</b>	<b>0.47 (0.8)</b>	<b>0.55 (1.0)</b>

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.17**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	0.26	0.77
Between group (Group)	1	0.76	0.38
Time × Group	2	4.60	0.01

**Table 5.18**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	1.27	0.29
Study group	1.53	3.92	0.04 <sup>a</sup>

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	0.61	*0.01
T1 & T3	0.53	0.07

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

There were very positive results for medication adherence following the nurse-led case management programme. The significant interaction effect was noted indicating that the rates of improvement between groups and assessment occasions were very different across time ( $F(2,150)=4.6, p<0.01$ ). The repeated measures analysis of the study group revealed significant differences at baseline measures and at the different time intervals ( $F(1.53, 54.50)=3.92, p<0.04$ ), indicating that there were differences in the improvement before and after intervention. The post hoc test with Bonferroni adjustment showed that after six weeks of intervention, the frequency of non-adherence to medication was greatly decreased, with  $p=0.01$ . For the control group, there was no improvement in medication adherence as indicated by the increased frequency of non-adherence over time.

Besides measuring the frequency of non-adherence, the self-reported questionnaire also investigated the intensity (level) of non-adherence of the four variables on a 5-point Likert scale. The Friedman test was used to compute the within-group comparisons across the three time intervals. The results showed no significant difference in the level of non-adherence to diet, fluid intake, medication and PD regimen across time in the two groups. The highest significant level was reported in the decreased level of medication non-adherence from the study group ( $p=0.16$ ). Pairwise comparisons were then conducted for the study group. The Wilcoxon sign

test showed no significant change in T1 vs. T2, and the result approached significant difference in T1 vs. T3 comparison ( $p=0.07$ ).

#### **5.4.6 Kidney Disease Quality of Life-Short Form (KDQOL-SF)**

The Chinese version of the KDQOL-SF comprised 86 items within 20 subscales. The subscales measure different perspectives on quality of life and are mutually exclusive. The scale consists of items on symptoms ( $n=15$ ), effects of kidney disease on daily life ( $n=9$ ), burden of kidney disease ( $n=4$ ), work status ( $n=2$ ), cognitive function ( $n=3$ ), quality of social interaction ( $n=3$ ), sexual function ( $n=2$ ), sleep ( $n=4$ ), social support ( $n=4$ ), dialysis staff encouragement ( $n=2$ ), and patient satisfaction ( $n=1$ ). Other than the disease-specific subscales, the remaining eight subscales are from Short Form-36 (SF-36), which provides a comprehensive assessment of physical and psychological health. SF-36 consists of items on physical function ( $n=10$ ), role limitation as related to physical health ( $n=4$ ), pain ( $n=2$ ), general health ( $n=5$ ), emotional well-being ( $n=5$ ), role limitation as related to emotional health ( $n=3$ ), social function ( $n=2$ ), and energy/fatigue ( $n=4$ ). The last subscale ( $n=1$ ) measures self-reported health. All the subscale scores were standardized and transformed so that higher scores represent a desirable quality of life when compared to lower scores (Li, 1998).

The repeated measures, GLM were performed to answer the research hypothesis of whether the nurse-led case management programme was able

to bring about positive outcomes on patients' quality of life. The results of the outcome measures on quality of life were mixed. Although a statistically significant within-group (time) and interaction effects were observed in some of the parameters within the scale, a non-significant main effect for intervention (between-groups) was observed in all of the parameters. Among the variables that showed significant differences across time were the effects of kidney disease on daily life, emotional well-being, role limitation due to physical health, quality of social interaction, symptoms that bother the patient and social functioning. The variables that demonstrated interaction effects included encouragement from staff, patient satisfaction, sleep and social functioning. For the variable on quality of social interaction, a non-significant effect for group (between-groups), time (within-group) and interaction was observed. However, the study group showed a significant difference in the own group repeated measures with significant differences observed also in the post hoc pairwise comparisons. Since a large number of repeated measures were necessarily calculated (n=20), due to the fact that each KDQOL-SF sub-scale required an individual computation, only statistically significant findings are reported for the purpose of brevity.

#### **5.4.6.1 Parameters demonstrated in the within-group (time) effects**

##### *Effects of kidney disease on daily life*

Tables 5.19, 5.20 and 5.21 show the perspective scores on the effects of kidney disease on patients' daily life. The results of repeated measures

included the between-groups, within-group and the interaction effects. The individual group analysis with post hoc test was also computed.



**Table 5.19**  
**Comparison of scores for the effects of kidney disease of the groups of patients at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
Effects of kidney disease	56.38 (19.4)	59.10 (20.1)	59.65 (20.3)	51.90 (15.8)	58.5 (20.9)	58.63 (18.0)

T1 = Before the intervention programme  
T2 = Immediately after the programme  
T3 = Six weeks after the programme

**Table 5.20**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	4.42	0.01
Between group (Group)	1	0.30	0.59
Time × Group	2	0.64	0.53

**Table 5.21**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	(P value)
Control group	2	0.88	0.42
Study group	2	4.12	0.02

Post hoc pairwise comparisons for the study group.  
Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-6.58	*0.02
T1 & T3	-6.73	0.03

The two groups of patients had no significant difference at the baseline measurement of the effects of kidney disease on daily life. After the nurse-led case management programme, the two groups did not show significant group effects or interaction effects. The repeated measures, GLM indicated that the within-group effect was found significant. There were significant differences in the scores at the three time intervals ( $F(2,152)=4.42, p=0.01$ ), when the individual groups were examined for changes over time. The result demonstrated that the study group indicated significant differences in the three measurements across time ( $F(2,74)=4.12, p=0.02$ ). The patients reported that they felt less inconvenienced by fluid/diet restriction, showed better ability to work around the house, were less dependent on doctors and perceived less stress. The post hoc tests showed that a significant effect was found at T1 and T2 ( $p=0.02$ ), and a borderline significant effect at T1 and T3 comparison was ( $p=0.03$ ) identified after the Bonferroni adjustment. For the control group, the effect of test time on the outcome measures was not significant and this result did not change significantly throughout the study period.

#### *Emotional well-being*

Tables 5.22, 5.23 and 5.24 show the perspective scores on the emotional well-being of the patients.

**Table 5.22****Comparison of scores on the emotional well-being of the groups of patients at the three time intervals**

	Control Group N = 41 Mean (SD)			Study Group n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Emotional well-being	61.00 (24.2)	66.63 (20.1)	64.41 (21.1)	59.05 (20.0)	64.32 (18.1)	66.00 (20.5)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.23****Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	5.23	0.01
Between group (Group)	1	0.07	0.80
Time × Group	2	0.85	0.43

**Table 5.24****Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	1.70	2.07 <sup>a</sup>	0.14 <sup>a</sup>
Study group	2	3.92	0.02

Post hoc pairwise comparisons for the control group.

Bonferroni adjustment for multiple comparison, \* p&lt;0.025 is significant.

	Mean difference	P value
T1 & T2	-5.26	0.04
T1 & T3	-6.95	<0.01*

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

Both the study and control group patients demonstrated improvement in emotional well-being during the course of the study. When comparing the improvement in scores among groups, there was no significant difference found in the scores on emotional well-being at the three time intervals between the study and control groups. The interaction effect was not significant between groups and assessment occasions across time. The repeated measures, GLM indicated that the within-group effect was found significant. There were significant differences in the scores at the three time intervals ( $F(2,152)=5.23, p=0.01$ ). When each individual group was examined for changes over time, the result demonstrated that the study group showed significant differences in the three measurements across time ( $F(2,74)=3.92, p=0.02$ ). The patients reported that they felt less nervous, were happier, calmer and more peaceful. For the control group, the effect of test time on the outcome measures was less significant than the study group despite the improvement in the scores at T2 and T3. The post hoc tests of the study group showed a borderline significant effect at T1 vs. T2 ( $p=0.04$ ) and a high significant effect at T1 and T3 comparison ( $p<0.01$ ) after Bonferroni adjustment.

#### *Role-physical*

Tables 5.25, 5.26 and 5.27 show the perspective scores on problems with work or regular activities as a result of physical health.

**Table 5.25**  
**Comparison of scores on role- physical of the groups of patients at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
<b>Role-physical</b>	<b>5.00 (14.1)</b>	<b>10.00 (21.8)</b>	<b>6.88 (15.0)</b>	<b>3.95 (12.4)</b>	<b>13.16 (20.7)</b>	<b>10.53 (19.8)</b>

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.26**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	6.09	<0.001
Between group (Group)	1	0.35	0.55
Time × Group	2	0.80	0.45

**Table 5.27**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	1.37	0.26
Study group	2	1.01	0.04

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-9.21	<0.01*
T1 & T3	-6.58	0.01*

Both the study and control group patients had improvements in emotional well-being during the intervention period (at T2). The retention effect remained for six weeks in the study group but not in the control group. When comparing the improvement in scores between groups, there was no significant difference found. The presence of an interaction effect between group and time was also examined and there was no significant difference between the two groups over time. The repeated measures, GLM indicated that the within-group effect was found highly significant. There were significant differences in the scores at the three time intervals ( $F(2,152)=6.09, p<0.001$ ); the individual groups were then examined for changes over time. The study group showed significant differences in the three measurements across time ( $F(2,74)=1.01, p=0.04$ ). The patients reported that they encountered fewer problems with work or regular activities as a result of physical health. The post hoc tests showed that all pairwise comparisons were significantly different. There was a high significant effect at T1 vs. T2 ( $p=0.004$ ), as well as in T1 vs. T3 comparison ( $p=0.01$ ) in the study group. For the control group, the effect of test time on the outcome measures showed no significant difference despite the fact that there was an improvement in the scores at T2.

### *Symptoms*

Tables 5.28, 5.29 and 5.30 show the perspective scores on the extent to which patients were bothered by the symptoms related to end-stage renal failure.

**Table 5.28****Comparison of scores on symptoms of the groups of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Symptoms	61.04 (15.9)	63.46 (13.9)	64.08 (14.5)	62.63 (17.0)	67.68 (17.4)	66.54 (17.9)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.29****Results repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	4.08	0.02
Between group (Group)	1	0.72	0.41
Time × Group	2	0.42	0.66

**Table 5.30****Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	1.69	1.23 <sup>a</sup>	0.29 <sup>a</sup>
Study group	2	3.26	0.04

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, if \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-5.04	*0.01
T1 & T3	-3.10	0.09

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

The two groups were comparable at the baseline scores on the extent to which patients were disturbed by the symptoms of end-stage renal failure. The study and control groups both demonstrated different levels of improvement at T2. In the first analysis, the repeated measures, GLM was used to determine the between-group factor with no significant difference found. The presence of an interaction effect between group and time was also examined and there was no significant difference between the two groups over time. For within-group effects, there was a significant difference in symptom control for the two groups ( $F(2,152)=4.08, p=0.02$ ). The effect of time in each group was also examined. There was a significant difference in the scores of patients disturbed by symptoms over time in the study group ( $F(2,74)=3.26, p=0.04$ ). The patients benefited from the intervention in the way that they were less bothered by muscle soreness, cramps, itchy skin, shortness of breath, dizziness, loss of appetite, numbness and nausea in the preceding four weeks as compared to their condition during the pre-intervention period. The post hoc pairwise comparisons in the study group revealed a highly significant difference in T1 vs. T2 ( $p=0.01$ ) but not in T1 vs. T3 ( $p=0.09$ ) comparison indicating that treatment effect was not sustained. The significant difference was not found in the control group.

### *Pain*

Tables 5.31, 5.32 and 5.33 show the perspective scores on the levels of bodily pain and how much pain interfered with normal work.



**Table 5.31**  
**Comparison of scores for pain in the groups of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n =38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
<b>Pain</b>	<b>50.00 (30.51)</b>	<b>48.92 (29.21)</b>	<b>58.04 (33.68)</b>	<b>48.28 (36.76)</b>	<b>61.31 (33.14)</b>	<b>60.32 (35.44)</b>

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.32**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	4.08	0.06
Between group (Group)	1	0.72	0.44
Time × Group	2	0.42	0.23

**Table 5.33**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	1.69	1.23 <sup>a</sup>	0.24 <sup>a</sup>
Study group	2	3.26	0.07

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, if \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-5.04	0.03
T1 & T3	-3.10	0.11

a. The degree of freedom of F ratio is evaluated by Greenhouse-Geisser (G-G) as estimates of adjustment (epsilon), if Mauchly's test of sphericity is not assumed.

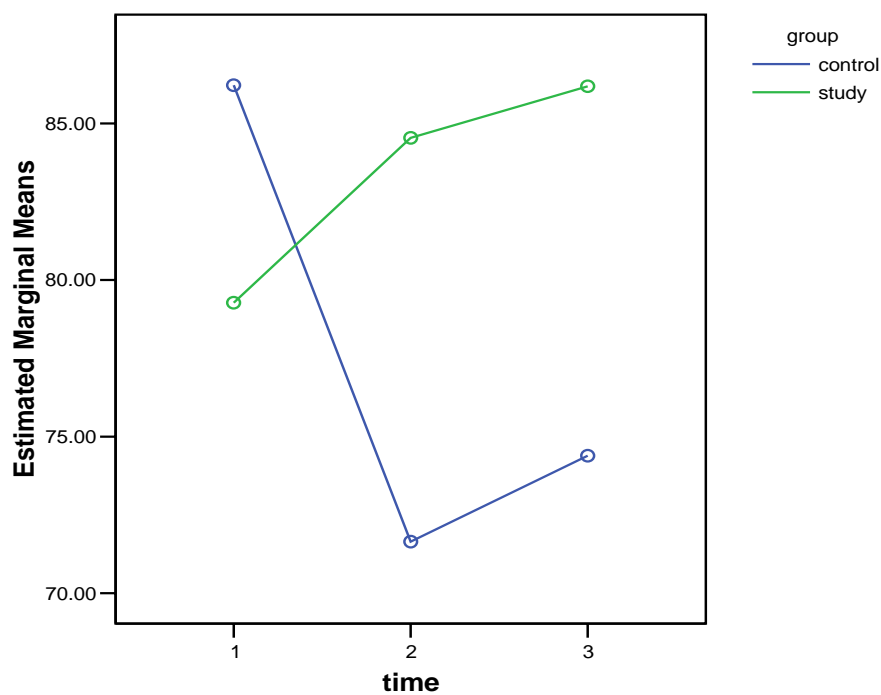
The baseline data of the two groups were similar. In the first analysis, the repeated measures, GLM was used to test between-group effects with no significant difference found. The presence of an interaction effect between group and time was also examined, and there was no significant difference between the two groups over time. For within-group effects, the result suggested a difference over time, which approached significant difference for the two groups ( $F(2,152)=4.08, p=0.06$ ). The effect of time in each group was also examined. The result illustrated that there was an approaching significant difference in pain over time in the study group ( $F(2,74)=3.26, p=0.07$ ). The patients had less bodily pain and felt that pain interfered less with normal work at four weeks after case management intervention. The post hoc pairwise comparisons in the study group revealed a result which approached significant difference in T1 vs. T2 ( $p=0.03$ ) but not in T1 vs. T3 ( $p=0.11$ ) comparison indicating that treatment effect was not sustained. The significant difference was not found in the control group.

#### **5.4.6.2 Parameters demonstrated in interaction (time x group) effects**

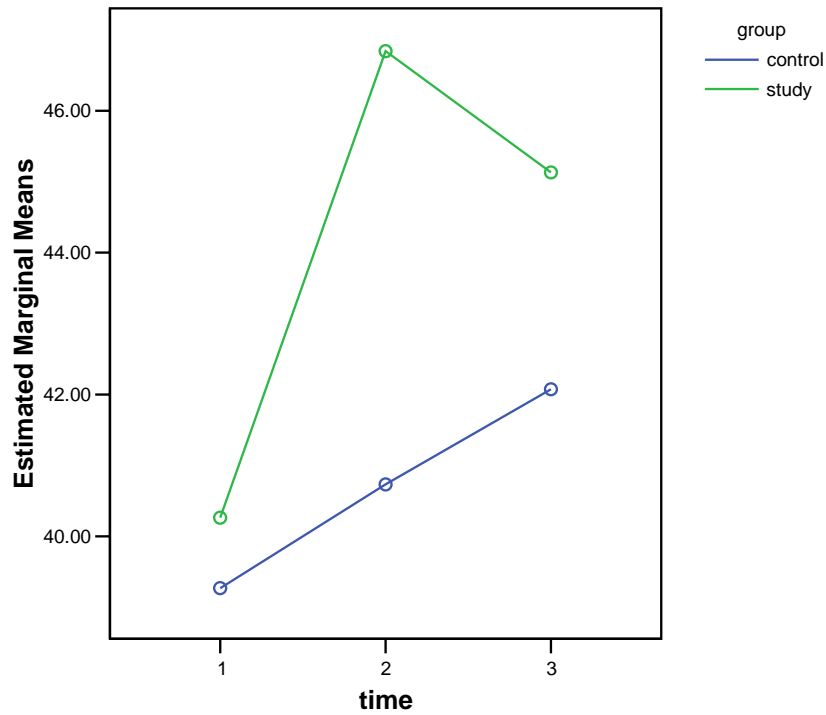
When there are two or more variables in an ANOVA, the interaction effects could be tested. Among the outcome variables in KDQOL were a few outcomes showing interaction effects between groups and assessment occasions across time. A significant ordinal interaction means that the two groups across the three time intervals do not intersect within the plot, and a disordinal interaction implies that these lines do intersect in the plot. A non-significant interaction is illustrated by nearly two parallel lines that

connect the means of the groups (Munro, 2005). The interaction effect, whether disordinal or ordinal, indicates that the rates of improvement between the two groups across time are very different and further implies that different approaches worked better at one point than another. Despite the fact that there is a significant disordinal interaction, a significant main or time effect may or may not exist. Figures 5.1 and 5.2 show the two types of interaction.

**Figure 5.1 Disordinal interaction**



**Figure 5.2 Ordinal interaction**



The outcome variables that showed significant interaction effects were encouragement and support from dialysis staff, patient satisfaction, quality of sleep and social function.

*Encouragement from dialysis staff*

Tables 5.34, 5.35 and 5.36 show the perspective scores on encouragement and support of the dialysis staff to the patients.

**Table 5.34****Comparison of scores on encouragement from dialysis staff for the groups of patients at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
Encouragement from staff	85.88 (22.1)	71.56 (36.0)	74.06 (34.6)	79.27 (22.0)	84.54 (23.1)	86.2 (27.2)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.35****Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	0.77	0.46
Between group (Group)	1	1.64	0.20
Time × Group	2	4.61	0.01

**Table 5.36****Repeated measures comparing the two groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	3.95	0.02
Study group	2	1.13	0.33

Post hoc pairwise comparisons for the control group.

Bonferroni adjustment for multiple comparison, if \* p&lt;0.025 is significant.

	Mean difference	P value
T1 & T2	14.31	*0.01
T1 & T3	11.81	*0.02

The statistical results showed the scores of dialysis staff encouragement among the two groups. The repeated measures, GLM showed no significant differences in the between-groups and within-group effects. The presence of an interaction effect between group and time was examined and there was a significant difference between the two groups over time ( $F(2,152)=4.61, p=0.01$ ), indicating that the trend was very different between the two groups across time.

The study and control groups were examined separately using repeated measures. The means at T1 scores showed that the control group patients were much more satisfied with the encouragement provided by the staff in the dialysis units. There was a significant difference in the scores over time in the control group ( $F(2,78)=3.95, p=0.02$ ). The post hoc pairwise comparisons in the control group revealed a highly significant difference in T1 vs. T2 ( $p=0.01$ ) and in T1 vs. T3 ( $p=0.02$ ) comparisons. The significant difference was not found in the study group across time.

There was no significant difference between the two groups as compared by independent t-test in the initial analysis. This is indicated in Table 5.3. Despite the significant differences reflected by the statistical results, the study group patients were more satisfied with the encouragement from the dialysis staff in the study. For the control group, the significant result was only due to a substantial drop in the T2 and T3 scores in comparison with

the baseline measurement (85.88 vs. 71.56 vs. 74.06). Therefore, the significant result was in fact not a desirable outcome. In contrast, patients in the study group showed good and steady progress in their T2 and T3 scores after case management intervention (79.27 vs. 84.54 vs. 86.20) despite the insignificant statistical results. Nevertheless, the interaction effects substantiated the huge variations between the group means across time.

#### *Patient satisfaction*

The other outcome variable on patient satisfaction shared similar results as the outcomes on staff encouragement. Tables 5.37, 5.38 and 5.38 show the perspective scores on patient satisfaction.

**Table 5.37**

**Comparison of scores on patient satisfaction for the groups of patients at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
<b>Patient satisfaction</b>	<b>61.67 (18.6)</b>	<b>61.25 (16.2)</b>	<b>54.58 (17.3)</b>	<b>60.96 (19.1)</b>	<b>60.53 (15.2)</b>	<b>63.60 (18.1)</b>

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.38**

**Results of repeated measures, GLM**

Effect	df	F	P
<b>Within group (Time)</b>	<b>2</b>	<b>0.55</b>	<b>0.58</b>
<b>Between group (Group)</b>	<b>1</b>	<b>0.72</b>	<b>0.41</b>
<b>Time × Group</b>	<b>2</b>	<b>3.11</b>	<b>0.05</b>

**Table 5.38**

**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
<b>Control group</b>	<b>2</b>	<b>3.79</b>	<b>0.03</b>
<b>Study group</b>	<b>2</b>	<b>0.46</b>	<b>0.63</b>

Post hoc pairwise comparisons for the control group.

Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
<b>T1 &amp; T2</b>	<b>0.42</b>	<b>0.89</b>
<b>T1 &amp; T3</b>	<b>7.08</b>	<b>0.03</b>



The statistical results showed the scores of patient satisfaction among the two groups. The repeated measures, GLM showed no significant differences in between-groups and within-group effects. The presence of an interaction effect between group and time was examined and there was a significant difference between the two groups over time ( $F(2,152)=3.11, p=0.05$ ), indicating that the study trend was different between the two groups across time.

The repeated measures were used to examine the separate groups. The T1 scores of the two groups were similar. There was a significant difference in the scores over time in the control group ( $F(2,78)=3.79, p=0.03$ ). The post hoc pairwise comparisons in the control group revealed no difference in T1 and T2 comparison, whilst for T1 vs. T3, the statistical result approached a significant difference ( $p=0.03$ ) as the Bonferroni correction was adopted for such comparison. The alpha value was set to 0.025 ( $0.05/2$ ).

Despite the significant differences reflected by the statistical results, the levels of satisfaction revealed by the study group patients were very stable across the three time intervals. For the control group, there was a substantial drop at the T3 interval in comparison with the baseline (61.67 vs. 61.25 vs. 54.58), causing the significant result. In contrast, the score for the study group remained stable at T1 and T2, with a gradual increase (60.96 vs. 60.53 vs. 63.60) when compared with the control group.

### *Sleep*

The outcome variable on quality of sleep demonstrated the interaction effects between groups and time intervals. Tables 5.41, 5.41 and 5.42 show the perspective scores on sleep quality.

**Table 5.41**  
**Comparison of scores on sleep for the groups of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n = 38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Sleep	42.63 (22.6)	38.06 (19.0)	38.36 (20.9)	35.20 (23.7)	45.66 (25.7)	46.84 (24.6)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.41**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	2.21	0.11
Between group (Group)	1	0.31	0.58
Time × Group	2	8.93	0.001

**Table 5.42**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	1.49	0.23
Study group	2	8.74	<0.001

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison,\* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-10.46	0.001*
T1 & T3	-11.65	0.001*

The repeated measures, GLM showed no significant differences in the between-group and within-group effects. The presence of an interaction effect between group and time was examined and there was a significant difference between the two groups over time ( $F(2,152)=8.93, p<0.001$ ). These results indicated that the trend effect was different between the two groups across time.

The study and control groups were examined separately using repeated measures. The means at T1 scores showed that the control group patients had a better quality of sleep than the study group. After case management intervention, there was a dramatic increase in the T1 and T2 scores in the study group, whilst the subsequent scores for the control group dropped. Repeated measures were used to examine the individual groups across time. There was a significant difference in the scores over time in the study group ( $F(2,74)=8.74, p<0.001$ ). The post hoc pairwise comparisons in the study group revealed highly significant differences in T1 vs. T2 ( $p<0.001$ ) and T1 vs. T3 ( $p<0.001$ ) comparisons. No significant difference was found in the control group across time.

The statistically significant interaction effects indicated that study group had improved significantly in the quality of sleep compared with the control group, with very different trends across time.

### **5.4.6.3 Parameter demonstrated both interaction and within-group effects**

#### *Social function*

The outcome variable on social function demonstrated the interaction effects between groups and time intervals, and within-group effect. Tables 5.46, 5.47 and 5.48 show the perspective scores on how physical and emotional problems interfered with social activities.

**Table 5.46**  
**Comparison of scores on social function of the groups at the three time intervals**

	Control Group n = 41			Study Group n = 38		
	Mean (SD)			Mean (SD)		
	T1	T2	T3	T1	T2	T3
Social function	31.3 (27.3)	28.8 (24.9)	37.8 (27.7)	26.32 (24.8)	42.43 (32.6)	41.5 (29.0)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.47**  
**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	6.30	<0.001
Between group (Group)	1	0.52	0.47
Time × Group	2	4.99	0.01

**Table 5.48**  
**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	2.34	0.10
Study group	2	9.50	<0.001

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	16.11	*<0.00
T1 & T3	14.14	*<0.00

The two groups of patients had no significant difference at the baseline measurement on social activities. After the nurse-led case management programme, no statistically significant differences were found regarding social function scores from baseline to 12 weeks between the two groups. The repeated measures, GLM indicated that the within-group effect was significant. There were significant differences in the scores at the three time intervals ( $F(2,152)=6.30, p<0.001$ ). The results also indicated that the interaction effects (time x group) were statistically significant ( $F(2,152)=4.99, p<0.01$ ). The individual groups were examined for changes over time. The result suggested a difference over time for the study group ( $F(2,74)=9.50, p<0.001$ ). The patients reported that the extent to which physical or emotional problems interfered with normal social activities was markedly reduced over the final four weeks. The post hoc tests were completed and they showed significant differences at T1 and T2 ( $p<0.001$ ), and at T1 and T3 comparisons ( $p<0.001$ ). The treatment effect was sustained six weeks after the programme had concluded.

The significant interaction effect indicated that the rates of improvement between the two groups were different, and the within-group effect substantiated a clinical improvement after case management interventions.

### *Quality of social interaction*

The non-significant results were observed for group (between groups), time (within group), and interaction effect. However, only the study group showed a significant difference in the repeated measures and in the post hoc pairwise comparisons. Tables 5.43, 5.44 and 5.45 show the statistical analysis on the patients' general physical and emotional well-being in the final four weeks.



**Table.5.43**

**Comparison of scores on quality of social interaction of groups of patients at the three time intervals**

	Control Group n = 41 Mean (SD)			Study Group n =38 Mean (SD)		
	T1	T2	T3	T1	T2	T3
Quality of social interaction	64.50 (22.2)	65.17 (25.6)	63.50 (23.4)	58.77 (23.6)	63.86 (23.0)	65.09 (21.8)

T1 = Before the intervention programme

T2 = Immediately after the programme

T3 = Six weeks after the programme

**Table 5.44**

**Results of repeated measures, GLM**

Effect	df	F	P
Within group (Time)	2	1.30	0.28
Between group (Group)	1	1.71	0.70
Time × Group	2	0.15	0.18

**Table 5.45**

**Repeated measures comparing the individual groups at the three time intervals**

	df	Within-group effect F value	P value
Control group	2	0.15	0.86
Study group	2	3.52	<0.05

Post hoc pairwise comparisons for the study group.

Bonferroni adjustment for multiple comparison, \* p<0.025 is significant.

	Mean difference	P value
T1 & T2	-5.01	0.04
T1 & T3	-6.32	*0.02

The repeated measures GLM did not review any statistically significant differences regarding scores on quality of social interaction from baseline to 12 weeks between the two groups. The interaction effect and within-group effects were also insignificant. When the individual groups were examined for changes over time, the study group showed significant differences in the three measurements across time ( $F(2,74)=3.52, p=0.04$ ). The patients were less isolated and irritable, and were able to get along well with other people in the last four weeks. The post hoc tests were completed and the results approached significant differences at T1 and T2 comparison ( $p<0.04$ ) and a significant difference at T1 and T3 comparison ( $p=0.02$ ). The individual group analysis on the within-group effect substantiated the findings of a clinical improvement after case management interventions in the study group.

Table 5.49 shows the summary of the statistically significant univariate analysis of the within-group and interaction effects in KDQOL.

**Table 5.49**  
**Summary of the multivariate tests on the within-group and interaction effects in**  
**KDQOL-SF**

	<b>Subscale</b>	<b>F</b>	<b>df</b>	<b>p value</b>
<b>Within-Group Effects</b>	Effects of kidney disease on daily life	4.42	2	0.01
	Emotional well-being	5.23	2	0.01
	Role-physical	6.09	2	<0.001
	Symptoms	4.08	2	0.02
	Pain	4.08	2	0.06
	Social function	6.30	2	<0.001
<b>Interaction Effects</b>	Encouragement from dialysis staff	4.61	2	0.01
	Patient satisfaction	3.11	2	0.05
	Sleep	8.93	2	0.001
	Social function	4.99	2	0.01

#### **5.4.7 Health service utilization**

The outcome indicators on health care utilization included the frequencies of emergency room attendance, frequencies of hospital readmission, total length of stay during hospitalization and length of stay per hospital readmission. Readmission was operationally defined as unplanned admission through emergency room to hospital wards. The comparisons on health care utilization encompassed the between-groups and within-group comparisons before and after intervention. The data were retrieved within 12 weeks before and 12 weeks after intervention from the two respective groups of subjects.

Nonparametric tests were used for data analysis as most of the outcome variables mentioned above indicated a substantially skewed distribution, with the Fisher's measure being greater or less than 2. Examination on kurtosis showed that some of the distributions were significantly kurtosed, with values greater or less than 3.

The Mann-Whitney U tests were performed as analogues for the independent sample t-test to test the difference in the ranks of scores of the two independent groups. The test results did not show a statistical difference between the groups in the frequency of emergency room attendance, number of hospital readmissions, total length of stay during hospitalization and length of stay per hospital admission before intervention. The results also did not show any significant difference

between the study and control groups in the total frequency of emergency room attendance, number of hospital readmissions, total length of stay during hospitalization and length of stay per hospital admission after intervention.

For own group comparisons, the Wilcoxon signed tests did not show the statistical difference 12 weeks before and after intervention in the following parameters: total frequency of emergency room attendance, number of hospital readmissions, total length of stay during hospitalization and length of stay per hospital admission.

Table 5.50 shows the descriptive statistics on the outcome variables on health care utilization.

#### **5.4.8 Need for referral to seek for further specialty services after telephone interview**

After the telephone interviews, some of the patients were referred to specialty services or emergency room for further management of the health problems. The information was retrieved from the documentations on telephone interview after the programme. There were three patients referred to the medical social worker, one patient referred to the community nurse and one patient referred to seek for emergency room service.

**Table 5.50 Descriptive statistics on health service utilization**

	Frequencies of emergency room attendance		Frequencies of hospital readmissions		Total length of stay during hospitalization		Length of stay/admission	
	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention	Pre-intervention	Post-intervention
<b>Study group</b>								
<b>Mean (SD)</b>	1.63 (3.34)	1.08 (1.97)	0.74 (1.08)	0.84 (1.32)	3.66 (5.86)	5.13 (8.61)	2.18 (3.27)	2.37 (4.09)
<b>Median</b>	1.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
<b>Range</b>	20	8	4	4	23	28	15.0	20.0
<b>Control group</b>								
<b>Mean (SD)</b>	0.83 (1.10)	0.88 (1.22)	0.57 (0.78)	0.70 (1.18)	3.63 (5.77)	4.45 (7.82)	2.89 (4.51)	2.52 (4.90)
<b>Median</b>	0.00	0.00	0.00	0.00	0.00	0.00	0.00	0.00
<b>Range</b>	4	4	3	4	21	26	20.0	26.0

## **5.5 Conclusion of section 1**

This chapter presented the research findings from the data analysis addressing the research hypotheses. Patients in the study group demonstrated improvement in diet and medication adherence after the programme. There was a significant within-group (time) effect revealed in the frequencies of dietary non-adherence and interaction effects on the frequencies of medication non-adherence. For symptoms and complications control, there was a significant difference in the within-group effect on blood sodium and potassium levels. Both the study and control groups showed a significant improvement in eradicating peritonitis during the course of study. For kidney disease quality of life, the following parameters demonstrated statistically significant results: effects of kidney disease, emotional well-being, role limitation due to physical health, quality of social interaction, patient satisfaction, sleep, social function, symptoms improvement, pain intensity and dialysis staff encouragement. For patient satisfaction, the within-group, between-groups, and interaction effects demonstrated statistically significant results. Lastly, the health care utilization pattern was unable to indicate a statistically significant effect after intervention.

## **Section 2**

The second section consists of regression analyses of the independent variables and their association with the key dependent variables, and an examination of the validity results of the research instruments.

### **5.6 Validity and reliability test on the dialysis diet and fluid non-adherence questionnaire**

The dialysis diet and fluid non-adherence questionnaire (DDFQ) was developed by Vlaminck et al. (2003). The original scale consisted of four questions measuring the number of days and levels of non-adherence to the diet and fluid regimen of patients reported in the last 14 days. In the present study, four additional items from two perspectives, non-adherence to medication and PD regimen, were included to provide a comprehensive assessment of non-adherence behaviours of PD patients.

#### **5.6.1 Internal consistency**

The internal consistency of the two new constructs was examined using Cronbach's alpha coefficients. As a result of the small sample size and the undefined results generated from the item scores in the pilot study as stated in Chapter 4, the investigator decided to include all the subjects in the study for analysis. The baseline score (T1) was used to compute the reliability and validity. Other than the Cronbach's alpha, the item-to-item and item-to-total correlations were also computed. Items having correlations with the overall scale were determined, and the effect of removing them



from their scale was examined. All of the above analyses were used to gather structural evidence for the construct validity of the scale. Item-to-item correlation ( $>0.30$  and  $<0.70$ ), corrected item-to-total scale correlation ( $>0.30$ ) and Cronbach's alpha coefficient ( $>0.80$ ) were used to determine the internal consistency of the new constructs of the scale (Nunnally & Bernstein, 1994., Ferketich, 1991).

#### *Medication non-adherence*

The alpha correlation for the construct 'medication non-adherence' was 0.85. The Cronbach's alpha value of 0.85 suggested that the subscale achieved high internal consistency. The desired Cronbach's alpha value indicated the homogeneity and consistency of all items within a subscale. The high item-to-total correlation represented the correlation of each item with the sum of the remaining items. Accordingly, a good positive correlation between an item and the corrected total indicates that an item assesses the relevant construct (Clark & Watson, 1995). Table 5.51 shows the Cronbach's alpha coefficient, item-to-item correlation and item-to-total correlation of the subscale on medication non-adherence.

**Table 5.51 Cronbach's alpha coefficient and item-to-total correlation on medication non-adherence**

Scale items	Item-to-total correlation	Item-to-item correlation
Frequencies of non-adherence	0.93**	0.85**
Level of non-adherence	0.84**	0.85**
Cronbach's alpha	0.85	

\*\* Correlation is significant at 0.01 level.

### *Non-adherence to PD regimen*

The alpha correlation for the construct ‘non-adherence to PD regimen’ was 0.65, suggesting that the internal consistency was not strong and that there was only a moderate correlation among the items. The high item-to-total correlation illustrated that an item assessed the relevant construct. Table 5.52 shows the Cronbach’s alpha coefficient, item-to-item and item-to-total correlation of the new subscale on non-adherence to the PD regimen.

**Table 5.52 Cronbach’s alpha coefficient and Item-to-total correlation on medication non-adherence**

Scale items	Item-to-total correlation	Item-to-item correlation
Frequencies of non-adherence	0.93**	0.57**
Level of non-adherence	0.92**	0.57**
Cronbach’s Alpha	0.65	

\*\* Correlation is significant at 0.01 level.

### **5.6.2 Criterion validity**

To assess the criterion validity of the newly developed subscales, the correlation matrix (Spearman’s rho correlation procedure) was generated between the variables of non-adherence to medication and PD regimen, and the biochemical rating of serum potassium, phosphate, calcium and albumin. The selection of the biochemistry ratings was based on the validity test, which originated from the original study of Vlaminck et al. in 2001. A new variable, calcium, was included to determine the criterion validity of the scale.

For medication non-adherence behaviour, there was a positive moderate significant correlation between the degree and frequency of medication non-adherence, and blood phosphorous level. No correlation was found between medication non-adherence, and potassium, calcium and albumin levels. For diet non-adherence behaviour, the frequency and level of non-adherence correlated positively and moderately with phosphate and negatively and weakly with calcium. There was no significant correlation between PD and fluid non-adherence behaviour as measured by the scale and the blood chemistry results. The univariate associations between blood chemistry results and each measure of non-adherence are shown in Table 5.53.

**Table 5.53 Correlation matrix DDFQ and biochemical variables**

	Potassium	Phosphate	Albumin	Calcium
Frequency of diet non-adherence Sig. (2 tailed)	.22 .05	.35** .01	-.14 .23	-.29* .01
Level of non-adherence Sig. (2 tailed)	.13 .25	.31** .01	-.12 .31	-.31** .01
Frequency of fluid non-adherence Sig. (2 tailed)	.04 .71	.15 .20	-.01 .96	-.13 .23
Level of non-adherence Sig. (2 tailed)	.07 .56	.16 .18	-.01 .94	-.13 .26
Frequency of medication non-adherence Sig. (2 tailed)	.02 .86	.31** .01	-.01 .98	-.08 .44
Level of non-adherence Sig. (2 tailed)	.02 .83	.34** .01	-.03 .82	-.06 .63
Frequency of PD regimen non-adherence Sig. (2 tailed)	-.04 .68	.11 .36	-.10 .39	.03 .81
Level of non-adherence Sig. (2 tailed)	-.02 .84	.14 .24	-.09 .42	.05 .65

\*\* . Correlation is significant at 0.01 level (2-tailed).

\* . Correlation is significant at 0.05 level (2-tailed).

### 5.6.3 Construct validity

To assess construct validity, the measures of frequency and degree of non-adherence in the four dimensions were examined using Spearman's rho correlation. There was a positive, strong, significant correlation between frequency, and degree of diet, fluid, medication and PD non-adherence. The correlation coefficient between frequency and level of diet non-adherence was 0.95,  $p < 0.001$ . The correlation coefficient between frequency and level of fluid non-adherence was 0.99,  $p < 0.001$ . The correlation coefficient between frequency and level of medication non-adherence was 0.95,  $p < 0.001$ . Lastly, the correlation coefficient between frequency and level of fluid non-adherence was 0.97,  $p < 0.001$ . These results illustrated that the items within the domain were tapping on the same kind of adherence behaviour.

With regard to the association of the various domains that measured different non-adherence behaviours, there was a positive weak to moderately significant correlation between frequency and level of diet non-adherence to medication and fluid non-adherence. There was no statistical correlation between diet non-adherence and PD non-adherence. The above results indicated that the four domains are independent of each other and measuring different non-adherence behaviours. Table 5.54 shows the correlation matrix of the scale items.

**Table 5.54 Correlation matrix for DDFQ items**

	Frequency of diet non-adherence	Level of non-adherence	Frequency of fluid non-adherence	Level of non-adherence	Frequency of medication non-adherence	Level of non-adherence	Frequency of PD regimen non-adherence	Level of non-adherence
Frequency of diet non-adherence	1.00	.95**	.28*	.29**	.21	.25*	-.07	-.08
Sig. (2 tailed)		.00	.01	.01	.07	.03	.56	.49
Level of diet non-adherence		1.00	.29**	.30**	.30	.32**	-.04	-.05
Sig. (2 tailed)			.01	.00	.01	.00	.73	.67
Frequency of fluid non-adherence			1.00	.99**	.04	.08	.47	.08
Sig. (2 tailed)				.00	.73	.51	.68	.51
Level of fluid non-adherence				1.00	.04	.07	.06	.09
Sig. (2 tailed)					.71	.54	.59	.44
Frequency of medication non-adherence					1.00	.95**	-.05	-.05
Sig. (2 tailed)						.00	.64	.69
Level of medication non-adherence						1.00	-.05	-.03
Sig. (2 tailed)							.66	.83
Frequency of PD regimen non-adherence							1.00	.97**
Sig. (2 tailed)								.00
Level of PD non-adherence								1.00
Sig. (2 tailed)								

\*\* Correlation is significant at 0.01 level (2-tailed).

\* Correlation is significant at 0.05 level (2-tailed).

## **5.7 Additional validity checks of the La Monica-Oberst Patient**

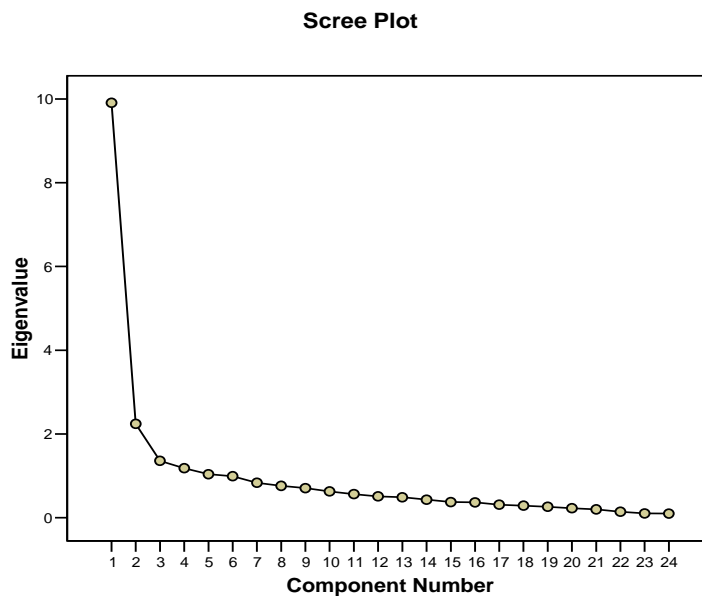
### **Satisfaction Scale (LOPSS revised version)**

The validity of the revised LOPSS was examined using factor analysis and some items were removed to ensure its suitability to the present study. In previous studies, the subjects were cancer patients and women with gynaecological conditions or undergoing childbirth. It is recommended that further analysis with other patient groups should be undertaken, to generate evidence for the overall validity of revised LOPSS (24 items). The baseline data (T1) were used for the analysis. To ensure comparability of the construct validity, as seen in the previous work of Munro, Jacobsen, and Brooten (1994), a factor analysis was performed using Principal Component Analysis with oblique rotation to estimate the underlying dimensions of the revised 24-item scale.

The results generated from the Principal Component Analysis showed that there were five factors extracted based on the initial eigenvalues greater than 1. The cumulative percentage of the five components accounted for 65.52% of the total variance. The eigenvalues of the extracted factors were 9.90, 2.24, 1.35, 1.18 and 1.03. Even though five factors were identified, several of these factors accounted for very small amounts of variance. As a result, a few of the factors did not really contribute in any way to an understanding of the structure of the data. Another criterion was therefore used to determine the number of factors to be retained for rotation by the Scree plot. All factors with eigenvalues in the sharp descent part of the

plot before the eigenvalues start to tail off could be retained. This method yielded accurate results more frequently than the eigenvalue-greater-than-1 criterion (Green & Salkind, 2005). Based on the Scree plot in Figure 5.3, it was concluded that three factors should be rotated for the scale.

Figure 5.3



To further determine whether the matrix was suitable for factor analysis, a lower p value of  $<0.05$  in Barlett's test of sphericity and the KMO  $>0.5$  were the criteria to support the use of factor analysis (Munro, 2005). The p value for Barlett's test of sphericity was  $<0.001$ , and the Kaiser-Meyer Olkin (KMO) measure was 0.85, as revealed from the analysis. These findings substantiated the suitability of factor analysis for the matrix.

Based on the eigenvalues and the Scree plot, the first three factors were rotated using a Varimax rotation procedure. The rotated solution, as shown in Table 5.55, yielded two interpretable factors. The rotated factor matrix showed that Factor 1 consisted of items on interpersonal support and Factor 2 included items on dissatisfaction with nursing services. The two-factor matrix explaining 50.62% of the total variance emerged.



**Table 5.55 Factor Loadings in the Rotated Factor Matrix for the revised 24-item LOPSS**

Item	Factor <sup>a</sup> Total rotated percent variance	
	Factor 1 41.3%	Factor 2 9.3%
<b>Interpersonal Support/Good Impression (14 items)</b>		
Is gentle in caring for me	.60	-.17
Helps me to understand my illness	.65	-.12
Understands me when I share my problems	.59	-.44
Is available when I need support	.68	-.24
Gives the impression that my care is top priority	.54	-.16
Makes me feel secure when giving care	.48	-.32
Gives complete explanations	.75	-.02
Gives directions at just the right speed	.65	-.17
Appears to enjoy caring for me	.48	-.41
Sees that I get physical assistance when I need it	.59	-.08
I can share my feelings when I need to talk	.63	-.34
Does things to make me more comfortable	.34	-.26
Just talking makes me feel better	.76	-.11
If I needed nursing care again, I would come back to this hospital.	.47	-.07
<b>Dissatisfaction (10 items)</b>		
Makes me feel like a “case,” not an individual	-.22	.36
Does not follow through quickly enough	-.13	.63
Should be more thorough	-.18	.74
Is not as friendly as he/she could be	-.30	.59
Seems more interested in completing tasks than listening to concerns	-.18	.73
Neglects to be sure I understand the importance of my treatments	-.25	.49
Acts like I cannot understand the medical explanation of my illness	-.11	.55
Does nothing with information I give	-.11	.78
Fails to consider my opinions and preferences regarding plans for my care	-.23	.54
Does not answer my phone call promptly enough	.05	-.18
<b>Eigenvalue</b>	9.9	2.2
<b>Cumulative total variance</b>	41.3	50.6

*Note:* “The nurse” was at the beginning of most items.

<sup>a</sup>Rotated factor loading of each item use of factor analysis.

Extraction method: Principal Component Analysis

Rotation Method: Varimax with Kaiser Normalization

The results of the Principal Component Analysis contained the factor loadings for each variable on each factor. A factor loading greater than 0.3 is generally considered to be indicative of some degree of relationship between the variable and the factor. The sign indicates whether the variable is positively or negatively correlated with the factor. After Principal Component extraction with Varimax rotation, the analysis of the revised 24-item scale resulted in two factors, one with interpersonal relationship and one with dissatisfaction with the nursing services. The result indicated that all except one variable were able to load well into the two factors. The last variable 'the nurse does not answer my phone call promptly enough' was unable to be loaded into any of the two factors. The item may therefore require further revision or deletion in future research. The current results were similar to those previously reported by Munro, Jacobsen, and Brooten in 1994 in which two factors instead of three were evidenced in the scale.

### **5.7.1 Reliability checks of the revised scale**

Further reliability tests were performed to determine the internal consistency of the 24-item scale. The Cronbach's alpha coefficient for Factor 1 was 0.92 and for Factor 2, it was 0.82. The results indicated that the items were homogeneous in the subscales. However, the Cronbach's alpha for the entire scale was 0.54, indicating that the subscales were measuring different traits with different constructs. The Pearson correlation between the two factors was  $r=-0.61$ , suggesting a negative correlation between the two

domains. The significant negative relationship between interpersonal support/good impression and dissatisfaction was expected because of the direction of these two scales that are supposed to be opposite each other. These findings further substantiated the diversification of the subscales in the entire scale measurement.

An instrument that may be valid for use in Western countries may not be suitable for use on Asian subjects. Since validity is not inherent in an instrument, a validity test should therefore be conducted in the context in which the test is intended to be used (Portney & Watkins, 2000). Other authors (Nunnally & Bernstein, 1994) have stated that validation is an unending process and that the validity of each use within a specific context must be documented empirically. Most measurements need to be constantly evaluated and re-evaluated to determine whether or not they are behaving as they should. This theory also applies to clinical measurements that are modifications of existing measurements. Researchers are always responsible for providing evidence to support the validity of an instrument. Given these issues, our study tried to test the validity and reliability of the measurement scales for their applicability among the Chinese patients in evaluating the nurse-led case management services.

## **5.8 Evaluation of factors associated with the outcome indicators using regression analyses**

The objective of using multiple/binary logistic regression analyses was to examine the possible factors associated with the outcome indicators. Regression makes use of the correlation between variables to develop a prediction equation. The independent variables are each assigned a weight, based on their relationship to the dependent variable (Portney & Watkins, 2000). The factors or predictors derived from regression analyses could best explain the possible underlying causes for the health-related behaviours or quality of life in relation to self-rated health among the patients in the study.

### **5.8.1 Results of logistic regression for factors associated with diet and medication non-adherence**

Diet and medication non-adherence behaviours were chosen as the outcome indicators, as these variables were able to demonstrate statistically significant effects after the nurse-led case management programme. To further enhance the adherence behaviours, it is worthwhile to analyze the predictors that determine non-adherence behaviours with nursing intervention to focus on the predictor variables.

#### *Dependent variable*

Dietary adherence at T2 was assigned as the dependent variable for logistic regression analysis. The measure was on a 2-point scale (1=does not

adhere to dietary/medication advice, 0=adherence to dietary/medication advice). In the analysis, the value of the 50<sup>th</sup> percentile was used as the cut-off point to differentiate adherence and non-adherence behaviours. The values below the 50<sup>th</sup> percentile were considered as adherence, while values above the 50<sup>th</sup> percentile were considered as non-adherence. Therefore, having a frequency of 0-1 days in a week of non-adherence to the treatment regimen was coded as 0 (adherence), and a frequency of 2-7 days was coded as 1 (non-adherence).

Patients who showed non-adherence to the diet and medication regimen constituted the referent group in all analyses. Other independent variables, such as fluid and PD regimen non-adherence, were not included because correlations did not exist between these variables and the independent variables.

#### *Independent variables*

Statistical procedure was used to determine the various factors associated with dietary non-adherence. The univariate analysis Spearman's rho correlation was performed to look into the associations between age, years of peritoneal dialysis, educational attainment, gender, existence of comorbidity and whether patients lived with the family. Of these factors, age and the number of years on peritoneal dialysis were significantly associated with dietary non-adherence behaviour. Table 5.56 shows the correlation matrix of the dependent and independent variables.

**Table 5.56 Association of variables with non-adherence behaviours at six weeks post-discharge**

Variable	Diet non-adherence		Medication non-adherence	
	Correlation Coefficient	Significance	Correlation Coefficient	Significance
Age	-0.17	0.14	-0.25	*0.03
Gender	-0.15	0.20	-0.13	0.26
Years of PD	0.40	*0.02	0.08	0.50
Comorbidities	0.04	0.72	0.01	0.98
Living with family	-0.12	0.31	-0.05	0.67
Education	0.16	0.16	0.22	0.05

\* Correlation is significant at 0.05 level (2-tailed).

The variables were coded into either binary or categorical variables. The number of years on PD regimen was coded into four categories: 0 = 0-3 years, 1 = 4-6 years, 2 = 7-9 years, and 3 = 10-12 years. Educational attainment was in three categories: 0 = primary education or below, 1 = secondary education, 2 = tertiary education or above. Living with the family and comorbidities were in two categories: 0 = live alone, 1 = live with family members; 0 = no major disease other than end-stage renal failure, 1 = with other diseases.

### **5.8.1.1 Diet non-adherence**

To identify the predictive factors associated with diet non-adherence at six weeks after intervention, potential predictors (those with significant differences in previous univariate analysis) were included in the logistic regression for analysis.

The above variables were entered into a comprehensive logistic regression that simultaneously considered the effects of these factors on dietary non-adherence. Using the “Enter” procedure, all the variables were entered together in each step. The variables retained in the final model were significant at 0.05 level. Model tests fitting (-2 Log Likelihood =73.62,  $\chi^2=30.88$ , df=10, p=0.001) and goodness-of-fit (Pearson  $\chi^2=4.67$ , df=8, p=0.79) indicated the data fitted this model. The approximately estimated Nagelkerke R square was 0.45.

The final model showed that age and sex were the only predictors of diet non-adherence behaviour. Patients’ age and sex were found to be significantly associated with diet non-adherence six weeks after discharge from the hospital. The greater the age, the less likely it was associated with diet non-adherence behaviour (OR= 0.94, 95%CI: 0.89-0.99, p<0.05). Males had a lower incidence than females in terms of self-reported diet non-adherence (OR= 0.14, 95%CI: 0.027-0.68, p<0.05). The results showed that men and older people had a lower probability of diet non-adherence six weeks after hospital discharge. The overall rate of correct classification was 76.3%. Table 5.57 shows the results of the logistic regression model of diet non-adherence.

**Table 5.57 Summary of the logistic regression model (Enter) to predict non-adherence to diet regimen**

<b>Predictors</b>	<b>Beta coefficients</b>	<b>Significance</b>	<b>Odds ratio</b>	<b>95% C.I. for EXP (B)</b>	
				<b>Lower</b>	<b>Upper</b>
<i>Age</i>	-0.06	<b>0.026*</b>	0.94	0.89	0.99
<i>Gender</i>					
Female			1		
Male	-1.99	<b>0.015*</b>	0.14	0.027	0.68
<i>Education</i>					
Below primary			1		
Secondary	-0.95	0.19	0.38	0.09	1.60
Tertiary or above	1.75	0.25	5.80	0.29	116.92
<i>Comorbidities</i>					
No			1		
Yes	1.19	0.09	3.28	0.80	13.45
<i>Lives with family</i>					
No			1		
Yes	-0.36	0.71	0.70	0.10	4.73
<i>Yrs on PD</i>					
0-3 years			1		
4-6 years	0.88	0.16	2.43	0.69	8.57
7-9 years	23.36	0.99	1.41E+10	0.00	
10-12 years	1.13	0.44	3.01	0.18	54.19
<i>Group</i>					
Control			1		
Study	-0.44	0.45	0.64	0.20	2.03

\*p<0.05

### **5.8.1.2 Medication non-adherence**

To identify the predictive factors associated with medication non-adherence at six weeks after intervention, potential predictors (those with significant differences in previous comparison) were included in the logistic regression for analysis.

The above variables were entered into the logistic regression to simultaneously consider the effects of these factors on medication



non-adherence. Using the “Enter” procedure, all variables retained in the final model were significant at 0.05 level. Model tests fitting (-2 Log Likelihood =52.23,  $\chi^2=20.37$ ,  $df=10$ ,  $p=0.03$ ) and goodness-of-fit (Pearson  $\chi^2=9.05$ ,  $df=7$ ,  $p=0.25$ ) indicated the data fitted this model. The approximately estimated Nagelkerke R square was 0.38.

The final model showed that patients’ education level, comorbidities, and assigned treatment group were found to be significantly associated with medication non-adherence six weeks after discharge from the hospital. Patients with secondary school education reported a higher incidence of medication non-adherence than patients who had lower educational attainment (OR= 6.62, 95%CI: 1.05-45.62,  $p<0.05$ ). Similarly, patients who were suffering from other diseases reported more medication non-adherence than those without comorbidities (OR= 13.26, 95%CI: 1.50-117.55,  $p<0.05$ ). Finally, the study group patients had a lower probability of medication non-adherence than the control group (OR= 0.22, 95%CI: 0.046-0.98,  $p<0.05$ ). The results showed that patients with a higher education level and who were suffering from other diseases, as well as the control group reported greater medication non-adherence than their counterparts. The overall rate of correct classification was 89.5%. Table 5.58 shows the results of the logistic regression model of medication non-adherence.

**Table 5.58 Summary of logistic regression model (Enter) to predict non-adherence to medication regimen**

<b>Predictors</b>	<b>Beta coefficients</b>	<b>Significance</b>	<b>Odds ratio</b>	<b>95% C.I. for EXP (B)</b>	
				<b>Lower</b>	<b>Upper</b>
<i>Age</i>	-0.06	0.09	0.94	0.88	1.01
<i>Gender</i>					
Female			1		
Male	-0.46	0.61	0.63	0.11	3.74
<i>Education</i>					
Below primary			1		
Secondary	1.89	<b>0.05*</b>	6.62	1.05	45.62
Tertiary or above	0.19	0.90	1.20	0.06	23.37
<i>Comorbidities</i>					
No			1		
Yes	2.58	<b>0.02*</b>	13.26	1.50	117.55
<i>Live with family</i>					
No			1		
Yes	-0.85	0.54	0.43	0.03	6.22
<i>Yrs on PD</i>					
0-3 years			1		
4-6 years	-0.19	0.83	0.83	0.15	4.69
7-9 years	-1.06	0.43	0.35	0.03	4.81
10-12 years	-19.73	0.99	0.00	0.00	
<i>Group</i>					
Control			1		
Study	-1.51	<b>0.05*</b>	0.22	0.04	0.98

\*p<0.05

### **5.8.2 Results of multiple regression for factors associated with self-rated health and Kidney Disease Quality of Life (KDQOL-SF)**

The one-item subscale in the Kidney Disease Quality of Life was assigned to examine patients' self-reported health status from 0 to 10 in a 10-point Likert scale. To examine the relationship of self-rated health and quality of life, multiple regression was conducted with self-rated health as the dependent variable at six weeks after discharge. Univariate correlations were used to test the linear relationships between self-rated health and the

variables that measure quality of life, specifically in relation to kidney disease. A multiple regression procedure was conducted to examine the contribution of the selected kidney disease variables and self-rated health (with a p-value of 0.05 or less from the univariate analyses).

The variables that had a significant correlation with self-rated health included physical role, emotional well-being, social function, symptoms, effects of kidney disease, quality of social interaction and sleep ( $p < 0.05$ ). Other demographic variables, such as comorbidities, living with the family, number of years on peritoneal dialysis, and patient group were also included in the regression analysis. Nominal-level variables were coded using dummy coding, such as comorbidities, whether or not the patient was living with the family and patient group (Munro, 2005). The stepwise regression model was significant (adjusted  $R^2 = 0.33$ ), with emotional well-being, sleep and effects of kidney disease accounting for 33% of the variance in the regression analysis ( $p < 0.05$ ). The result for the patient group approached a significant difference with  $p = 0.08$ . Table 5.59 shows the results of the multiple regression analysis.

**Table 5.59 Predictors of self-rated health at six weeks post discharge, multiple regression result**

<b>Predictors</b>	<b>Regression Parameter (Beta)</b>	<b>t-Statistics</b>	<b>P-value</b>	<b>Tolerance</b>	<b>VIF</b>
Patient group	0.16	1.76	0.08	0.95	1.04
Emotional well-being	0.24	2.01	0.04*	0.61	1.62
Sleep	0.25	2.51	0.01*	0.86	1.15
Effects of kidney disease on daily life	0.27	2.37	0.02*	0.65	1.55
Years having PD	-0.02	-0.19	0.84	0.94	1.06
Comorbidities	0.04	0.42	0.67	0.93	1.07
Lives with family	-0.02	-0.16	0.86	0.97	1.03
Physical role	0.05	0.5	0.61	0.90	1.10
Social function	-0.03	-0.32	0.75	0.77	1.29
Symptoms	0.08	0.69	0.47	0.61	1.62
Quality of social interaction	0.18	1.44	0.15	0.59	1.69
(Constant)		1.83	0.07		

VIF (variance inflation factor): The higher the VIF value, the more unstable the regression estimation.

## **5.9 Conclusion of section 2**

This chapter presented the results, focusing on an examination of the psychometric properties of the research instruments. The construct and criterion validity, and internal consistency of the DDFQ were tested. The new subscales were to provide a comprehensive assessment of the non-adherence behaviours of PD patients. An additional validity check of the LOPSS was examined using factor analysis. The revised 24-item scale resulted in two factors which were similar to those of the previous validation, conducted in 1994 by Munro. Further reliability tests using Cronbach's alpha further substantiated the two-factor structure of the scale. The results of the logistic regression analysis provided new insights into the predictors of diet and medication non-adherence. The relationship between self-reported health and quality of life was examined using multiple regression analysis.

## **CHAPTER 6**

### **DISCUSSION**

This chapter discusses the study's results, which were summarized in Chapter 5 in relation to the research objectives and the hypotheses presented in Chapter 2. These results are discussed in light of previous studies and the literature and are followed by a discussion on the predictors of the target patient-related outcome variables. This chapter also presents a discussion of the psychometric properties of the research instruments used in the study.

This study revealed significant differences in patient satisfaction, diet and medication adherence behaviours and some of the variables in Kidney Disease Quality of Life. However, there was no significant change in utilization of health care services, or in symptoms and complication control. The results of this study confirm that the use of a nurse-led case management programme significantly improves patients' quality of life, satisfaction in health care services and health related behaviours in a sample of renal patients receiving peritoneal dialysis and living in community settings.

Overseas studies have demonstrated the impact of an approach that incorporates nurse-led case management as an intervention to achieve desirable outcomes for chronically ill patients. The outcomes consisted of high patient satisfaction, lower hospital readmission, decreased length of

stay in the hospital, and ultimately, a decrease in health care costs (Katz et al, 2001; Weinberger et al, 1998; Cline et al, 1998; Naylor et al 2004). This study is one of the first randomized controlled trials to investigate the effect of nurse-led case management intervention on renal patients in Hong Kong.

The provision of an effective health care service for end-stage renal failure patients is considered essential, as the outcomes are not only beneficial to the patients but also to the health care system at large. This study provides empirical evidence for a nurse-led case management model that incorporates a multidisciplinary approach to facilitate patient referral, continuous monitoring after discharge from the hospital, collaboration across specialities and efficient utilization of available resources to promote the well-being of patients on peritoneal dialysis. The success of the model yielded encouraging results, as only renal unit nurses were employed as case managers in organizing services for the patients. The arrangement facilitated mutual trust in the nurse-patient relationship as these specialist renal unit nurses, with their depth of knowledge and understanding of the system, were better able to relate to the patients in the study and to negotiate change and collaborate with physicians and other health care team members. This model offers a framework to address the needs of patients who require continued, close follow-ups and coordination of care following discharge after an acute hospital admission. Nurse-led case management is the process of coordinating resources in such a way as to improve the wellbeing

of patients and improve the health care delivery system through advanced nursing practices.

Despite the positive development and success of the nurse-led case management programme in countries such as the USA and the UK, there has never been any formal and structured programme implemented in Hong Kong for end-stage renal failure patients on dialysis. Some hospitals have implemented small-scale and less well-structured projects in similar fashion to provide continuity of care to chronic or elderly patient groups. Most previous attempts have been focused on elderly patients in the community, and scarce attention has been given to promoting the well-being of patients on peritoneal dialysis. Other hospitals are reluctant to use the nurse-led case management programme due to a lack of understanding of the case manager's role and the unclear procedures regarding the actual implementation process. The investigator tried to develop a case management protocol that emphasized pre-discharge assessment, discharge planning, patient education and telephone follow-up for renal patients receiving peritoneal dialysis. This study explored a new model of care by assisting patients with complex discharge needs to collaborate with nurse case managers for continuity of care. Not only was the aim to arrange and organize discharge services for the renal patients, but it was hoped that these services would be adequately and effectively provided to the patients both before discharge and after hospitalization, utilizing pre-discharge assessment and telephone follow-ups.



## **6.1 The effectiveness of case management and discharge planning in improving the process of care**

The purpose of this study was to examine the effects of the nurse-led case management programme on discharge planning and the continuity of care for hospitalized PD patients. The independent variable, a nursing model on discharge planning and continued follow-up, was of primary interest. The outcome components focused on the programme's impact on the total well-being of the patients.

The new model presented in this study emphasises the nursing process, which includes assessment, planning, implementation, and evaluation. This new model differs from those interventions tested previously by other studies, in the following ways. The comprehensive strategies included pre-discharge assessment, patient education, and post-discharge telephone follow-ups with mutual goals established by the patient and the nurse. The patient outcomes commonly measured in the discharge planning literature were, hospital length of stay, cost of care, hospital readmissions and patient satisfaction. The most frequently used outcome measure presented in most of the empirical studies was hospital length of stay. The outcome variables in the present study encompassed patient-related and health system variables, such as patient satisfaction, symptom and complication control, adherence to treatment regimen, quality of life, and health service utilization.

### **Transitional care in the nurse-led case management programme**

In this study, the nurse case managers offered flexible and individualized strategies through the assessment of individual patient needs in order to decide the best possible proactive planned care. The nurse-led case management programme is regarded as a “transitional care model”. The essence of this model resembles the account by Schaefer and Davis (2004) that through the case management programme, patients are informed and are able to understand their chronic conditions, including what to expect from the health care system. The nurse-led transitional care model by Clark and Nadash (2004) focused on improving the transition from hospital to home care by improving transitional discharge practices. Different case management models have been used for different disease-specific interventions or in different practice settings. There is no one model that is able to accommodate and is applicable across all conditions and risk factors. In each trial, the intervention strategies should be determined by protocol and provider judgement, rather than by health care reimbursement plans (Brooten, Naylor, York, Brown, Munro, Hollingsworth, Cohen, Finkler, Deatruck & Youngblut, 2002). The adoption of any specific model should therefore refer to patients’ practical needs and respond to ad hoc environmental changes. Other models should also be explored to facilitate care within the complex treatments for patients receiving dialysis. Lastly, the model of care in this study is patient-specific rather than disease-specific: the programme aims to offer multiple modalities to patients and families on

stabilizing patient condition and emphasizing the role patients must play in managing the disease.

Case management should be a system of care that is collaborative, coordinated and resource efficient. Any nursing interventions that merely focus on cost containment are not considered to be true case management models. The highest level of patient-centred interventions are individualized interventions that include highly customized strategies to suit the health care needs and individual situations of patients (Lauver, Gross, Ruff & Wells, 2004). In working with patients to assist them in changing their behaviours, goal setting as a shared activity between health professionals and patients is important in order to achieve lifestyle changes (Stuifbergen, Becker, Timmerman & Kullberg, 2003). The new model of case management in this study involved the abovementioned concept, which brought about positive results for PD patients. The protocol focused on addressing the individual needs of the patients and their families, delivering nursing interventions at the appropriate time, providing continuous support during the transitional and stable phases of post-discharge, developing mutual goals by the nurse and the patient, a multidisciplinary approach, and utilizing an effective and successful referral system. Crumbley, Ice, and Cassidy (1999), who reported that chronically ill patients who generate enormous health care costs are at a higher risk of non-adherence to medical regimens, require special support and should benefit greatly from a case management programme.

## **6.2 The influence of patient education on discharge planning**

Patient and family education is an important aspect of chronic transitional care nursing. Holistic discharge planning bridges the gap between the hospital and the community, thus ensuring the continuity of care. Nurses need to concentrate on instilling knowledge into patients on different therapy regimens, especially to the elderly and patients lacking in formal schooling.

### **Key issues on patient health education**

The significant differences revealed in patient satisfaction and adherence behaviours in this study was related to the fact that the focus of patient education was aligned with patient assessment to develop an individual view of the patient's condition, and addressed the specific learning barriers of the individual patient. The focus of education is not solely on teaching patients about diet, medication, activity and follow-up; it also covers the early assessment of patient care needs (Tilus, 2002). Patient teaching or education may be carried out through face-to-face teaching, telephone consultations, pamphlet and educational material distribution for self-learning, and the use of new technology, such as the internet. To achieve the best learning results, the case managers should identify the appropriate teaching content that works in line with the psychosocial responses, as well as the learning needs of the patients. Even if a teaching protocol is developed in advance, based on the experiences of the renal nurses and the investigator, or the protocol has already been validated by experts in the

related area, its further refinement should be considered so that it meets the needs of the specific patient population.

Regarding the suitable time for patient education, the implementation must consider patients' readiness to learn. In this study, the case manager tried to provide comprehensive discharge education to patients and their families at a date as close to the day of discharge as possible to ensure patients' readiness to learn. It was found that people learn best when they need the information urgently, and particularly, when they are about to be discharged home. As Whitman (1998) illustrated, education provided during the early stages of hospitalization is of little use for the recovery, as the huge physical demands of the disease result in reduced energy levels for learning. As such, the nurse case manager schedules the health teaching programme at a date close to the day of discharge to ensure effectiveness of the learning outcomes in the continuity of care and the integration of evidence-based intervention into practice.

### **Individualized patient teaching and evaluation**

In view of the whole phenomenon of nurse-led case management, the provision of individualized health teaching and evaluation at the appropriate time could enhance the development of collaborative partnerships, and increase the means to improve the productivity and quality of care delivered. Most of these contributions do not only provide functional service but also

fulfil the new role of providing seamless care and working as an appraiser within the domains of nurse-led case management.

In this study, 50.6% of the patients had primary or lower educational attainment. Patients who have had little schooling present a challenge to the case managers for patient education. These patients are often unable to assimilate the same amount of information as those patients who are well educated. The use of oral teaching, supplemented by audiovisual materials is necessary when teaching patients who are illiterate or who have low educational attainment. An issue that is often neglected by the nurse is the evaluation of learning outcomes in terms of teaching quality or patient outcomes. It is the responsibility of the case manager to measure teaching effectiveness through the knowledge gained by the patients. The evaluations are to be conducted during follow-up telephone interviews or out-patient clinic visits. In this study, the telephone follow-ups were considered to be a very effective means in reinforcing and evaluating the teaching content, which was previously given to the patients in the hospital. Moreover, the telephone follow-ups afforded the patients the opportunity to clarify with the nurses any misconceptions on the information given. The follow-up telephone interviews after discharge served both the purpose of intervening on health-related behaviours or triage for physiological problems, and as a reinforcement and evaluation tool for pre-discharge patient education.

The pre-discharge education provided to patients is not solely focused on providing health information or meeting the needs of the “average” patient. There are many factors that can present barriers to learning, such as culture, belief systems, age, physical or mental disabilities and educational attainment (Boyd, Graham, Gleit & Whitman, 1998). The case managers may be unable to completely eliminate these barriers, but effective teaching is an essential component of care, ensuring the maximization of patient learning. As with other chronic conditions, end-stage renal failure patients need to absorb a large quantity of information prior to discharge. This information is best presented by nursing staff able to relate well with the patient, enabling the patient to more clearly understand the condition and the requisites of self-care. Consideration of the context of each individual patient’s needs should be the key to providing effective health teaching, in addition to a standardized protocol or checklist. It is only through individualized education that nurses can help to increase patients’ ability to survive the disease and to optimize adjustment in the community.

### **6.3 Telephone intervention as the therapeutic regimen for continuity of care after discharge**

The results of this study suggest that the use of standardized protocols for telephone interviews after discharge was able to bring about positive patient outcomes through continuity of care. In Hong Kong, the use of the telephone is inexpensive, efficient, widely accessible, and convenient for coordinated care for discharged patients.

The results of the present study demonstrated that through a bi-directional approach, the nurse case manager was able to assist patients and their families in solving everyday problems and in providing feedback to them on the appropriateness of the techniques they were using to manage the disease. Each telephone contact concluded with the nurse summarizing the main points covered and emphasizing the objectives mutually agreed upon for the next telephone contact. It is of utmost importance for nurses to provide clearly understandable advice to the patients. In addition, the pre-discharge family assessment enabled the nurse case manager to have a deeper understanding of the patient's profile such as his/her level of adherence to health-related behaviours, knowledge related to diet and medication, problem-solving capabilities, and education needs. The systematic and thorough pre-discharge assessment would guide the nurse in prioritizing the patient's needs and in ensuring that the intervention strategies were tailor-made, hence resulting in improved patient well-being through telephone follow-ups. As previously stated, telephone follow-ups serve the purpose of reinforcing and evaluating the effectiveness of health teaching that has been given prior to discharge.

Cost containment in health care services is motivating members of health care teams to develop innovative ways to meet the needs of medically complex patients (Driver, Hinegardner, Rea, Reed & Ward, 2001). As part of a chronic disease management strategy, telephone services can improve outcomes and decrease treatment costs. Telephone-supported diabetes care



demonstrated empirical evidence in improving glycaemic control and patient adherence behaviour (Wong, Mok, Chan & Tsang, 2005; Piette, Weinberger, Kraemer & McPhee, 2001). Depending on each patient's abilities, limitations, outside support, resources availability, and home situation, the discharge process can be an overwhelming experience. Telephone care has been used widely in primary care settings and as an adjunct to hospital discharge programmes (Shu, Mirmina & Nystrom, 1996). Most importantly, telephone follow-ups offer opportunities to provide emotional support to patients between hospital and home.

The use of telephone interviews is considered a partnership programme between the nurse and the patient. The interview protocol in this study contains the elements for designing the service and subsequent checks for quality control. In addition, the questions raised during telephone follow-ups suggested the topics that needed to be revised or added to the standard discharge instructions. For example, many patients raised questions on bowel function, daily activities, bodily pain, and insomnia, which generally received little attention during the giving of discharge instructions. Hence, a telephone interview is able to reinforce the discharge instructions and thus benefit the discharge process.

The results from this study provide evidence that telephone interventions after discharge have beneficial effects in the management of patients with end-stage renal failure. Telephone counselling may be used as an extension

or substitute for traditional out-patient care and can result in better adherence behaviour, increased patient satisfaction with the services and improved quality of life. The study results also revealed pain reduction and better quality of sleep in the study group after the series of telephone follow-ups that were made.

### **6.3.1 Nurse dose for telephone intervention**

Regarding the frequency of telephone interviews after discharge, the therapeutic intervention normally depends on the intensity of the treatment or the seriousness of the condition. The case managers contact the patients in an attempt to review and resolve any unmet needs, in order to achieve desirable outcomes. Nurse dose refers to the amount and type of nursing interventions needed to effect patient outcomes (Brooten & Naylor, 1995). The case manager is required to determine the types of patient outcomes that are to be measured, and decide the type and amount of nursing interventions needed according to the specific health care environment.

Non-adherence, unmet social needs, unrecognized clinical deterioration, and inadequate patient education have all been implicated as reasons for preventable admissions (Fitzgerald et al., 1994). The frequencies of telephone calls vary among clinicians in different health care settings, from just one intervention to a series of prolonged follow-ups for 12 months. Regardless of the frequency of intervention, the important issue to be considered is the type of patient outcomes that should be measured. The

purpose of the telephone contact is therefore to effect patient outcomes and to demonstrate the successfulness of the interventions. Brooten's report in 1995 on the 'nursing dose' needed to effect patient outcomes through telephone follow-up and home visits by community nurses demonstrated effectiveness of up to six weeks post-discharge but not beyond the six week period. This study design was based on Brooten's model on transitional care. The discharged patients in the study group were followed up by the case managers through telephone calls for six weeks post-discharge. The community nursing services were made available only to high-risk patients, or those patients who were in need of frequent and close monitoring of medication adherence and health care delivery.

Unlike patients suffering from other acute or subacute diseases, the study results demonstrate that chronic renal patients require a longer period of continuous intervention after discharge. For example, the adherence behaviour for medication showed that the significant result was observed at T1 and T2 comparison, which was during and immediately after the intervention phase. The effects diminished across time, as revealed by T1 and T3 comparison, which indicates the non-sustainability of the interventions. For diet adherence, although the results represent clinical improvement, the initial effect of the intervention required further nursing dose to maintain a more robust improvement over time. For the parameters on quality of life, some of the perspectives suggest non-sustainable case management interventions. The specific areas include how patients were

bothered by the effects of kidney disease on everyday life, including stress, sex life and being dependent on doctors, the extent to which patients were bothered by the symptoms and pain intensity. Although significant differences were noted during the sixth week of the follow-up sessions, no significant differences were observed at the baseline and 12-week comparisons. To minimize the risk of a further drop in the quality of life of renal patients, close monitoring and continued nursing interventions are crucial to the success of managed care.

Lastly, we have at issue, the question of what outcome the research will measure. It is well-known that, where empirical studies are concerned, informative data such as mortality and morbidity rates are the key measures for treatment success. However, looking at these variables alone does not yield enough data to understand the effects of nursing interventions, as these outcomes are confounded by the practices in other health care disciplines within the team (Naylor, Munro & Brooten, 1991). For nurse-sensitive outcomes, such as maintaining the quality of patients' lives, the process involves nursing activities in making an improvement in the outcomes. Nurse-led case management is considered an extension of the practice of professional nursing. The therapeutic dose thus requires an analysis of the intensity of treatment or the specific disease conditions. Nurse case managers should try to select and test the different nursing doses within different clinical environments, cultures, and patient groups. Only through

continuous empirical research and evaluation can nursing intervention be tailored to the needs of specific patient groups in transitional care.

Another emerging role of the nurse case manager is as an agent of change. Nurse case managers act as role models in promoting and leading change by encouraging other health care professionals to adapt to the new method of care delivery (Cohen & Cesta, 1997). The challenge for nurses, therefore, is to confront ambiguous practices and improve conventional services within the context of patient care. New practices are to be empirically and critically tested, using sophisticated research methods to verify whether the changes are within the realm of scientific, evidence-based practice.

#### **6.4 Improvement of outcomes by discharge planning and follow-up interventions**

The following sections will present the discussions on patient-related and clinical outcomes as a result of the nurse-led case management interventions.

##### **6.4.1 Patient satisfaction**

Patient satisfaction is a valid indicator for the measurement of service quality. Nursing care plays an important part in overall patient satisfaction with health care services. Patient satisfaction with service therefore involves measuring both the quality of the nursing service and the health care facility. This is considered an aspect of psychological patient outcome,

regardless of physical health status (Gonzalez-Valentin, Padin-Lopez & Ramon-Garrido, 2004).

In reference to the hypothesis being tested in this study, there were statistically significant differences in the between group, within group, and in the interaction effect of the repeated measures analysis. Therefore, the null hypothesis, which states that there is no difference in patient satisfaction between the study and control groups, is rejected.

Multiple studies on patient satisfaction have been reported over the decades using different methodologies and measurement scales according to the purpose of the studies. The revised 24-item, La Monica Oberst Patient Satisfaction Scale used in this study appraised patients' perception of the nurse case manager's services. The items were summed up for each patient in the cohort and a higher score represented a higher level of satisfaction. The scores of the control group remained consistent, with mean scores of 84.58 – 85.75 recorded out of a possible 120 points across the three time intervals. The highly positive results from the study group patients showed that they were highly satisfied with the quality of services received from the case manager and through the facility, and were less dissatisfied with the negative behaviour of the case manager, as stated in the questionnaire. The mean scores of 86.66 – 92.21 were recorded across the three time intervals. Most importantly, satisfaction was retained despite the discontinuation of the interventions.

The nurse-led discharge planning and collaborative model offers a new directive to address the continuum of patient-needs during hospitalization and after hospital discharge. Through the empowerment approach and mutual goals developed between the nurse and the patient, nurse-patient relationship was enhanced. The resulting, overall differential score of patient satisfaction among the two groups substantiated the assertion that their satisfaction with the nurse-led case management services was high.

The majority of studies on patients' satisfaction have revealed high levels of satisfaction if intensive nursing care was received. To avoid bias in the data collected in this study, a member not associated with patient care delivery administered the questionnaires. The patients indicated very positive responses when asked about the issue. The results yielded positive findings rather than revealing patients' negative feelings towards either the nursing staff or the facilities. Since the scale was revised and specifically asked for patients' perceptions of the nurse case manager, the data collected solely reflected either the degree of satisfaction with the nursing care received from the case manager in the study group or the satisfaction with the general nursing staff in the control group. These results agree with those of Munro, Jacoben, and Brooten (1994), in which patients receiving intensive nursing care gave higher scores on the LOPSS than those receiving standard care. The high level of satisfaction with case management services was an indicator of the tested model's excellent nursing services.

### **Other issues regarding patients' satisfaction to service**

Thomas and Bond (1996) stated that if the purpose of a piece of research is to evaluate an outcome for particular nursing interventions, tools have to be psychometrically robust, specific, and sensitive to the intended interventions. The revised LOPSS in the study, which underwent stringent validity and reliability analyses, demonstrated good psychometric properties. The constructs of the scale focused mostly on interpersonal support and dissatisfaction between the nurse and patients, with less emphasis placed on the technical procedures. The structure of the constructs was considered appropriate in evaluating patients' satisfaction with case management services in transitional care.

While the implication of this study's findings on satisfaction was substantially positive, a few patients did reveal certain negative sentiments to the investigator. Often, patients preferred to verbalise their feelings to the interviewer rather than put them in writing on the questionnaire while completing the interviews. One frequently mentioned concern was that of insufficient manpower in the hospital, which affected the health care staff's ability to respond to patients' requests and needs during hospitalization. Other concerns included the long waiting time during out-patient follow-ups and the overcrowded environment of the out-patient clinic. Despite the statistically significant difference in patient satisfaction noted in the group in this study, some members of both the study and control groups revealed a certain degree of dissatisfaction during the interviews. This discontent was not related to the case manager's service but was associated with the overall



services of the facility. In relation to this, Zahr, Soheir, and El-Hadad (1991) noted that patients may be hesitant to express negative feelings about the nursing care they receive, due to an awareness of their possible dependency on that care in the future. Furthermore, patients may feel that their feedback may not bring about any desired changes and, therefore, just do not bother to express their true feelings anymore.

In order to delineate and capture the true picture of patient satisfaction with service, interview techniques and strategies are of equal value to the use of a sensitive and reliable instrument. A good interviewer and patient rapport, a comfortable and safe environment, good probing skills, reassurance of service improvement following feedback, a qualitative and quantitative approach for data collection and support of the patients throughout the interview process are the required skills for valid data collection. Lastly, it must be ensured that the true feelings of the patients, whether positive or negative, are captured during the interviews for genuine service improvements.

There is one crucial issue that researchers need to bear in mind: health care quality improvement is the ultimate purpose of the patient survey. It is common to receive positive feedback from patients since they believe it is required of them as an act of courtesy. They prefer to give positive feedback, rather than negative comments about the staff concerned after receiving special interventions. Therefore, case managers should try to look into the various aspects that warrant further investigation, as the high

positive results may be deceptive in some circumstances. Obtaining the patients' perspective is an important component of evaluating health services, and as such, patient surveys should form a routine part of the assessment of case management services.

#### **6.4.2 Symptoms and complication control**

The outcome measures for symptom and complication control in the study include an examination of changes in blood chemistry, percent change in body weight, level of oedema, existence of peritonitis and exit site condition across the study period.

The blood chemistry results demonstrated significant within-group (time) effects in the serum levels of sodium and potassium. No statistically significant differences were identified in serum haemoglobin, albumin, urea, creatinine, calcium and phosphorous levels. The results demonstrated a significant difference attributed to the control group and not to the study group after repeated measures analysis. For outcome measures on symptoms and complication control, significant differences were noted in the reduction of peritonitis in both groups of patients. No statistical treatment effect was found on percentage body weight change, exit site condition and level of oedema.

#### **6.4.2.1 Blood chemistry results**

The variables that influence blood chemistry results include diet, medication and dialysis adherence. In addition to checking on self-reported adherence to the treatment regimen, blood chemistry testing also offers a relatively reliable means of measuring the level of adherence. Weight gain and serum potassium and phosphorous levels are the three major indicators of diet adherence behaviour for dialysis patients (Brown & Fitzpatrick, 1988; Rushe & McGee, 1998). Despite the presence of significant treatment effects on medication adherence in the study group patients, the blood chemistry results did not seem to improve in line with the adherence behaviours. This indicates that behaviour changes do not necessarily translate into immediate symptom improvements but may instead require a longer follow-up period before the desired health outcomes are achieved. The findings echoed those of Howe, Jawad, Tuttle, Moser, Preis, Buzby, and Murphy (2005) who reported that subsequent improvement in disease control required patients to develop positive, progressive and sustained health related behaviours. Other scholars (Connelly, 1993 & 1987) also related the limitations in applying the concepts of patients' adherence behaviours to the successful management of chronic illness. Patient adherence did not necessarily result in achievement of treatment goals and some patients, who only partially adhered to their treatment, appeared to do well.

Preventing the effects of chronic diseases from taking a heavy toll on patients requires the support of the health care system and sustained behavioural changes from the patients, which includes adherence to effective long-term therapies. Neither the acute nor the chronic care nursing model was able to change all of the clinical outcomes. Therefore, the goal of nursing intervention is to try to stabilize the symptoms to improve patients' quality of life. According to Corbin, (2001) the key goal in nursing management of stable, chronic disease is to maintain that stability. However, when patients are in the unstable trajectory phase, the main nursing goal is to return to the stable phase. To date, most researches have concentrated substantively on the notion of keeping symptoms under control and preventing the reactivation of illness. The trajectory framework offers nursing professionals a foundation for developing a model of nursing care that is specifically geared toward the problems of the chronically ill by clearly defining the realistic and feasible intervention focus. Naylor, Munro, and Brooten (1991) stressed that the concept of outcome should specifically focus on patients' well-being and a priority should be to link outcomes to processes of care, as some of the outcome measures have significant limitations, to examine the impact of nursing interventions.

The intervention model in this study aimed to reduce infection, improve education, and increase treatment adherence in order to maximize therapy success. The results of this study showed that, through discharge education and continuous support and encouragement to patients and their families by

means of telephone interviews, the patients were able to maintain their normal serum sodium and potassium levels. The within-subject effect was attributed to the control group patients. Despite this, the mean sodium (135.44–137.63 mmol/L) and mean potassium levels (3.7–4.09 mmol/L) of both the study and control group patients remained within normal values during the course of the study. The normal range of sodium lies between 135–145 mmol/L, while that for potassium is 3.5–5.0 mmol/L as stated by Longmore, Wilkinson, and Torok (2001). Serum potassium and serum sodium are two of the valid indicators of diet adherence. These favourable outcomes could be related to the continuous encouragement of case managers and nurses regarding medication and diet adherence, to all the patients during hospitalization and out-patient visits.

Both the study and control group patients were able to achieve the normal range of blood calcium level but the serum albumin level was slightly reduced from the normal range of 35–50 g/L (Longmore, Wilkinson, and Torok, 2001) in both groups. The mean values were 32.90–33.89 g/L and 32.73–33.50 g/L for the study and control groups, respectively. The blood phosphorous level in both groups was raised from the normal range of between 0.8–1.45 mmol/L (Longmore, Wilkinson, and Torok, 2001) to a mean of 1.77–1.88 mmol/L and 1.92–2.07 for the study and control groups, respectively. Nevertheless, the study group patients had more satisfactory blood phosphorous results as compared to the control group. The desirable normal range for serum haemoglobin level is within 11.5–15 g/dL. The

mean blood haemoglobin for the control group was 8.91–8.94/dL, while that for the study group it was 8.56–9.13/dL during the course of the study. Although these results showed no statistically significant difference, the study group patients demonstrated greater improvement over the control group. For serum urea and creatinine levels, both the study and the control group patients were unable to achieve the desirable or normal laboratory results.

Effective nursing interventions were able to maintain the stability of certain blood chemistry values through the assessment of the nutritional status of the patients, the monitoring of their nutritional support, advice on diet, reinforcement of diet and medication adherence, and advice on salt and fluid intake. However, the abnormalities could still be related to non-adherence behaviours or to other confounding causes such as complications associated with chronic renal failure in the prolonged disease phase or the progressive deterioration of end-stage renal failure (Kutner, Zhang, McClellan & Cole, 2002).

Referring to the hypothesis stated, there was no statistically significant difference found in the blood chemistry results. There were only exceptional variables on sodium and potassium levels, which were attributed to the control group across time. Therefore, the null hypothesis, which states that there is no significant difference in symptom and complication control

within and between the study and control group at baseline and over the course of the study, cannot be fully rejected.

#### **6.4.2.2 Symptoms and complications control**

The outcomes of symptom control include the improvement in exit-site condition, percentage body weight, and level of oedema and peritonitis. The results of this study indicate non-statistically significant differences in percentage body weight change and exit site condition. However, the study group patients showed greater improvement in exit site management than the control group. The study group patients demonstrated greater improvements in oedema reduction than the control group, despite failing to obtain statistically significant results. There was a nearly significant difference found in the level of oedema for the study group in T1 vs. T3 comparison ( $p=0.06$ ). Lastly, a statistically significant difference was noted in the decrease of peritonitis in both the study and control groups. The result indicates that both groups received effective treatment therapies during hospitalization, with no recurrence having occurred during the course of the study irrespective of the patient group assignment.

The PD patients were unable to achieve favourable variables, or even variables within normal limits, in many areas. These include the correlations between the doctor's prescribed treatment including the prescription itself, technical- and personnel-related factors, patient-related causes, and most importantly, the nature of the disease (Latham, 1998). Nursing

interventions work best to help patients understand the regimen that has been designed for their own benefit. Nurses also consider the social and emotional needs of patients, but this does not provide sufficient data for nurses to measure and treat physical signs and symptoms in the model of nursing, since their responsibility is to care, rather than to cure. The case managers have the responsibility of supporting patients with abnormalities in physical conditions, and of collaborating and consulting with other health care professionals regarding patients' concerns and problems.

For the management of symptoms such as infections of the exit site, other than the doctor's prescriptions for antibiotics and antiseptics, the nurse case manager is in the best position to provide evidence-based, effective exit site care. The reduction of infections in PD patients through continuous quality improvement and development of methods that help identify the causes of infections not only improves patient outcomes but also increases the job satisfaction of case managers. Wong's study (2001) confirmed the value of nurse specialists in initiating strategies to promote cost-effective and quality care. Through the experimental research, the nurse specialist was able to reduce treatment costs by using different antiseptic spray solutions whilst producing similar treatment effects for PD patients. The protection of the exit site during PD is an important outcome measure. With this in mind, the best practice of case management would be to consolidate empirical studies and continue patient monitoring to reduce disease complications and ultimately improve clinical outcomes. During the course of exit site



management, both within and outside the hospital, case managers perform several roles: change agent, through evidence-based new practice, health advocate, through health education and training of patients on clinical procedures and techniques, and appraiser, through the evaluation of clinical outcomes and the reduction of disease complications.

In conclusion, there was no statistically significant difference found in most of the variables in symptom control in the study and control groups across time. The treatment was successful in reducing peritonitis in both the study and control groups, with statistically significant results indicated. Therefore, the null hypothesis, which states that there is no significant difference in symptom and complication control within and between the study and control group at baseline and over the course of the study could not be fully rejected.

#### **6.4.3 Non-adherence to treatment regimen**

The revised dialysis and fluid non-adherence questionnaire (DDFQ) was used to determine the effectiveness of the nurse-led case management programme in improving patients' adherence to the different treatment regimens. The scale measured both the frequency and intensity of health-related non-adherence behaviours.

#### **6.4.3.1 Improvement on diet non-adherence behaviour**

In the study, the mean values of frequencies of diet non-adherence ranged from 1.76-2.24 days (over a seven-day period) for the study group, and 2.05-2.37 days for the control group during the study period. There were significant within-group effects over the 12-week period. The differences were noted especially at the six-week follow-up point in both groups. These results indicate that diet adherence improved independently of intervention after hospital discharge in these groups. The study group demonstrated the approach significant difference ( $p=0.09$ ) in own group comparison across time. No statistically significant difference was observed in the intensity (level) of non-adherence, in the two groups.

Although it is well known that nurses can make a significant contribution to patients' adherence behaviours, their professional training is often insufficient for them to assist patients in making these behavioural changes (Smirnoff, Reynolds & Sabate, 2004). The nurse teacher, instead of solely educating the patients on the importance of adherence behaviour for their physical health, should spend more time with the patients' families in order to understand the factors that hinder the individual patient from adhering to the diet regimen. Evidence suggests that personality and locus of control can influence adherence behaviour to treatment (Vives, Pujolar, Junyent, Flores, Cordovilla & Izquierdo, 1999). Other than locus of control, health beliefs, patient characteristics, age and family support are also predictors of diet non-adherence of PD patients.

When working with patients on adherence, the quality of interaction has been recognized as an important factor, as the behaviour and attitude of the nurse can engender either a positive or negative impact on patient adherence (Cameron, 1996). As well as an appropriate and caring attitude, communication and interaction skills are also recognized as key elements in influencing behavioural change for patients. Flexibility, a caring tone, and a non-authoritative manner in dealing with patients are the key variables to ensure the collaborative relationship between the nurse and the patients. To change an individual's eating habits may be difficult as it involves lifestyle changes. End-stage renal failure patients are advised against eating large amounts of meat, chocolate, fruits, and vegetables, which have high potassium content. For the Chinese, the ability to eat and enjoy delicious food is considered a blessing. There is much symbolism involved with eating in Chinese society - feasts are an integral and highly valued part of festivals and special occasions, such as the Chinese New Year. Food is not simply for subsistence but is a source of satisfaction and psychological fulfilment. However, despite their symbolic social meanings and value, some of the traditional Chinese foodstuffs, such as Chinese pudding and dumplings are not suitable for ESRF patients. Dietary habits, therefore, rely on an individual's beliefs and attitudes toward the disease and his or her lifestyle, which is perhaps a particularly important issue for patients who have recently begun renal replacement therapy.

In this study, the case managers utilized the empowerment approach instead of the medical or behavioural change approach to facilitate patients' behaviour change during hospitalization and after discharge. Empowerment includes an assessment of the social context and everyday life of the patients before working on a mutually agreed plan of action. According to the health promotion/education theories, any change must be voluntary and self-initiated (Naidoo & Wills, 2000). In normal circumstances, unless a person is ready to take action, any plan is likely to be ineffective in bringing about the necessary behavioural changes. Therefore, the role of the case manager is to assist patients in identifying their health concerns, taking into account what patients think is important, through their extended interactions. Baines and Jindal (2000) stated that empowerment is becoming increasingly popular, and a significant number of patients are indicating their willingness to take control of the non-technical aspects of dialysis. Further, the use of the reward system and formal counselling are strategies that might also improve adherence behaviours (Hansen, 2001). Within the context of chronic renal nursing, the new nursing care model focuses on humanizing the renal replacement therapy with negotiated care (Polaschek, 2003b). The nurse-led case management programme in this study adopted the empowerment approach in the manner that the changes were suited to the patients' individual lifestyles and needs. The patients actively participated in every stage of care and were not just passive recipients, whilst the case managers tried to integrate their sophisticated medical knowledge with the

needs of the patients in a humanized way through the establishment of mutual goals in the pre-discharge assessment and telephone follow-ups.

The second question is, 'How much adherence is enough?' Dietary and medication adherence is often gauged by serum potassium and phosphorous levels (Hailey & Moss, 2000). Following analysis of the self-reported questionnaire, the results (see chapter 5) showed a weak to moderate positive correlation between diet and medication non-adherence behaviour and the serum phosphorous level. As stated, the renal nursing role is one of negotiated care. In the follow-up interviews, the patients' hospital records, including the discharge summary, prescribed medications, pre-discharge assessment, and blood chemistry results were prepared to serve as the basis for individual preferences and treatment negotiation. Dietary restrictions vary from individual to individual, and a higher serum phosphorous or potassium level indirectly indicates the non-adherence behaviours. While a high phosphorus level may be related to diet non-adherence, it may also be related to other complications associated with chronic renal failure. The case managers possess the professional knowledge to interpret the blood chemistry results and assist patients in making meaningful choices that best suit their lifestyles and habits. As a result, these patients should have sufficient food choices and may be able to increase their intake of foods that contains a higher potassium or phosphate content if this does not contradict their specific clinical conditions. As stated by Thomas (2002), diet flexibility must be incorporated while educating the patients, in order to

promote dietary compliance and enable patients to lead near-normal lives without altering the nutritional quality of their diet. This requires nurses to focus the intervention efforts on changing the health behaviour of selected PD patients and not on the whole population group.

The case manager works as a health advocate promoting patient empowerment in facilitating treatment adherence. Moreover, a longer period of dietary success is required before clinical changes can result. To conclude, a six-week intervention period might be too brief to detect a difference in the clinical outcomes in blood chemistry results, since patients may require continuous motivation to follow the given prescriptions. The nursing dose needs to be extended to enforce treatment adherence and behavioural change, and to consequently enable positive clinical outcomes.

#### **6.4.3.2 Improvements on medication non-adherence**

For the frequency of medication non-adherence, the mean values ranged from 0.47-1.08 days (over seven days) in the study group and 0.68-1.05 days in the control group. A significant change was observed in the study group over the 12-week period, in particular, in T1 and T2 comparison. The difference was noted especially at the six-week follow-up ( $P < 0.01$ ) period. The results also indicate the significant interaction effect between time and group. For intensity (level) of non-adherence, no statistically significant differences were observed in the two groups.

This study found differences on medication non-adherence scores and change in score between the two study groups. The interventions designed to help to improve medication non-adherence were similar to those strategies used to improve diet non-adherence behaviours. Despite the huge impact that medication adherence has on the morbidity of the disease, there are very few studies describing the various interventions and strategies to increase medication adherence. Most studies simply use the educational approach to examine the effect of education sessions in improving adherence. Whether the approach has been successful or not, is determined by the level of improvement in serum phosphorus and potassium levels. Through education, nurses can help increase the patients' knowledge and consequently, their decision making process. However, formal and continuous support, available to clarify misconceptions about medication side-effects, encouragements, appropriate reminders about the regimen, reinforcement of previous learning, and praise for positive behaviours are considered significant interventions in improving medication adherence in a nurse-led case management programme. Moreover, strategies should also be designed to involve patients in problem solving and address their cultural and psychosocial needs.

To most health care professionals, teaching patients about medication compliance seems much easier than changing lifestyle behaviours, such as their eating habits. This contention is considered valid, since nurses simply implement what is the best from the professional viewpoint without a

detailed negotiation with the patients. The patients do not need to alter their preferred lifestyle or everyday habits to be able to comply with the treatment. Most importantly, the benefits of adherence behaviour could quickly and easily improve their physical health status. Patients tend to change their behaviour, as behavioural change is correlated with better clinical outcomes. The report of DiMatteo (2004) concluded that among various treatment regimens, medication has the greatest adherence from patients than any other health behaviour, whilst diet has a lower adherence.

#### **6.4.3.3 Non-adherence to fluid and PD regimen**

The study was unable to demonstrate case management effects to improve non-adherence behaviours in fluid and PD regimen. The results reviewed a small variance before and after intervention among the two groups of patients. The range of days of non-adherence to fluid intake for the study group was 0.58-0.89 days (over a period of seven days), and 0.95-1.10 days for the control group. The intervention could achieve only minimal effects as the study group patients had already been performing well before intervention, thus producing a minimal treatment effect.

With regard to adherence to PD regimen, the situation was fairly similar to that of fluid non-adherence. Again, the small variance that resulted from treatment intervention was unable to sustain statistically significant results. The range of days of non-adherence to PD regimen for the study group was 0.55-0.66 days (over a period of seven days), and 0.41-0.88 days for the



control group. The nursing intervention could only impact very small changes in patients' adherence behaviours due to their overall satisfactory adherence behaviours.

In conclusion, there were statistically significant differences found in two of the variables relating to adherence behaviour, namely, diet and medication. There was no significant difference found in the other variables, such as PD regimen and fluid intake. The results on non-adherence behaviours are mixed. Thus, the null hypothesis stating that there is no significant difference in self-care adherence within and between the study and control group at baseline and over the course of the study cannot be fully rejected.

#### **6.4.4 Improvement in Quality of life (QoL)**

Studies carried out prior to this project indicated that end-stage renal failure patients have a negative association with their well-being, both physically and mentally. The aim of this study, therefore, was to assess the extent of improvement in the quality of life of patients in relation to nurse-led case management intervention. The study further aimed to identify specific variables that are the predictors in determining the quality of life of PD patients.

#### **Quality of life of the two groups of patients**

With regard to the first objective, the study's results confirmed that the quality of life of the study group patients was substantially higher than that

of the control group in 10 out of 20 dimensions in the Kidney Disease Quality of Life–Short Form (KDQOL-SF). The health-related concerns included both the general dimension and kidney disease-related quality of life. The results of this study highlighted the importance of a nurse-led case management programme in maintaining the optimal life qualities of patients in the transitional phase.

### **General dimensions of quality of life**

The general dimensions of quality of life were measured by the SF36 Health Survey. The parameters demonstrating statistically significant effects included emotional well-being, physical role functioning, pain and social functioning. The study group patients reported a better emotional state, less bodily pain, improved social functioning, and fewer problems with work or other regular activities due to their physical health, as compared to patients who were not included in the follow-up. Other dimensions that did not have significant statistical effects were, physical functioning, general health perception, perceived fewer problems with work or other regular activities due to emotional health, and level of fatigue.

The nurse-led case management intervention was immediately able to show efficacy in improving patients' emotional well-being following treatment, and was sustained for at least six weeks afterwards. Regarding the dimensions of physical well-being, the treatment effect was positive only after intervention and was not sustained. The results conferred important

findings and highlighted the greater success of nurse-led case management intervention in improving the psychological well-being of the patients.

### **Kidney disease-specific quality of life**

The kidney disease-targeted scales within KDQOL-SF denote the disease-specific dimensions of quality of life. The parameters that demonstrated significant statistical effects included the effects of kidney disease on daily life, symptoms, quality of social interaction, staff encouragement, patient satisfaction, sleep, and social functioning. Similar to the general subscales, most of the dimensions that demonstrated statistical significance were related more to psychological or emotional perspectives than to physical ones.

These findings further indicate that a positive influence on the quality of life of PD patients can result from a well-structured and protocol-driven nurse-led case management programme on discharge planning and follow-up. The disease-specific QoL measures are able to provide meaningful results that can be interpreted to improve patient care.

Despite nursing interventions being able to effect changes on patients' quality of life, the QoL of end-stage renal patients is in fact influenced by a number of variables. These variables include biological and physiological factors underlying the comorbid conditions, blood albumin and haemoglobin levels and the type of treatment given (Frank, Auslander &

Weissgarten, 2003). As mentioned, nursing intervention is able to provide only limited effect in the clinical outcomes; other dimensions, such as comorbid conditions cannot be addressed merely through nursing strategies. One of the important roles of nurse-led case management is to motivate patients and their families to adhere to the prescribed treatment regimens. It is through the improvement of adherence in medication and diet that the serum albumin and haemoglobin levels might be increased, leading to a subsequent improvement in patients' quality of life. Studies have shown that low levels of albumin and haemoglobin in the blood are associated with a low quality of life (Bakewell, Higgins & Edwards, 2001; Baiardi et al., 2002; Valderrabano, Jofre & Lopez-Gomez, 2001). Other variables that influence the quality of life of end-stage renal failure patients include the number of years on the PD regimen and frequency of hospital admissions (Martin & Thompson, 2000; Bakewell, Higgins & Edmunds, 2002). Moreover, deteriorating residual renal function and comorbid conditions give rise to a poorer QoL (Kerkus, Jager, Dekker, Boeschoten, Stevens & Krediet, 1997).

The new model of care represents a substantial improvement in the health-related quality of life of patients through collaboration and continuity of care. A key strategy for its success were the telephone follow-ups, the provision of advice and support by the case managers in order to improve patients' emotional wellness, and the satisfaction with the quality of care given. Nurse-led case management is essentially a humanistic approach in

which patients' concerns and needs are the primary agenda of the intervention. The nurse case managers call the patient and review the previously identified problems in order to solve them. They also attempt to elicit new complaints, problems, or needs in subsequent telephone calls. These interventions appear promising in terms of decreasing the impact of serious illnesses that threaten the patients and their families, after hospitalization. Peritoneal dialysis is a complex procedure for patients, which also affects their families and requires careful medicine administration and compliance with health-related requirements. If the patient's community has adequate support from the health care team, a significant improvement in his/her emotional well-being is most likely to result, along with an increased perceived health status. Similarly, through the continuous and comprehensive intervention of the case management programme, patients feel less bothered by the kidney disease, which is reflected in reduced feelings of anxiety, increased confidence, the ability to better cope with fluid and dietary restrictions and increased ability to work at home. These changes promise not only to improve patients' quality of life but also to enhance their self-perceived health.

In conclusion, there were statistically significant differences been demonstrated in half of the subscales within the KDQOL-SF instrument during the study period. Thus, the null hypothesis, which states that there is no significant difference in the quality of life measures within and between

the study and control group at baseline and over the course of the study cannot be fully rejected.

#### **6.4.5 Health service utilization**

The high hospitalization rates among end-stage renal failure patients in Hong Kong impose a substantial burden on the health care system. The rising resource expenditures related to the care of PD patients are a cause of concern.

In this study, the results did not show significant differences before and after intervention in the two patient groups in terms of frequency of emergency room attendance, hospital readmission, total length of stay during hospitalization, and length of stay per hospital admission. This suggests that the nurse-led case management programme was unable to facilitate the financial/economic outcome in the interventions. The results confirmed that hospital utilization among patients in the study group remained high.

Referring to previous discussions, the nurse-led case management programme was most successful in improving patients' psychological wellness rather than their physiological health status. The case manager facilitated an improved quality of life for the patients as evidenced by their satisfaction with case management services and the positive ratings in KDQOL-SF. In addition, the case manager facilitated the patients and their families' psychosocial adjustment and ability to cope with life changes after

hospitalization (Powell, 2000). Hospital readmission is a complex phenomenon, which includes factors related to patients, disease and the health care system. Elderly patients and patients with a lower functional score tend to have a high risk of readmission (Tierney & Worth, 1995). Increased age has been identified as an independent predictor of hospitalization in the ESRF patient population (Thamer, Fox Ray & Fehrenbach, 1996). Looking at the demographic characteristics of the patients in our study sample, the mean age of the study and control group patients was 42.2 and 55.5, respectively. Patients in the study sample could not be considered as elderly patients, since they were below the age of 60 and only a minority of the patients were in the age range of 76-81.

With regard to comorbid conditions, only one-third of the total patients in the study and control groups did not suffer from other chronic diseases. The majority of the subjects had comorbid conditions such as cardiovascular disease, diabetes, cancer, or respiratory diseases. Khan, Kazmi, Abichandani, Tighiouart, Pereira, and Kausz's study (2002) stated that cardiovascular comorbidity was strongly associated with an increased risk of hospitalization. Our study revealed that 37.8% and 33.3% of patients in the study group and control groups, respectively, suffer from cardiovascular diseases. This factor may serve as an indicator affecting the risk of hospital utilization. Apart from cardiovascular diseases, the impact of anaemia may also contribute to cardiovascular complications and hospital readmission. Despite the increase in the haemoglobin level of the study group patients

from T1 to T3, the mean haemoglobin level of 9.15 g/dL at T3 was below the normal range of a healthy adult. A low level of haemoglobin is associated with longer hospitalization and frequent readmissions. The report from Thamer, Fox Ray, Fehrenbach, Richard, and Kimmel (1996) in the USA illustrated that renal failure patients were 10 times more likely to be hospitalized as compared to persons with diabetes, ischaemic heart disease, hypertension, and emphysema because renal patients have a higher risk for congestive heart failure, pneumonia, sepsis, electrolyte disorders, and gastrointestinal haemorrhage.

Although there are many studies which substantiate that a telephone case management approach is able to reduce hospital service utilization, the disparity in findings suggest that the utilization of health care services in hospital readmission is related to a complex array of factors including severity of illness and patient characteristics (Khan, Kazmi, Abichandani, Tighiouart, Pereira & Kausz, 2002). Patients suffering from end-stage renal failure and who are undergoing peritoneal dialysis are overwhelmed by the complex regimen they have to follow. The loss of normal body function and the complications associated with long-term dialysis therapy affects their physical well-being. The nursing interventions are able to bring about very positive outcomes on the psychosocial perspectives, but effects on the biological dimension are limited. In contrast, the pathology is less complicated and the symptoms are controlled well after close monitoring of the diet and medications of patients belonging to other groups, such as those



with diabetes mellitus. The complex biopsychosocial links in ESRF patients suggest that nurses need to respond to the tremendous impact that the disease itself and its treatment can have on the patients (White & Grenyer, 1999). Renal nurse-led case management intervention is undoubtedly able to improve the emotional well-being of patients by enhancing their quality of life. For health care cost savings, however, the interventions can only be successful to a very minimal extent due to the complex and progressively deteriorating nature of the disease.

Therefore, the null hypothesis in the study which states that there is no significant difference in health service utilization within and between the study and control group at baseline and over the course of the study cannot be rejected.

## **6.5 Discussions on secondary analysis**

Diet and medication non-adherence behaviours were chosen as the outcome indicators for regression analysis, as these variables were able to demonstrate statistically significant effects after the nurse-led case management programme. The non-adherence on fluid and PD regimen were not included, as most patients were able to manage these behaviours prior to the case management interventions, thus resulting in an insignificant difference after the programme. Patient's self reported health was selected to analyse the predictors that might influence the perceived health status.

### **6.5.1 Predictors of diet non-adherence behaviour in improving patient-related outcomes**

In addition to studying the frequency and intensity of diet non-adherence, the investigation of predictors that may lead to non-adherence is an important aspect for dialysis patients. This analysis helps to shed light on why the nurse-led case management programme does and does not work on some adherence behaviours. The predictors for non-adherence behaviours provided understanding and insights on their potential contributory factors, which could be used by case managers as empirical and theoretical bases for the effective continuity of health care in future studies.

The variables tested in this study were drawn from Connelly's model of self-care in chronic illness (Connelly, 1993). The variables conceptualized in the self-care model, including patient demographic characteristics, regimen characteristics, social support, gravity of disease, illness history and cost. The initial univariate analysis showed that age and the number of years on PD were associated with the diet non-adherence behaviour. The final model from the logistic regression suggested that only the patients' age and gender had statistically significant effects on diet non-adherence. The older the patients were, the less likely they were to demonstrate diet non-adherence behaviour. Furthermore, men reported less diet non-adherence than women. Despite the weak to moderate correlation between the number of years on PD and diet non-adherence, the variable was not included in the

final model after the inclusion of other demographic variables into the regression analysis.

For the association between age and diet adherence findings were consistent with other studies that older people were more likely to report themselves as complying with their diet and engaging in self-care (Brown & Fitzpatrick, 1988; Kart & Engler, 1994; Chriss, Sheposh, Carlson & Riegel, 2004). Other studies also showed that with increasing age, adherence to all aspects of the therapeutic regimen improved (Leggat, Orzol, Hulbert-Shearon, Golpher, Jones, Held & Port, 1998). The results of this study were similar, i.e. that the older the patient is, the less likely is he/she to display diet non-adherence behaviour. The younger group, on the other hand, may demonstrate the ability to manipulate the treatment regimen or have greater control over their lives. These findings may simply reflect that the younger group has greater confidence in their ability to care for themselves. Their lives may be shaped by work, for example. As independent working adults, they may have greater confidence in their own decision-making skills than older patients, whose confidence becomes eroded as their removal from the workforce takes them further away from those sources of validation that working adults take for granted. Consequently, younger patients are more likely to depend on themselves for solutions to their health problems than to strictly obey advice or instructions from health care workers and older patients are more likely to rely on the guidance of healthcare specialists to

manage their symptoms. The relationship between age and diet adherence was found to have a crucial role in supporting diet adherence.

The study results indicate that family support and education did not contribute significantly to the dietary behaviour of patients. These findings corroborate the report of Brown and Fitzpatrick (1988), stating that the positive correlation between family support and social functioning would diminish three years after the patient had begun dialysis, suggesting that the family influence reduced over time. The mean number of years that patients were on PD in our study sample was 3.17 years, which could be a factor suggesting that family influence does not contribute to adherence behaviour over time. The previous literature also mentioned that the longer the patients were on dialysis, the more likely were they to report themselves as not complying with the regimen. The correlation analysis in the present study also indicated the same phenomenon, with a positive correlation existing between the number of years patients had been on dialysis and the frequency of non-adherence to diet.

Another important finding in the analysis was that of gender difference in diet non-adherence. The study showed that men reported less diet non-adherence than women. This result is contrary to the literature on the significant relationship between gender and dietary adherence, which stated that women were more able to provide self-care than men (Kart & Engler, 1994). However, Chriss et al. (2004) presented different findings, whereby

elderly men with heart diseases were most successful at self-care. Gender differences in the management and control of chronic disease were highlighted, and gender was found to have a major impact on individual disease management. Whether gender differences are related to diet adherence and self-care remains an empirical question. Further nursing research is required in order to understand the relationship between gender difference and adherence behaviour.

Gender was found to have a major impact on how people manage the disease. Family support has also been identified as an important variable to be considered in evaluating patient compliance with the dialysis regimen. In the case of male patients, the family or the significant other (usually a wife) may play a crucial role in supporting the patient's behaviour adherence during the illness. Although family support was a non-significant predictor in this study, it has been found to be a predictor of compliance and positive health practices in other studies (O'Brien, 1990; Lorenc & Branthwaite, 1993). The caring role of a female family member may partly explain the better diet adherence behaviour of male patients. The female partner plays an essential role in supporting the adherence behaviour of the sick male. Another finding from Lindqvist, Carlsson, and Sjoden's study (1998) reported that women use less effective strategies in handling their illnesses, such as emotive, evasive, and palliative coping techniques to be able to adhere to health-related behaviour along with the ability of problem solving and control of the disease in their lives. Men had higher ratings for coping

with the disease than women. The maladaptive coping strategies employed by women may further explain their lower coping efficacy in relation to the various aspects of the treatment regimen, including diet adherence. Considering these results, the simple teaching model of information transfer by means of leaflet distribution is inadequate to address the problem, given the identified gender behaviour. Patient education must move beyond knowledge transfer and must take into account the coping strategies employed by both genders in adjusting to the disease (Glasgow & Osteen, 1992). It is essential for the case managers to also consider the gender and age of patients in providing individualized education. Teaching chronically ill patients requires case managers to rationally adopt evidence-based new practice and to take gender into consideration in designing future study programmes.

### **6.5.2 Predictors of medication non-adherence**

In order to gain a better understanding of the various predictors of medication adherence, the present study tested a model of individual characteristics to provide evidence for predictors of medication non-adherence among PD patients. The potential variables included patients' age, length of years on PD, treatment group and demographic characteristics, which were included in the statistical computation. The final model from the logistic regression suggested that educational attainment, the existence of comorbidities and the patients' group assignments were statistically significant in predicting medication non-adherence.

The regression model demonstrated that the non-mutable variables had an impact on medication non-adherence behaviour. For example, patients with secondary school education had a 6.6 times higher chance of reporting medication non-adherence than those patients who achieved only a primary level of education or lower. Patients having comorbid conditions were more likely to show non-adherence behaviour to the medication regimen than those without comorbidities. Lastly, the study group patients, after the case management programme, demonstrated reduced non-adherence to the medication than the control group.

First, the group with lower education reported the most positive adherence, implying that the relationship between education and medication adherence is dynamic. Other researchers who conducted studies on medication non-adherence and self-care revealed contrary findings. Rockwell and Riegel's study in 2001 reported that patients with higher education and who were symptomatic were more likely to engage in self-care, including taking medication as prescribed. Presumably, patients having a higher educational attainment are more motivated and rational in decision making, which results in better adherence behaviours and self-care. In the present study, medication adherence was negatively associated with the compliance behaviour of patients having middle educational level as compared to the group with lower education. The results indicate that patients with secondary school education perceived themselves as having the ability and sense of control over events without strictly adhering to the prescribed

medication regimen. Patients from the less-educated cohort appeared to be more reticent about violating the instructions given by the medical professionals and simply followed the advice given.

Through the review of the patients' medical records, it was found that all recruited patients, regardless of their treatment group assignment were required to take at least four or more kinds of prescribed medication. The different therapeutic doses per day could cause inconvenience to the working group patients or the patients who were socially active. To provide better discharge education to address the specific needs of patients, and taking into account their understanding of the side-effects of medications, it is important to observe participatory decision making between the patient and the nurse, and continued counselling by the case manager during the transitional period; this the cornerstone for success. To date, there has been no study that offers a universally accepted analysis of the non-adherence problem, which is an indication of a knowledge gap. More conclusive results on how social variables are involved in medication non-adherence are therefore needed.

### **Comorbidities as a predictor for medication non-adherence**

The present study showed that patients suffering from ESRF without other diseases had a more positive adherence to medication than those with comorbid conditions. The results also indicate that the less severely ill patients were more willing to pay attention to their health and comply with



medication than those patients having comorbidities. The finding was contrary to the health belief model (Becker, 1984) in which individuals are not likely to take health actions unless they are susceptible to ill-health conditions. Chriss et al.'s (2004) discussion suggested that persons with heart disease and with fewer comorbid illnesses were most successful at self-care. Other similar results revealed by Nagy and Wolfe (1984) advised that patients who were seriously ill and had multiple symptoms were non-compliant. Comorbidity has rarely been studied as a potential predictor of adherence, yet the results of this study were consistent with those of Nagy and Wolfe, and Chriss et al., despite the differences in patient population. The medication non-adherence behaviour in this patient group may be related to negative emotions such as fear and anger, resulting in reduced motivation to maintain daily routines that may alleviate symptoms. Second, there is a significant relationship between 'cost' and medication adherence (Connelly, 1993). In Hong Kong, medications were provided to patients at a minimal financial cost, in public hospitals. Cost, however, is not limited to financial considerations: it also refers to human cost, evidenced in the side effects or discomfort incurred from taking the medications.

For end-stage renal failure patients, coping with dialysis can be complex and demanding especially for those on peritoneal dialysis. Patients and their caregivers are relied upon to carry out relatively complicated procedures to sustain life and to avoid complications. Without adequate support from the family and health care professionals, it is common for patients to become

frustrated and undetermined to continue with the prescribed treatments. For a patient with comorbid conditions, self-care can become more complex, as poor treatment adherence contributes to the exacerbation of several diseases. With the increasing types of medication being taken and the different side effects that may occur due to poly-pharmacies, it may be confusing for the patient, particular the elderly, to distinguish which of the medications is responsible for the symptoms. This leads to the hypothesis that patients with comorbid symptoms tend to give up active treatment because they are unable to cope with the problems associated with the disease. Patients with comorbid conditions also show poorer social and physical functioning and mental health, and greater pain than patients who are not suffering from other diseases. These patients' conditions require close monitoring and treatment, with a combination of medication and lifestyle changes. These conditions often result in unhealthy adjustment and psychological deterioration. Social support and sustained relationships with the nurses promise considerable benefits to patients in coping with multiple illnesses.

Lastly, the regression analysis showed a statistically significant difference between the two patient groups. The positive results provide empirical evidence to indicate that the nurse-led case management intervention was able to bring about improvement in patients' behaviour in medication adherence. The therapeutic effect was observed through continuous encouragement and patient empowerment from the nurse case manager.

The objective of nurse-led case management is not solely to help patients comply with the treatment regimen but to also help support the need for behavioural change, including adherence to effective long-term therapies (Smirnoff, Reynolds & Sabate, 2004). If nurses can understand or predict which patients need the most assistance to maintain adherence behaviours, intervention can be more focused to achieve the best possible results. The new model of nursing in this study capitalizes on partnership and has less emphasis on enforcing adherence. Although the patients are strongly influenced by the education and advice they receive from credible health personnel, adherence to medication does not simply require them to do what their health professionals recommend. Extending this theme, health education involves planned opportunities for people to learn about health and to undertake voluntary changes in their behaviours (Ewles & Simnett, 2003). In addition, health education involves developing patients' sense of critical consciousness in the decision-making process. Nurses have to bear in mind that patients have the right to choose their preferred treatment. All health care professionals need the competency to understand the variables that influence patients' decisions about medication choices and to collaboratively design the strategies that assist patients in making the best decisions.

Although the behavioural change approach sounds appropriate and relevant in promoting medication adherence, this traditional model of health promotion is unable to instil a sense of commitment in making lifestyle

choices. To ensure a long-term effect in enforcing adherence behaviour, the new model should focus on collaboration, with advocacy on self-care (Naidoo & Wills, 2000). To promote medication adherence, the approach should encompass knowledge and understanding, needs assessment, social context assessment, problem identification, and health locus of control identification. The nurse case manager, through the use of these proactive strategies, is able to enhance patients' self-reliance behaviours and subsequently improve adherence behaviour over time. The new model of care with continuous intervention and support to patients is able to achieve the desirable health outcomes and to improve self-care among patients on peritoneal dialysis.

### **Issues on self-report adherence behaviours**

Despite entering the same variables into the logistic regression analysis, the models illustrated that the significant contributory variables were found to be different in a variety of situations. As a result, these confirm that patients adhering to specific types of health behaviour may not necessarily comply with other related behaviours. This message is crucial to reflect issues that affect ambulatory care in chronic renal disease and to avoid a limited compliance approach. The demographic differences found in this study explained that most of the variables that influence adherence behaviours are non-mutable, except co-morbid conditions. It is important to take the individual differences under consideration when designing a nursing intervention, to meet the different needs and demands of male and female

patients, patients of different age groups and those with different educational attainments.

This study used the self-reporting method for the identification of non-adherence, Kavookjian (2004) reported that ‘some patients may report self-care in a socially desirable manner such as under-reporting some undesirable behaviours (diet non-adherence) and over-reporting other desirable behaviours (exercise habits). These self-reported responses could introduce bias into studies on patient self-care behaviours. Other objective measures should also be used in conjunction with subjective measurement scales to accurately capture behaviour, particularly for patients who are new to the treatment regimen. The individual case manager should utilize all the available resources to detect non-adherence behaviours in addition to the patient self-reported adherence scales. McNabb (1997) concluded that it is worthwhile for researchers to develop and use multiple measures of adherence rather than to rely on a single method to examine adherence behaviours.

### **6.5.3 Predictors of self-rated health in relation to QoL**

Kidney disease quality of life is not merely determined by the presence of the disease and related health. There is an existing association between self-rated health and kidney disease quality of life, as the person’s perception of his/her own health is influenced by the dimensions of the scale. In other

words, if some of the dimensions in the KDQOL are improved, the overall self-rated health of patients could also be enhanced.

An individual's self-rated health represents the summary statement concerning his/her perceived subjective and objective health status (Liang, 1986). Wong, Chow, Chang, Lee and Liu's study (2004) revealed that perceived improved health condition is significantly associated with fewer attendance of hospital emergency department. The variable particularly warrants investigation because it reflects patients' own assessment of his/her health which may provide a different perception of needs to the health care providers. Quality of life and perceived health status are important indicators of patient care, which are needed to explore morbidity, mortality, and health-care resource utilization (Rosenberger, van Dijk, Nagyova, Roland, Geckova, van den Heuvel & Groothoff, 2005). Few studies have distinguished between the effects of quality of life and self-reported health status.

The multiple regression analysis in this study aimed to explore how quality of life might influence the perceived health status. The regression analysis showed that emotional well-being, quality of sleep, and effects of kidney disease on patients' daily life were the significant predictors that determined patients' perceived general health status. These three variables were considered to have an influence on patients' perceived health, although they could explain only up to one-third (33%) of its total variance. Other

dimensions in the KDQOL and the demographic variables had a weak influence on the perceived health status of PD patients. The results presented some interesting findings and shed new light on understanding the concepts of perceived health and quality of life.

Anger, anxiety, and depression are common symptoms that occur in older patients suffering chronic-disease. Older patients often suffer from sleep disturbance, which is caused by age-related physiological changes and poly-pharmacy (Avidan, 2005). Kurella, Luan, Lash, and Chertow (2005) used the KDQOL sleep scale to determine the sleep quality of patients with chronic kidney disease. The multivariate analysis showed that age and end-stage renal disease status are significant predictors of lower KDQOL sleep scores. These findings showed that elderly ESRF patients are in particular need of assistance from medical professionals regarding their sleep problems. It is clear that if the patients' sleep problems are resolved, they may perceive a subsequent better health status in relation to sleep improvement. Medical and nursing interventions should always be available to patients when they experience insomnia, and insomnia resolution should be made a priority for patients with chronic renal diseases.

With regard to emotional well-being and the effects of kidney disease on patients' daily life, the assessment of their psychological needs should be an integral part of the nursing interventions for dialysis patients. Clearly, a holistic treatment requires nurses to take into account the psychosocial well-

being of patients in planning for care intervention. The case manager in the team works with the patients and their families to strengthen their ability to cope with the disease and the treatment regimen. Other forms of support include financial assistance and the introduction of patient support groups, where available. These interventions have the potential of reducing uncertainty and relieving patients' anxiety, which may in turn improve their perceptions of their symptoms and emotional well-being.

Transitional care has an important role to play in altering the quality of life of patients. The components of intervention, particularly in sleep improvement and emotional well-being, should be evaluated routinely at an early stage before discharge and during the telephone follow-ups by the case manager. The quality of life model in the social science paradigm focuses on the dimensions of functioning and the overall well-being of people (Wilson & Cleary, 1995). The case manager providing care during the transitional phase should not only include the traditional clinical or hospital system variables but should also take into account the overall quality of life and the general health perception of patients, because these are the predictors of health services utilization and morbidity.

#### **6.5.4 Psychometric properties of the research instruments**

The validation study aims to validate two research instruments employed in the present study. These were the La Monica-Oberst Patient Satisfaction Scale (LOPSS revised version), which was used to measure patient



satisfaction, and the questionnaire on treatment non-adherence (DDFQ). This section discusses and interprets the results of the validation studies, and draws conclusions on the psychometric properties of the instruments.

#### **6.5.4.1 La Monica-Oberst Patient Satisfaction Scale (LOPSS revised version)**

Due to the nature of the present study, the revised version of the LOPSS was tested further, in order to establish its validity and reliability, and to ensure its suitability for use in the local study context. The previous tests of the scale were performed on cancer patients and women having gynaecological disorders, for overall impression of the nursing service. The purpose of this test was to provide further psychometric testing of the revised LOPSS on a different patient population.

##### **Content validity**

The results of the content validity study showed that there were a few items in the revised LOPSS (Munro, Jacobsen & Brooten, 1994) that were considered as only marginally relevant or not relevant to the theoretical domain. Four items were removed, and the modified scale with 24 items was field tested before being used in the main study. This served to check the item content of the Chinese version of the LOPSS, which was tailor-made for the case management service evaluation of renal patients in Hong Kong.

### **Issues of instrument translation**

There were several possible explanations for the difficulties in establishing translation equivalence. First, the problems may be the result of language and cultural differences. Language could affect the relevance and representativeness of items that were developed overseas, when used in a local context. In this study, the original translation was verbatim from English to Chinese and aimed to preserve the meaning and concept of every individual item as much as possible. However, it was found that verbatim translation sounded inappropriate for the negatively phrased items in the scale. The Chinese language in itself is different from English, such that many of the phrases are reversely structured. The investigators then tried using the non-verbatim approach but placed emphasis on preserving the essence, meaning, and fluency in expression of the original source. The panel members agreed that the non-verbatim translation was appropriate due to differences in grammatical and syntax style of both languages. The above is supported by Yu, Lee and Woo's findings (2004) that the primary concern should be to convey the overall meaning of the original version in a way that is culturally relevant to the translated version, with the original linguistic structure being of secondary importance, when former criteria was fulfilled. After this translation process, verbatim translation was deemed inappropriate, especially for the negatively phrased items that appeared in the original English source.

In addition to maintaining the validity and cultural sensitivity in the translation, readability in both the source and translated languages is essential. Since the research instrument is to be distributed to laypersons with a mean age of 56.5 years, the instrument should be written at the primary five to six reading level to ensure adequate understanding of the language by the interviewees.

### **Construct validity**

Construct validity was evaluated using factor analysis. This local study followed the same approach used in overseas studies in determining the number of factors in the scale. The exploratory factor analysis was used to establish the construct validity of the Chinese version of the revised LOPSS. The two-factor solution from this study was consistent with Munro's (1994) finding that items on interpersonal support and good impression were combined. The items on dissatisfaction remained as independent factors of the scale. The only item not loaded into the two-factor solution was 'The nurse does not answer my phone call promptly enough'. A three-factor solution was attempted in the present study, but it failed to provide a more stable solution than the two-factor solution. These results suggest the deletion or further revision of the item in order to achieve a satisfactory loading value onto the existing factors. The investigator suggests deleting the item, since the raw data scores indicated that most of the patients do not initiate telephone calls to case managers or renal nurses, thus resulting in a number of missing values, which may cause the unstable factor loading.

Lastly, item analysis was used to gather structural evidence for construct validity. An analysis of the individual items seems to be a reasonable approach in addressing questions relating to total instrument performance (Ferketich, 1991). The basic indices of item analysis included internal consistency and item-total correlation.

### **Item-total correlation**

The coefficient for corrected item-subscale correlation on interpersonal support/good impression was between 0.61-0.79. The corrected item-subscale correlation on dissatisfaction lay between -0.40-0.66. A higher corrected item-total correlation ( $>0.3$ ) generally indicates a better item. As expected, the analysis showed that 'The nurse does not answer my phone call promptly enough' scored -0.40 in the corrected item-subscale correlation. Under this circumstance, researchers should choose the items that have high positive correlations to be included in the scales, and delete or revise those that have a negative or low positive correlation (Green & Salkind, 2005). This analysis further substantiated that the item mentioned above showed a poor representation of the construct because it required further revision or deletion.

### **Internal consistency**

The internal consistency of the scale was determined by means of Cronbach's alpha coefficient. The Cronbach's alpha coefficient for the first subscale on interpersonal support/good impression was 0.92, and the second

subscale on dissatisfaction had a 0.82 coefficient. Both results indicate a very acceptable value that demonstrates the reliability of the different subscales. However, when the items of the two subscales were merged to determine the alpha coefficient, the alpha value dropped to 0.54 for the entire scale. This suggests that the summated scores of the two subscales may not be appropriate to create a meaningful total score for the whole scale. Since the different subscales consisted of different dimensions, the investigator advises computing for two separate scores instead of one, in order to capture the distinguishable characteristics of the domains in the scale.

### **Reliability tests**

The instrument demonstrated good test-retest and inter-rater reliability as previously stated in chapter 4. The scale is considered to be stable, with high repeatability.

The use of retrospective data is an interesting approach in instrument validation. Since the tests previously mentioned covered only some aspects of the psychometric qualities of the scale, the translated LOPSS could further be improved by adding some relevant questions or modifying the existing items in order to gain a better understanding of patient satisfaction with nurse-led case management services. Considering that there are no known validated instruments on patient satisfaction in the nursing field in Hong Kong, the revised LOPSS can be regarded as a useful instrument for

assessing the satisfaction of patients toward nurse-led case management services. To further confirm the psychometric qualities of the LOPSS, further studies should focus on examining the applicability of the scale in other patient groups.

#### **6.5.4.2 Revised Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ)**

Two new domains with four items were added to the existing DDFQ to obtain a comprehensive view of the non-adherence behaviours of PD patients. The two new domains included non-adherence to medication and non-adherence to PD regimen. The purpose of this test was to provide further psychometric testing of the newly added domains. This validation study mainly collected evidence for the instrument's criterion and construct validity, and reliability.

#### **Criterion validity**

To assess criterion validity, a correlation matrix was generated from the variables of non-adherence behaviour on PD and medications regimen as measured by the revised DDFQ and the biochemical ratings of serum potassium, phosphate, calcium, and albumin. The exact values of the biochemical ratings obtained were used for statistical computation and not interpreted into a corresponding rating system indicating poor, fair, and good adherence, as these ratings are considered arbitrary and not clinically relevant. The serum potassium, calcium, and albumin levels were found to

have no correlation with medication and PD non-adherence behaviour. The serum phosphorous level was found to have a weak to moderate positive significant correlation with medication non-adherence, but no correlation with PD non-adherence behaviour.

The results suggest that the highest scores for medication non-adherence were found in patients with a higher blood phosphorus level. Medication non-adherence was significantly only correlated with serum phosphorus level and not with other blood chemistry levels. At the present stage, it is not a surprise that the research is unable to achieve good criterion validity. The weak to moderate correlation coefficient found in this study suggests that the biochemical values may be affected by variables other than medication and PD non-adherence, such as disease deterioration, comorbid conditions or nutritional status. For serum albumin level, the concentration could be affected by dietary intake, hydration, and nutritional status of the patients, and not solely by medication or PD adherence. The albumin level reflects protein loss through peritoneal dialysate and poor dietary intake. Other causes of low albumin levels are related to decreased absorption and increased breakdown in malignancy (Thomas, 2002). As previously noted, Vlamincx et al.'s study concluded that diet non-adherence is correlated with serum albumin level. In the present study, however, the non-significant correlation between medication and PD regimen non-adherence and serum albumin suggests that serum albumin level is not an important factor related to PD regimen and medication non-adherence.

There was insignificant correlation between serum calcium level, and medication and PD regimen non-adherence behaviour. Since patients were prescribed calcium supplements due to vitamin D deficiency and retention of phosphate, there should be a negative correlation between the frequency and intensity of non-adherence behaviour, and serum calcium level. Better medication adherence could result in a higher level of serum calcium. The study was unable to find a significant correlation between the above mentioned variables probably due to the small variation in the serum calcium level of the subjects, which was from 1.68-3.04mmol/L. Unlike other blood chemistry values, the small variance only partially reflects the effects of serum calcium level on non-adherence behaviours.

Despite the identification of serum potassium level as a predictor of non-adherence behaviours in some previous studies (Vives et al., 1999; Brown & Fitzpatrick, 1988; Hailey & Moss, 2000; Baines & Jindal, 2000), the number of exchanges missed and the skipping of medications during the last seven days as reported by the patients found no statistical association with serum potassium level in the study. The results of this study demonstrated that both the study and control group patients were able to achieve a normal and desirable range of serum potassium (from 3.70-4.09 mmol/L). Again, it is not surprising that the narrow range of variance is unable to demonstrate a significant association with the frequency and intensity of medication and PD non-adherence behaviours. The desirable blood chemistry results indicate that the hospital nurses strongly emphasized the risks of high



potassium values to the patients. As a result, the patients were fully aware of their potassium intake, which explains the corresponding effect for the control group patients.

For future criterion validation of PD non-adherence, another variable such as  $kt/V$  is suggested to be included as a measure of dialysis adequacy, which in turn indicates the degree of PD non-adherence.  $Kt/V$  is an index of urea removal from the body for each patient, achieved over time (Thomas, 2002). Even if this is a known variable that can be beneficial in determining criterion validity, the test is not routinely carried out by physicians in Hong Kong, and therefore, data was not available for analysis in the study. As a valid measure of PD non-adherence, future studies can consider using  $Kt/V$  index in determining criterion validity; creatinine clearance is also strongly advised.

### **Construct validity**

The results of the present study indicate construct validity of the scale. The very high, positive, statistically significant correlation between frequency and level of non-adherence behaviour within the subscales suggests that the above two items are tapping into similar characteristics in each of the respective subscale. For the weak to moderate correlations among diet, medication, and fluid non-adherence, the results suggest that the non-adherence behaviour to different treatment regimens should be treated independently. Patients showing non-adherence in one aspect may not

necessarily demonstrate the same behaviour in other aspects of the treatment regimen. The scale is therefore able to distinguish among different health-related non-adherence behaviours.

### **Reliability tests**

The internal consistency of the four constructs in the questionnaire was examined using Cronbach's alpha coefficients. The computed alpha correlations of the new subscales on medication and PD regimen were 0.85 and 0.65, respectively. These new subscales revealed satisfactory internal consistency and good stability. The very high test-retest reliability of the subscales (intraclass correlation coefficient = 0.98-1.00) showed that all of the subscales were stable and reproducible.

The revised DDFQ is considered a reliable instrument because of its high scores in the reliability tests. However, the scale required further testing for criterion validity on PD regimen non-adherence. This validation study of the DDFQ (revised version) has practical significance because no known measures for self-reported adherence behaviours have been validated in the nursing field in Hong Kong. Further validity tests are required to substantiate the criterion validity to improve the overall psychometric qualities.

## **6.6 Summary**

The study found that case management intervention that focuses on a discharge planning and follow-up programme could provide effective follow-up support for patients on PD. The patients in the study group received pre-discharge assessment and a comprehensive education programme. The six weeks post-discharge follow-up sessions by the case manager indicated that the patients were more satisfied with the health care services, had a better quality of life, and displayed better medication adherence behaviours than those in the control group. The predictors for medication and diet non-adherence, and self-rated general health were also identified in the study. The new model of advanced nursing practice, which focuses on patient empowerment and collaboration, provides evidence-based practice for enhancing self-care and the quality of life of peritoneal dialysis patients. The traditional patient care approach focuses mostly on symptom management and aims to improve the physiological well-being of patients. In contrast, advanced nurse-led case management intervention is concerned, not only with sustaining life, but also with ensuring the total well-being of patients and leading them to live meaningfully by coping with the disease. Lastly, the validation study established the psychometric properties of the two research measurement tools used in the study.

## **CHAPTER 7**

### **LIMITATIONS, IMPLICATIONS AND RECOMMENDATIONS**

This chapter discusses the limitations of the present study and the implications of the nurse-led case management programme for clinicians, nursing practitioners, researchers, and health administrators. Recommendations are also suggested for future research directions related to this topic.

#### **7.1 Limitations**

The primary limitation in this study was that of recruitment. Subjects were recruited from only two regional general hospitals in Hong Kong. Since the majority of hospitals with specialized renal care facilities and staff were not involved in the study, the results cannot be generalized for the whole population of peritoneal dialysis patients in Hong Kong. It would increase the relevance to the general population if more hospitals with specialist renal care facilities were included in future studies.

Use of the double-blinded design with a placebo control group is the best way to reduce most of the possible biases in clinical trials. Theoretically, in the context of the current study, the placebo group might also receive phone calls from the nurse to discuss issues not indicated in the usual structured telephone interview. However, such a design would create uncertainty and be meticulously demanding on the part of the unit and case managers. Another anticipated problem is the possibility of contamination

of the intervention for the placebo group during telephone conversations. It would be unethical for nurses not to provide support or information to patients during telephone interviews when problems were identified during the conversations. A control group receiving routine care with no telephone follow-up was therefore used for the comparison of patient outcomes in the study.

Another limitation of the study was the possible contamination of the interventions by the nursing staff. It is almost certain that subjects in the control group received informal health teaching as an integral part of their nursing interventions during their hospital stay, since every nurse-patient interaction affords the opportunity for teaching and learning, the majority of patients have questions and nurses are obligated by the ethics of their profession to do their best to answer those questions. Finally, the study's design did not establish controls for the telephone hotline contacts between the nurse, the patients and their families. Because all patients (i.e. in both the study group and the control group) were provided with the hotline service and were free to call in to review problems after discharge, the frequency and duration of the calls were not noted in this study. It is possible that the study failed to see the large differences in between-group effects because there was not enough difference in the outcome scores between the interventions.

## **7.2 Implications**

The implications of this study are specifically focused for clinicians, nursing practitioners, researchers, and health administrators.

### **7.2.1 Clinical implications**

The benefits of the nurse-led case management programme are substantial. Over the years, the Hong Kong government has striven to develop a quality health care system but the services involved focused mostly on acute care. Furthermore, advances in medical technology have led to higher health care costs and over-stretched hospital services (Health, Welfare, and Food Bureau, 2005). Long-term rehabilitation care services that encourage home care and include community outreach support should be, as suggested by the government, the future service delivery model for patients with chronic disease.

The new model in this study is designed to ensure that the community will continue to enjoy a sustainable and fully accessible quality health care service. One of the essential characteristics of the nurse-led case management programme includes continuous and comprehensive approaches in nurse-patient care. The essential feature of this advanced care model is for patients to have a continuing relationship with the health care staff to ensure that problems are managed in a holistic way. It is believed that the new nursing model could commit to provide three levels of prevention and specialized services to enhance the physical and

psychosocial wellness of renal patients undergoing peritoneal dialysis. Nurses should play a leading role and actively participate in this new nursing care approach in order to empower themselves, to maintain quality health care services.

### **Pre-discharge assessment as a routine practice**

Identification of physical, social and psychological status of the patients is the foremost step for future post-discharge interventions. Assessment using the Omaha system offers the potential to assist nurses in identifying patients' unmet needs before discharge. This process should include the patient and relevant kin as this is an important strategy to facilitate participation. Due to the decrease in length of hospital stay, pre-discharge assessment is a relatively simple procedure to determine the patient's home environment, self-care ability, and health care needs. Needs assessment is an important first step in improving the management of patients with chronic diseases and highlighting risk factors in order to facilitate future follow-up actions. Pre-discharge screening opportunities should be made available to every patient who has been admitted to the hospital. This could save valuable time and ensure the availability of individualized interventions, focused according to need. As an added benefit, patients who are well informed of their risk factors and the issues surrounding the physical and psychosocial perspectives could be more easily convinced to adhere to the various health related behaviours and to attend follow-up meetings regularly. The pre-discharge assessment using the Omaha

system, which was tested in this research study, should become a routine step in providing clinicians with the background to the nature of the interventions to be implemented within the nurse-led case management programme.

### **Focus on patients with high risk for non-adherence behaviours**

Ideally, all patients undergoing peritoneal dialysis can benefit from nurse-led case management interventions for support of self-management and to enhance quality of life in the community. The result of this study revealed that patients having secondary school education and having comorbid conditions contributed significantly to medication non-adherence. While for diet non-adherence, males and older patients were found to be significantly associated with non-adherence behaviour after discharge from hospital. Emotional well-being, quality of sleep and impact of kidney disease in daily life were variable and contributed significantly in patients' self reported health. These predictive factors should assist nurses to identify patients who are at higher risk of non-adherence to treatment regimens and reporting poor quality of life. Nurses can then focus on these patients and offer tangible help in maintaining their behaviours at home. The data in this study indicated that, while short-term gains were evident, telephone intervention did not affect adherence behaviours in the long-term. It is therefore critical to provide additional help to these high risk patients to improve the adherence behaviours once they have been selected and



enrolled in the programme in order to maintain ongoing support and achieve the desirable patient related and clinical outcome.

### **A new information system to support coordinated care**

Case management intervention is considered an effective strategy to reduce service fragmentation, increase the quality of life and provide cost controls in health care delivery service. It is therefore recommended that the hospital structure to be reorganized to accommodate this new model of care and to give support to nurses as they devote time and effort in their new role. A fully integrated clinical information system to support the management of end-stage renal patients is needed. The data that should be included in the system are standard quality indicators, key outcomes, and data on patient assessment, care management, and comorbid conditions (Mattern & Scott, 2001). The new information system is able to accommodate the evolving scope of the case management programme, and to minimize the time and cost for data management, with the support of a well-developed and sophisticated database. Lastly, the system provides an opportunity for the team to collaborate, share, and compare practices for the continuous delivery of quality services through the integrated system.

### **7.2.2 Research implications**

Case management and discharge planning are established areas of research overseas. In Hong Kong, there is a paucity of empirical findings or

published reports related to discharge planning, nurse-led case management, and nurse follow-up of patients after discharge.

Discharge planning and case management studies have largely concentrated on the elderly in the community. In Hong Kong, Wong recently pioneered clinical trials on nurse follow-up for acute patients following hospital discharge. The studies showed positive clinical outcomes with reduced health care costs, as related to nurse interventions (Wong, Wong & Chan, 2005; Wong et al. 2005). To date, there are no published studies on randomized controlled trials or comparative studies related to case management programmes for end-stage renal failure patients, both overseas and in Hong Kong. Most of the current studies on end-stage renal patients focus primarily on disease or symptom control without giving a clear direction of how nurse-led case management intervention is able to improve the total well-being of patients.

The present study concludes that the nurse-led case management programme was able to bring about some long-term and short-term treatment effects. Based on the initial findings, new modes of telephone follow-up should be developed in a longitudinal manner across time. The extended nursing intervention was able to provide longer follow-ups and to align with the essential component of nurse-led case management in terms of continuity of care. The six-week follow-up period used for the study was not long enough to fully assess the impact of telephone follow-up.

Therefore, a twelve-week follow-up period of telephone interviews should be designed to determine the impact on behavioural changes, improvement in symptoms and complication control, and quality of life, as some of the outcomes may take time before the treatment's effects are seen.

In addition to lengthening the duration of intervention, further research is necessary to substantiate the findings presented in this thesis. There is a need to extend the randomized controlled trial to other renal units in Hong Kong to further compare the results between the existing patient group and other patients receiving peritoneal dialysis. Making use of a wider patient population may help in the development of a more effective and innovative nurse-led case management programme for dialysis patients.

This study did not include an analysis on cost-effectiveness. "Cost", includes utilization of resources within and outside the institutionalized health care system. Nevertheless, future research to include cost containment of the nurse case management model is recommended, as minimizing health care cost is considered one of the outcomes of a case management programme. Researchers need to determine whether an innovative, nurse-led case management programme would benefit both patients and the health care system as a whole.

When considering the area of satisfaction, patient satisfaction is becoming the benchmark for measuring health care quality and included in most of the

outcome measure of service. However, most research studies have neglected the job satisfaction of the case manager. Cohen and Cesta (1997) illustrated that this enhanced role for nurses builds the feelings of professionalism and self-esteem because nurses' input is valued and deemed important to the patient's progress. The evaluation process should include tests for job satisfaction before and after implementation of the nurse-led case management model. Future research needs to focus on nurses' experiences as the positive result from empirical research allows for a greater feeling of team work and increases the momentum for future new practices.

### **7.2.3 Health policy implications**

In Hong Kong, patients who are ready for discharge from the hospital but are still in need of nursing and personal care do not have an appropriate source of support outside the hospital. Much of the work involved in patients with chronic illness can be carried out by qualified nurses. However, the scope of the Community Nursing Services (CNS) of the Hospital Authority is not broad enough to accommodate patients' needs which are increasingly becoming taxing (Health, Welfare & Food Bureau, 2005). Discharge planning with nurse telephone follow-ups, supplemented by selected CNS home visits, is able to strengthen the present health care delivery system for chronically ill patients who require prolonged and regular care for disease management during the stable phase of illness trajectory. The future service delivery model should include a good

interface between the hospital in-patient service and supportive home follow-up. This model needs the repositioning of hospitals' advanced nursing practices to be able to utilize the best available health resources in the new dynamic system. In order for sound healthcare rules to be set in place, collaboration is needed between the academics, who perform the health-related researches and the government, who dictate policy.

### **7.3 Recommendations**

End-stage renal failure patients are at high risk for hospital readmission and emergency room attendance. The provision of discharge planning strategies prior to discharge for both the patient and his/her family is recommended for this population group. For patients who are at a greater risk of complications and whose recovery or translocation is difficult, a case manager is certainly warranted to implement intensive discharge planning and appropriate referrals. The duration of telephone follow-ups should be adjusted accordingly to suit individual patients' needs. For less severe cases without complications, a general renal nurse would be an acceptable alternative to a case manager in implementing discharge planning with the patient-initiated telephone hotline service.

### **7.4 Conclusion**

This randomized, controlled trial is the first local study to implement a nurse-led case management programme focusing on discharge planning and telephone follow-ups for end-stage renal failure patients. The primary

objective of the study was to examine the effectiveness of a nurse-led case management programme on end-stage renal failure patients. Further, the study tested the psychometric properties of the research instruments, and identified the predictors of diet and medication non-adherence behaviours, and self-perceived general health. From the clinical perspective, the study revised an assessment protocol (Omaha system) to make it suitable for use in the renal patient group and developed the pre-discharge protocols and telephone interview guides that are essential as future reference for nurses.

Despite there being no significant difference noted by the group selected for intervention, except on patient satisfaction, there were differences for the main effect of time noted on the dependent variables in adherence behaviours, patient satisfaction, and some dimensions in Kidney Disease Quality of Life-Short Form (KDQOL-SF). There were also differences noted in some of the dimensions in KDQOL-SF by the interaction of time and intervention. Routine discharge procedures involve cost-effective nursing care services, which should be implemented routinely in a planned manner for all hospitalized patients. A more intensive discharge planning, such as the one studied here is appropriate for high-risk patients or patients demanding a high level of support. This initial work in examining the effects of nurse-led case management interventions is encouraging. Therefore, further research should be carried out on a similar patient group over a longer time period and with a larger sample. It is only through continuing research, that adjustments can be made to determine which

strategies will have the greatest impact on the provision of quality care in advanced nursing practices.

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## **List of Appendices**

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**INFORMATION SHEET**  
**EFFECTIVENESS OF CASE MANAGEMENT PROGRAMME FOR  
RENAL PATIENTS UNDERGOING PERITONEAL DIALYSIS**

You are invited to participate in a study conducted by the School of Nursing, The Hong Kong Polytechnic University, Queen Elizabeth Hospital and United Christian Hospital.

This objective of this research is to examine the effectiveness of nurse case management approach on peritoneal dialysis patients. This research involves the pre-discharge planning and telephone follow-up of 6 weeks post-discharge, and community nurse visit if required. You are invited to participate in the assessment interviews before discharge, at about one week after the programme, and twelve weeks after discharged from the hospital.

This research will not cause any uncomfortable feeling and the telephone interviews will be tape recorded. All information related to you will remain confidential, and will be identifiable by codes known only to the researchers.

You have every right to withdraw from the study before or during the measurement without penalty of your treatment and nursing.

If you have any complaints about the conduct of this research study, please do not hesitate to contact the Secretary of the Human Subjects Ethics Sub-Committee of The Hong Kong Polytechnic University in person or in writing (c/o Human Resources Office in Room M1303 of the University).

If you would like to have more information about this study, please contact Ms Susan Chow (The Hong Kong Polytechnic University) at tel. no. 2766 , Ms Rosaline Yip (Queen Elizabeth Hospital) at tel. no. 2958 , Ms Chan Nim Chi (United Christian Hospital) at tel. no. 3513 ,or Professor Frances Wong (The Hong Kong Polytechnic University) at tel. no. 2766 .

Thank you for your interest in participating in this study.

Professor Frances Wong  
Susan Chow



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POLYTECHNIC UNIVERSITY  
香港理工大學



## 有關資料

### 腹膜透析病者個案處理成效研究

誠邀閣下參加由香港理工大學護理學院與伊利沙伯醫院及基督教聯合醫院負責執行的研究計劃。

這項研究的目的是探討個案處理對腹膜透析病者的成效。研究會涉及出院後六星期的電話個案跟進、電話訪問，或社康護士的探訪。研究小組希望這些資料能有效地改善腎病病者的康復。閣下將會被邀在出院前，出院後六及十二星期接受三次跟進訪問。

這項研究不會引起任何不適的感覺，閣下之訪問皆會被錄音。凡有關閣下的資料均會保密，一切資料的編碼只有研究人員知道。

閣下享有充分的權利在研究開始之前或之後決定退出這項研究，而不會影響閣下所接受的治療及護理。

如果閣下有任何對這項研究的不滿，請隨時親自或寫信與香港理工大學人事倫理委員會秘書聯絡(地址：香港理工大學人力資源辦公室M1303室轉交)。

如果閣下想獲得更多有關這項研究的資料，請與周家儀小姐(理工大學護理學院)，電話 2766 ，葉銀蓮女士(伊利沙伯醫院),電話:2958 ，陳念芝女士(基督教聯合醫院),電話:3513 或黃金月教授(理工大學護理學院)電話 2766 聯系。

謝謝閣下有興趣參與這項研究。

黃金月教授

周家儀



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## CONSENT FORM

### EFFECTIVENESS OF CASE MANAGEMENT PROGRAMME FOR RENAL PATIENTS UNDERGOING PERITONEAL DIALYSIS

I \_\_\_\_\_ hereby consent to participate in the captioned research conducted by the School of Nursing, The Hong Kong Polytechnic University and Queen Elizabeth Hospital/United Christian Hospital. The programme includes the pre-discharge planning, telephone follow-up of 6 weeks post-discharge, and community nurse visit when needed. I am required to participate in the assessment interviews before discharge, at about one week after the programme, and twelve weeks after discharged from the hospital.

I understand that information obtained from this research may be used in future research and published. However, my right to privacy will be retained, i.e., my personal details will not be revealed.

The procedure as set out in the attached information sheet has been fully explained. My participation in the project is voluntary.

I acknowledge that I have the right to question any part of the procedure and can withdraw at any time without penalty of any kind.

Name of participant \_\_\_\_\_

Signature participant \_\_\_\_\_

Name of parent or guardian (if applicable) \_\_\_\_\_

Signature of parent or guardian (if applicable) \_\_\_\_\_

Name of researcher \_\_\_\_\_

Signature of researcher \_\_\_\_\_

Date \_\_\_\_\_



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## 參與研究同意書

### 腹膜透析病者個案處理成效研究

本人\_\_\_\_\_同意參加由香港理工大學護理學院與伊利沙伯醫院/基督教聯合醫院負責執行的研究項目，內容包括協定出院計劃，出院後六星期的電話跟進、電話訪問或社康護士探訪。

我理解此研究所獲得的資料可用於未來的研究和學術交流。然而我有權保護自己的隱私，我的個人資料將不會被洩漏。

我對是次研究的有關步驟已經得到充分的解釋。我是自願參與這項研究。

我理解我有權在研究過程中提出問題，並在任何時候決定退出研究而不會受到任何不正常的待遇或責任追究。

參加者姓名 \_\_\_\_\_

參加者簽名 \_\_\_\_\_

研究人員姓名 \_\_\_\_\_

研究人員簽字 \_\_\_\_\_

日期 \_\_\_\_\_

## **The four essential components of case management programme**

### **Comprehensiveness**

- The case manager is to provide comprehensive nursing care and support to the renal patient within and outside the hospital;
- Various perspectives including the holistic assessment prior to discharge using the Omaha system are considered in the care planning. The Omaha system consists of assessment on environmental, physiological, psychosocial, psychological, health related behaviour and disease specific issues.
- Comprehensive patient education on discharge is to ensure that the patient and family are adequately prepared to be independent upon discharge. The various components include advice on medication, CAPD procedures, dialysis regime, exit site care, infection control, fluid balance, exercise, and ordering of PD supplies.
- The protocol-driven phone call check list ensures the patient's needs and concerns are well addressed. The content of communication includes telephone triage, checking on adherence of diet, fluid, medication and PD regime, care of exit site, self monitoring of symptoms and complications, assessment of psychosocial status, and making referral to appropriate health care professionals when necessary.

### **Continuity**

- The case manager addresses continuity of care through pre-discharge assessment and to provide continuous and on-going support through telephone follow-up with the patients. The weekly telephone communication facilitates continued support, monitors the progress of mutually set goals and detects of unmet and potential needs of client after discharged from hospital.

### **Collaboration**

- The case manager collaborates with patient and family for achievement of better and improved health.
- The collaboration between physicians, nurse specialist, community nurses, social worker and other related disciplines is able to develop an effective and efficient patient referral system.
- The collaboration alongside with the referral system enables better symptom control and decrease inpatient care demand.

### **Coordination**

- The case manager coordinates all levels of patient care activities within and outside the hospital to ensure a smooth transition from institutional to home. The activities include health teaching, counselling and surveillance, referral and telephone follow-ups.
- The patient is able to contact and refer to the case manager for the full spectrum of health needs including emotion and physiological supports.



## Checklist on pre-discharge patient and family education

### *Medication*

- Patient's own medication to be focused in this session.
- The exact dose, frequency, route and why each medicine is taken.
- Side effects of medications.

### *CAPD or CCPD procedures*

- Competent in bag exchange procedure techniques and handwashing
- Encourages questions that patients had not thought or not relevant during the initial training period.
- Discuss the success and problems they have encountered.

### *Dialysis regime*

- Understand the prescribed PD options including the dialysis fluid fill volume per exchange; number of dialysis fluid exchanges; length of dialysis fluid dwell time, and osmotic strength of dialysis fluid.

### *Catheter and catheter exit-site care*

- Understand the differences between healthy and an infected exit site.

### *Diet management*

- Understand the aims of dietary management and consequences of diet non-compliance.
- Understand dietary modification is to help prevent malnutrition and controlling the accumulation of urea, potassium, phosphates, and correction of metabolic acidosis.

### *Infections*

- Understand peritonitis is a major complication of PD and can be associated with inadequate self-care.
- Understand peritonitis is the single biggest cause of peritoneal membrane failure.
- Able to detect early signs of peritonitis

### *Fluid balance*

- Understand the rationale of restriction of fluid intake.
- Aware signs of fluid overloaded.

### *Ordering and delivery of PD supplies*

- Understand the practicalities of ordering and delivery of the PD supplies.

### *Exercise for PD patients*

- Understand the importance of a healthy lifestyle and the type of activities that are best suited to the individual.
- Aware of the warning signs ( shortness of breath or swollen ankles) to stop an activity or exercise

## **PROTOCOL OF NURSE INITIATED TELEPHONE FOLLOW-UP**

**(1<sup>st</sup> call) To conduct the comprehensive assessment**

### **IS ANY OF THE FOLLOWING SYMPTOMS PRESENT AFTER DISCHARGE?**

- Patient feels ill and lethargic
- Difficult or rapid breathing
- Severe ankle oedema
- Fever
- Pain
- Fainting / headache
- Palpitation
- Nausea and vomit
- Leaks of dialysate around PD catheter

### **A. ADHERENCE WITH DIET AND FLUID INTAKE**

- Avoid food with high sodium content
- Avoid food with high potassium content
- Avoid food with high phosphate content
- Avoid excessive fluid intake

### **B. ADHERENCE WITH MEDICATION**

- Right drug
- Right route
- Right dose
- Right time
- Adherence to antibiotics treatment

### **D. ADHERENCE WITH DIALYSIS REGIMEN**

- Right dialysis fluid;
- Right number of dialysis fluid exchanges;
- Right length of dialysis fluid dwell time;
- Right osmotic strength of dialysis fluid.

### **E. CARE OF EXIT SITE, CATHETER PATENCY AND POSITIONING**

- Site clear of exudates or debris
- Use recommended solutions to clean the site
- Avoid harsh solutions
- Exit site is carefully dried to avoid maceration
- Tapes used to secure catheter immobilization
- Check tubing for kinks
- Avoid tub bath

### **F. SELF-MONITORING OF BODY WEIGHT, INTAKE AND OUTPUT**

- Record body weight daily
- Record fluid intake and output daily

- Record in and out flow of dialysis fluid

#### **G. MONITORING SIGNS OF COMPLICATION**

- Cloudy PD effluent
- Abdominal pain and tenderness
- Pyrexia

#### **H. SKIN CONDITION**

- Presence of erythema and purulent exudate at the catheter exit site
- Swelling, pain and redness over subcutaneous tunnel
- Pruritis associated with chronic renal failure

#### **I. PSYCHOSOCIAL STATUS**

- Patient perceived unmet needs (transportation, personal care services, meal services, homemaker services, financial etc)
- On-going support from family and friends
- Satisfaction with care
- Social activities in the past one week
- Activities of daily living
- Insomnia
- Anxiety
- New complaints, problems or needs

#### **Conditions that require emergency room referral (please refer to individual hospital protocol for ER referrals)**

- Patient feels ill and lethargic
- Difficult or rapid breathing
- Fever
- Palpitation
- Hypotension / Hypertension

#### **Conditions that warrant medical advice (please refer to individual hospital protocol for medical referrals)**

- Cloudy PD effluent
- Presence of purulent exudate at the catheter exit site
- Swelling, pain and redness over subcutaneous tunnel
- Intolerable medications side effect
- Fainting / headache
- Infections not resolve after finished antibiotic course

#### **Conditions that require nurse clinical consultation (please refer to individual hospital protocol for nurse clinical consultations)**

- Inconsistent dietary / fluid management
- Presence of erythema at the catheter exit site
- Medication nonadherence
- Unmanaged kinks and malpositioned catheter (UCH patients refers to doctor)
- Constipation

- Shoulder / back pain
- Mild purities
- Severe ankle oedema
- Nausea and vomit
- Leaks of dialysate

## **PROTOCOL OF NURSE INITIATED TELEPHONE CALL**

**(2nd call onward) Focused assessment on mutual goals and expected outcomes established on the previous calls. Check for understanding of advice provided by the nurse in the previous phone contacts.**

### **A. IS ANY OF THE FOLLOWING PRESENT AFTER DISCHARGE?**

- Patient feels ill and lethargic
- Difficult or rapid breathing
- Severe ankle oedema
- Fever
- Pain
- Fainting / headache
- Palpitation
- Nausea and vomit
- Leaks of dialysate around PD catheter

### **B. CARE OF EXIT SITE, CATHETER PATENCY AND POSITIONING**

Check for redness, swelling, hot, pain, unusual sensation and purulent discharge from the exit site

### **C. BODY WEIGHT**

Check for excessive weight gain/weight loss

### **D. BLOOD PRESSURE**

Check for abnormal blood pressure

### **E. PD REGIME**

Check: Dialysis solution concentration  
Frequencies of daily regime  
Intake and output record

### **F. PERITONITIS**

Clear/cloudy effluent

### **G. MEDICATIONS**

Check for non-compliant medications in previous calls  
Spot check on one to two types of medicine to determine the level of compliance

### **H. DIET**

Check dietary adherence focus on blood results: Potassium, Sodium and Phosphate intake  
Enquire what have been eaten recently

**I. FLUID**

Check daily intake of fluid to determine the level of fluid compliance

**J. PSYCHOSOCIAL**

Any unhappy/unpleasant feelings noted

References:

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Research code. \_\_\_\_\_

Name \_\_\_\_\_

Date of discharge \_\_\_\_\_

_____ telephone call Between ____/____/____ to ____/____/____
---

Patient not available:  refusal nobody answers the callNumber of calls attempted  1 Date \_\_\_\_\_ Time \_\_\_\_\_  2 Date \_\_\_\_\_ Time \_\_\_\_\_ 3 Date \_\_\_\_\_ Time \_\_\_\_\_**Summary of telephone call**

Put a ✓ on items that have been discussed in the telephone interview

**1. Body weight / intake and output**

- assess weekly body weight gain  
 assess balance on fluid intake and output  
 advise on excessive weight gain  
 advise on fluid intake and output

Advice given: \_\_\_\_\_

**2. Diet and fluid adherence**

- assess adherence  
 remind on diet adherence  
 remind on fluid restriction  
 encouragement and positive reinforcement

Advice given \_\_\_\_\_

**3. Medications adherence**

- assess adherence  
 provide information on medications adherence  
 remind on drug dose, route and frequency  
 inform of medications side effects

Advice given \_\_\_\_\_

**4. Dialysis treatment adherence**

- assess adherence  
 provide information on dialysis adherence  
 remind on dialysis regime  
 encouragement and positive reinforcement

Advice given \_\_\_\_\_

**5. Exit site, skin and catheter care**

- assess skin condition of exit site and tunnel
- general health teaching on exit site and catheter care
- advise on report of any condition change
- advise on change of dressing solution
- instruct on how to relieve symptoms
- instruct on how to relieve pruritis

Advice given \_\_\_\_\_

**6. Peritonitis**

- assess signs of peritonitis
- advise on close observation
- reassurance

Advice given \_\_\_\_\_

**7. PD complications**

- assess signs of PD complications
- advise on leakage of drainage system
- advise on fibrin in drainage system

Advice given \_\_\_\_\_

**8. Problems on elimination**

- Assess problems on bowel open
- advise on diet to relieve bowel problems

Advice given \_\_\_\_\_

**9. Psychosocial**

- review previously identified unmet needs
- assess signs of depression and anxiety
- encouragement and positive reinforcement
- elicit new complaints/ needs/problems

Advice given \_\_\_\_\_

**10. Equipment and supplies**

- supplies and equipment come as arranged
- advice on inadequate supply
- advice on handle malfunction equipments

Advice given \_\_\_\_\_



**11. Appropriate referral of health services**

- self health maintenance  
 arrange CNS visit when needed  
 arrange nurse clinic for assessment  
 attend specialist out-patient department as scheduled  
 attend nurse clinic as scheduled  
 attend A&E department  
 rearrange ward follow-up / Specialist out-patient clinic when needed

**12. Other problems and advice given**


---

**13. Care recipient's response to advice**

- recipient agreed with the advice given by the nurse  
 recipient did not agree with the advice given by the nurse

Reasons: \_\_\_\_\_

 additional telephone follow-up is required.

Date of next call \_\_\_\_\_

**Mutual goals and expected outcomes:**


---

Mutual goals	Expected outcomes
1	
2	
3	
4	
5	

Signature of Case Manager: \_\_\_\_\_

Duration of call: \_\_\_\_\_ mins

Date \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

## **Training Protocol for Case Managers**

The selected case managers in renal unit are required to undergo special training in case management to be competent with the key objectives identified. The trainers of the programme will include a nurse specialist of the renal unit, a psychologist experienced in Chinese Health Psychology and the investigators. Each training session would be around 3 hours.

### **Aim:**

To prepare nurse case managers in providing competent and continuing care to peritoneal dialysis patients after discharge.

### **Key Objectives :**

1. To introduce the concepts and specific roles of case manager;
2. To have an in-depth exploration on discharge planning and continuity of care;
3. To identify client and family's special needs using the OMAHA system;
4. To introduce telephone communication and interview skills;
5. To explore the key concepts of the case management approach: continuity, coordination, collaboration and comprehensiveness.
6. To review the principles of health promotion with special emphasise on individualized and holistic care;
7. To review the concept of outcome management in relation to case management in renal nursing.

The case management committee will organize case conferences to meet once every two months. In the case conferences, team members can ask for clarification and raise questions on client's conditions and the related care provided. This serves as a process evaluation to monitor the operation of the case management approach.

***Session 1*****Concepts of case management, discharge planning and continuity of care.**

- To review the definitions and practices of case management;
- Discussions on the various case management models;
- The role of case manager in a disease management programme;
- How case management is able to transform current practices and meet the demands of an evolving health care system.
- To explore the new wave of discharge planning;
- Standards of practice and discharge planning;
- Coordination and facilitation of clients in the discharge planning process.

***Session 2*****Patient and family needs identification before discharge**

- Use the Omaha system to identify patient and family's physical and psychosocial needs before discharge.

**Telephone and communication skills**

- To explore the use of telephone follow-up in providing continuity of care to patients after discharge;
- Telephone counselling and communication skills;
- Ethical issues related to telephone counselling to clients.

***Session 3*****Health promotion and outcome management**

- To review the principles and theories of health promotion;
- Understand holism and individualism in health promotion;
- To explore how client's health and wellbeing could be improved through discharge planning and telephone follow-up.

**Concepts of outcome management**

- To review the various outcomes (patient and clinical) in relation to case management;
- To explore how case management is able to achieve some of the outcome measures.

***Session 4***

Individual practice on telephone interviewing skills using the pseudo patient and scenario developed by the investigator.

The telephone interviews are audio taped and for review by the renal unit nurse manager, nurse specialist, physicians and the investigators. Some of the interviews will be shared among the case managers in the meetings to ensure safe and reliable management options are provided to the recipients. Written and verbal feedbacks are provided to the individual case manager by the investigator and the unit managers.

**Renal patient pre-discharge assessment form**

Date: \_\_\_\_\_

Name: \_\_\_\_\_

		Health teaching, guidance and counselling	Treatments and procedures	Case management	Surveillance
Environ-mental	1. Income				
	2. Sanitation				
	3. Residence				
	4. Neighbourhood/workplace safety				
	5. Transportation				
	6. Meal and homemaker service				
Psychosocial	7. Communication with community resources				
	8. Social contact				
	9. Role change				
	10. Interpersonal relationship				
	11. Spiritual distress				
	12. Grief				
	13. Emotional stability				
	14. Human sexuality				
	15. Caretaking				
	16. Neglected adult				
	17. Abused adult				
	18. Growth and development				
Physiological	19. Hearing				
	20. Vision				
	21. Speech and language				
	22. Dentition				
	23. Cognition				
	24. Pain				
	25. Consciousness				
	26. Integument				
	27. Neuro-musculo-skeletal function				
	28. Respiration				
	29. Circulation				
	30. Digestion-hydration				
	31. Bowel function				
	32. Genito-urinary function				
Health Behaviour	33. Nutrition				
	34. Sleep and rest patterns				
	35. Physical activity				
	36. Personal hygiene				
	37. Substance use				
	38. Family planning				
Related	39. Health care supervision				
	40. Prescribed medication regimen				
	41. Technical procedure				
Disease specific	42. Arrangement of equipment and supplies				
	43. Purchase of equipment and supplies				
	44. Exit site care				
	45. Fluid and diet restriction				
	46. Hypertension				
	47. Blood sugar monitoring				
	48. Symptom management				
	49. Oedema				
	50. Body image				

## Definitions of Adherence Behaviours

### Adherence to dietary intake

Correct dietary intake = Follows dietician's instructions to adhere to individual food eating pattern; avoids taking contraindicated foods.

No deviation = Strictly follows the instructions every day

Mild deviation = Follows the instructions most of the time; consumes special or favoured food occasionally.

Moderate deviation = Follows the instructions most of the time; occasionally fails to follow instructions at weekends, festivals, or social gatherings.

Severe deviation = Ignores the instructions most of the time, with only occasional adherence.

Very severe deviation = Never consciously follows the instructions; eats according to own personal preferences.

## **Adherence to fluid intake**

Correct fluid intake = Follows dietician's instructions on fluid intake; avoids or consumes only the appropriate amount and type of food and drink that has high water content.

No deviation = Strictly follows the instructions everyday.

Mild deviation = Follows the instructions most of the time; occasionally consumes special or favoured soup, congee, juice, or soft drinks.

Moderate deviation = Able to follow the instructions most of the time, occasionally refuses at weekends and/or festivals.

Severe deviation = Ignores the instructions most of the time, with only occasional adherence.

Very severe deviation = Never follows the instructions; consumes fluids according to own personal preferences.

|

## **Adherence to medication intake**

Correct medication intake = Follows the nurse's or pharmacist's instructions on medicine intake.

No deviation = Strictly follows the instructions everyday.

Mild deviation = Follows the instructions most of the time, ignores the instructions about intake time but not the medicine dosage.

Moderate deviation = Follows the instructions most of the time; occasionally ignores the intake time and changes the dosage of one of the prescribed medicines.

Severe deviation = Ignores the instructions most of the time; often changes the intake time and dosage of more than two of the prescribed medicines.

Very severe deviation = Never follows the instructions; takes the prescribed medicines according to own personal preferences.

## **Adherence to peritoneal dialysis regimen**

Correct PD regimen = Follows the prescribed regimen on peritoneal dialysis.

No deviation = Strictly follows the instructions everyday.

Mild deviation = Follows the instructions most of the time; increases or decreases the duration of dialysis by three hours or less. The frequency of dialysis, concentration and the amount of dialysate remain unchanged.

Moderate deviation = Able to follow the instructions most of the time; increases or decreases the duration of dialysis to more than four hours. The frequency of dialysis, concentration, and the amount of dialysate remain unchanged.

Severe deviation = Unable to follow the instructions most of the time; increases or decreases the duration of dialysis to more than four hours. Does not follow the frequency, concentration and the amount of dialysate as prescribed

Very severe deviation = Never follows the instructions; performs the regimen according to own personal preferences.



## 腎病患者行爲遵從問卷

定義 (解釋):

正確飲食指示 = 依從營養師個別指示進行飲食，包括適宜或避免某些食物

全無偏差 = 每日依從指示。

少許偏差 = 大部份時間依從，只是偶然不遵從，例如遇上極喜愛的食物，只是偶然一次或間中一餐。

中等偏差 = 大部份時間仍然依從，週末、喜慶或節日便會偏差。

嚴重偏差 = 大部份時間不遵從飲食飲食，只是偶然遵從。

極嚴重偏差 = 從來沒有依從指示，祇隨自己喜好。

## 腎病患者行爲遵從問卷

定義 (解釋):

正確液體飲量指示 = 依從營養師個別指示進行液體飲量，包括適宜或避免某些高水份食物及飲料。

全無偏差 = 每日依從指示。

少許偏差 = 大部份時間依從，只是偶然不遵從，例如遇上極喜愛的湯、粥或果汁汽水，只是偶然或間中一次。

中等偏差 = 大部份時間仍然依從，週末、飲宴或特殊節日便會偏差，例如：湯、粥或果汁汽水。

嚴重偏差 = 大部份時間不遵從飲量指示，只是偶然遵從。

極嚴重偏差 = 從來沒有依從指示，祇隨自己喜好。

## 腎病患者行爲遵從問卷

定義 (解釋):

正確服藥指示 = 依從護士或配藥員指示按時服用藥物。

全無偏差 = 每日全部依從服藥指示。

少許偏差 = 大部份時間依從，只是偶然不遵從服藥時間，每日藥物劑量沒有變更。

中等偏差 = 大部份時間仍然依從，偶然不遵從服藥時間及變更一種藥物劑量。

嚴重偏差 = 大部份時間不遵從服藥時間及變更兩種或以上藥物劑量。

極嚴重偏差 = 從來沒有依從指示，祇隨自己喜好。

## 腎病患者行爲遵從問卷

定義 (解釋):

正確透析指示 = 依從個別指示進行腹膜透析  
(洗肚)。

全無偏差 = 每日依從指示

少許偏差 = 大部份時間依從，只是偶然不遵從，例如自行縮短或增加透析時間少於三小時，每日透析次數、濃度及容量不變。

中等偏差 = 大部份時間仍然依從，自行縮短或增加透析時間多於四小時，每日透析次數、濃度及容量不變。

嚴重偏差 = 大部份時間不遵從，自行縮短或增加透析時間多於四小時，沒有遵從每日指定透析次數、濃度及容量。

極嚴重偏差 = 從來沒有依從指示，祇隨自己喜好。

**KIDNEY DISEASE  
AND  
QUALITY OF LIFE<sup>TM</sup>**

**SHORT FORM  
(KDQOL-SF<sup>TM</sup>)**

**VERSION 1.3**

<b>Your Health</b>
--------------------

1. In general, would you say your health is:

(Circle one number)

- Excellent..... 1
- Very good.....2
- Good..... 3
- Fair.....4
- Poor.....5

2. **Compared to one year ago**, how would you rate your health in general now?

(Circle one number)

- Much better now than one year ago.....1
- Somewhat better now than one year ago..... 2
- About the same as one year ago.....3
- Somewhat worse now than one year ago.....4
- Much worse now than one year ago..... 5

3. The following items are about activities you might do during a typical day.

**Does your health now limit** you in these activities? If so, how much?

(Circle one number on each line)

	<b>Yes, Limited a Lot</b>	<b>Yes, Limited a Little</b>	<b>No, Not Limited at All</b>
a. <b>Vigorous activities</b> , such as running, lifting heavy objects participating in strenuous sports.....	1	2	3
b. <b>Moderate activities</b> , such as moving a table, pushing a vacuum cleaner, bowling or playing golf.....	1	2	3
c. Lifting or carrying groceries.....	1	2	3
d. Climbing <b>several</b> flights of stairs.....	1	2	3
e. Climbing <b>one</b> flight of stairs.....	1	2	3
f. Bending, kneeling, or stooping.....	1	2	3
g. Walking <b>more than a mile</b> .....	1	2	3
h. Walking <b>several</b> blocks.....	1	2	3
i. Walking <b>one</b> block.....	1	2	3
j. Bathing or dressing yourself.....	1	2	3

4. During the **past 4 weeks**, have you had any of the following problems with your work or other regular activities **as a result of your physical health**?

(Circle one number on each line)

	<b>Yes</b>	<b>No</b>
a. Cut down the <b>amount of time</b> you spent on work or other activities?	1	2
b. Accomplished less than you would have liked?	1	2
c. Were limited in the kind of work or other activities?	1	2
d. Had difficulty performing the work or other activities (for example, it took extra effort)?	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Circle one number on each line)

	Yes	No
a. Cut down the <b>amount of time</b> you spent on work or other activities?.....	1	2
b. <b>Accomplished less</b> than you would like?.....	1	2
c. Didn't do work or other activities <b>as carefully as usual</b> ?.....	1	2

6. During the past 4 weeks, to what extent have your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

(Circle one number)

- Not at all.....1  
 Slightly.....2  
 Moderately.....3  
 Quite a bit.....4  
 Extremely.....5

7. How much **bodily pain** have you had during the **past 4 weeks**?

(Circle one number)

- None.....1  
 Very mild.....2  
 Mild.....3  
 Moderate.....4  
 Severe.....5  
 Very severe.....6



8. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

(Circle one number)

- Not at all.....1
- Slightly.....2
- Moderately.....3
- Quite a bit.....4
- Extremely.....5

9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**.....

(Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the **past 4 weeks**, how much of the time have your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

(Circle one number)

- All of the time..... 1
- Most of the time..... 2
- Some of the time..... 3
- A little of the time..... 4
- None of the time..... 5

11. Please choose the answer that best describe how **TRUE or FALSE** each of the following statements is for you.

(Circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get sick a little easier than other people...	1	2	3	4	5
b. I am as healthy as anybody I know.....	1	2	3	4	5
c. I expect my health to get worse.....	1	2	3	4	5
d. My health is excellent.....	1	2	3	4	5

<b>Your Kidney Disease</b>
----------------------------

12. How **TRUE or FALSE** is each of the following statements for you?

(Circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. My kidney disease interferes too much my life.....	1	2	3	4	5
b. Too much of my time is spent dealing with my kidney disease.....	1	2	3	4	5
c. I feel frustrated dealing with my kidney disease.....	1	2	3	4	5
d. I feel like a burden on my family.....	1	2	3	4	5

13. These questions are about how you feel and how things have been going during the **past 4 weeks**. For each question, please give the one answer that comes closer to the way you have been feeling.

How much of the time during the **past four weeks**.....

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
a. Did you isolate yourself from people around you?	1	2	3	4	5	6
b. Did you react slowly to things that were said or done?	1	2	3	4	5	6
c. Did you act irritable towards those around you?	1	2	3	4	5	6
d. Did you have difficulty concentrating or thinking?	1	2	3	4	5	6
e. Did you get along well with other people?	1	2	3	4	5	6
f. Did you become confused?	1	2	3	4	5	6

14. During the **past four weeks**, to what extent were you bothered by each of the following?

(Circle one number on each line)

	Not at All bothered	Somewhat bothered	Moderately bothered	Much bothered	Extremely bothered
a. Soreness in your muscle?	1	2	3	4	5
b. Chest pain?	1	2	3	4	5
c. Cramps?	1	2	3	4	5
d. Itchy skin?	1	2	3	4	5
e. Dry skin?	1	2	3	4	5
f. Shortness of breath?	1	2	3	4	5
g. Faintness or dizziness?	1	2	3	4	5
h. Lack of appetite?	1	2	3	4	5
i. Washed out or drained?	1	2	3	4	5
j. Numbness in hands or feet?	1	2	3	4	5
k. Nausea or upset stomach?	1	2	3	4	5
(Haemodialysis Patients only)					
l. Problems with your access site	1	2	3	4	5
(Peritoneal Dialysis Patients only)					
m. Problems with catheter site	1	2	3	4	5

<b>Effects of Kidney Disease on your Daily Life</b>
---

15. Some people are bothered by the effects of kidney disease on their daily life, while others are not. How much does kidney disease bother you in each of the following areas?

(Circle one number on each line)

	Not at All bothered	Somewhat bothered	Moderately bothered	Much bothered	Extremely bothered
a. Fluid restriction?	1	2	3	4	5
b. Dietary restriction?	1	2	3	4	5
c. Your ability to work around the house?	1	2	3	4	5
d. Your ability to travel?	1	2	3	4	5
e. Being dependent on doctors and other medical staff?	1	2	3	4	5
f. Stress or worries caused by kidney disease?	1	2	3	4	5
g. Your sex life?	1	2	3	4	5
h. Your personal appearance?	1	2	3	4	5

The next two questions are personal and relate to your sexual activity, but your answers are important in understanding how kidney disease impacts on people lives.

16. Have you had any sexual activity in the **past 4 weeks**?

No        1    Please skip to Question 17  
 Yes        2    Please continue with the below

How much of a problem was each of the following in the **past four weeks**?

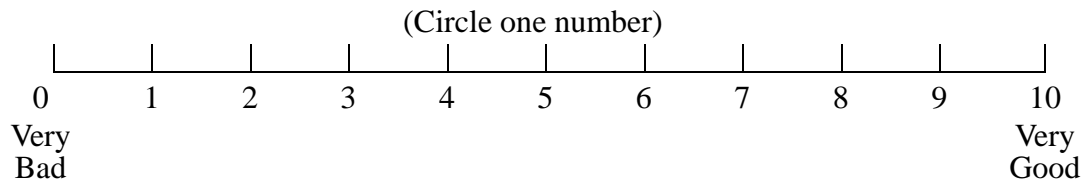
(Circle one number on each line)

	Not a problem	A little problem	Somewhat of a problem	Much a problem	Severe problem
a. Enjoying sex?	1	2	3	4	5
b. Becoming sexually aroused?	1	2	3	4	5

For the following question, please rate your sleep using a scale ranging from 0 representing “very bad” to 10 representing “very good”.

If you think your sleep is half-way between “very bad” and “very good”, please circle 5. If you think your sleep is one level better than 5, circle 6. If you think your sleep is one level worse than 5, circle 4 (and so on).

17. On a scale from 0 to 10, how would you rate your sleep overall?



18. How often during the past 4 weeks did you.....

(Circle one number on each line)

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
a. Awake during the night and have trouble falling asleep again?	1	2	3	4	5	6
b. Getting the amount of sleep you need?	1	2	3	4	5	6
c. Have trouble staying awake during the day?	1	2	3	4	5	6

19. Concerning your family and friends, how satisfied are you with.....

(Circle one number on each line)

	Very Dissatisfied	Somewhat Dissatisfied	Somewhat Satisfied	Very Satisfied
a. The amount of time you are able to spend with your family and friends?	1	2	3	4
b. The support you receive from your family and friends?	1	2	3	4

20. During the **past 4 weeks**, did you work at a paying job?

(Circle one number)

Yes..... 1

No..... 2

21. Does your health keep you from working at a paying-job?

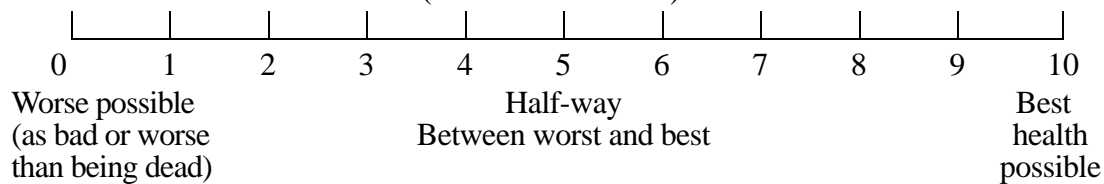
(Circle one number)

Yes..... 1

No..... 2

22. Overall, how would you rate your health?

(Circle one number)



<b>Satisfaction with Care</b>
-------------------------------

23. Think about the care you receive for kidney disease. In terms of your satisfaction, how would you rate the friendliness and interest shown in you as a person?

- Very bad..... 1
- Bad..... 2
- Fair..... 3
- Good..... 4
- Very good..... 5
- Excellent..... 6
- The Best..... 7

24. How **TRUE or FALSE** is each of the following statements?

(Circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. Dialysis staff encourage me to be as independent as possible.....	1	2	3	4	5
b. Dialysis staff support me in coping with my kidney disease.....	1	2	3	4	5



## 腎病患者生活質素研究 (中文版)

研究編號 \_\_\_\_\_

填寫說明

這項調查是詢問您對自己健康狀況的了解和患腎病對生活的影響。此項資料記錄您的自我感覺和日常生活的情況。

請您按照說明回答下列問題。如果您對某一個問題不能做出肯定的回答，請按照您的理解選擇最合適的答案。

1. 總括來說，您認為您的健康狀況是：

(只圈出一個答案)

- |          |   |
|----------|---|
| 極好 ..... | 1 |
| 很好 ..... | 2 |
| 好 .....  | 3 |
| 一般 ..... | 4 |
| 差 .....  | 5 |

2. 和一年前相比較，您認為您目前全面的健康狀況如何？

(只圈出一個答案)

- |               |   |
|---------------|---|
| 比一年前好多了 ..... | 1 |
| 比一年前好一些 ..... | 2 |
| 比一年前差不多 ..... | 3 |
| 比一年前差一些 ..... | 4 |
| 比一年前差多了 ..... | 5 |

3. 下列各項是您日常生活中可能進行的活動。以您目前的健康狀況，您在進行這些活動時，有沒有受到限制？如果有的話，程度如何？

(每項只圈出一個答案)

活動	有很大限制	有一點限制	沒有任何限制
a. 劇烈活動，比如跑步、搬重物，或參加劇烈的體育活動	1	2	3
b. 中等強度的活動，比如搬桌子、使用吸塵器清潔地面、玩保齡球或打太極拳	1	2	3
c. 提起或攜帶蔬菜、食品或雜貨	1	2	3
d. 上幾層樓梯	1	2	3
e. 上一層樓梯	1	2	3
f. 彎腰、跪下、或俯身	1	2	3
g. 步行十條街以上 (一公里)	1	2	3
h. 步行幾條街 (幾百米)	1	2	3
i. 步行一條街 (幾十米)	1	2	3
j. 自己洗澡或穿衣服	1	2	3

4. 在過去四星期裏，您在工作或其他日常活動中，有沒有因為身體健康的原因而遇到下列的問題？

(每項只圈出一個答案)

	有	沒有
a. 減少工作或其他活動的時間	1	2
b. 實際做的比想做的要少	1	2
c. 工作或其他活動種類受到限制	1	2
d. 完成工作或其他活動時有困難 (比如覺得更為吃力)	1	2

5. 在過去四星期裏，您在工作或其他日常活動中，有沒有由於情緒方面的原因 (比如感到沮喪或焦慮) 而遇到下列的問題？

(每項只圈出一個答案)

	有	沒有
a. 減少工作或其他日常活動的時間	1	2
b. 實際做完的比想做的要少	1	2
c. 工作或其他活動時不如往常細心了	1	2

6. 在過去四星期裏，您的身體健康或情緒問題在多大程度上妨礙了您與人、朋友、鄰居或社團的日常社交活動？

(只圈出一個答案)

毫無影響 .....	1
有很少影響 .....	2
有一些影響 .....	3
有較大影響 .....	4
有極大影響 .....	5

7. 在過去四星期裏，您的身體有沒有疼痛？如果有的話，疼痛到什麼程度？

(只圈出一個答案)

完全沒有 .....	1
很輕微 .....	2
輕微 .....	3
有一些 .....	4
劇烈 .....	5
非常劇烈 .....	6

8. 在過去四星期裏，您身體上的疼痛對您的日常工作 (包括上班和家務) 有多大影響？

(只圈出一個答案)

毫無影響 .....	1
有很少影響 .....	2
有一些影響 .....	3
有較大影響 .....	4
有極大影響 .....	5

9. 下列問題有關您在過去四星期裏的自我感覺和其他情況。請針對每一問題，選擇一個最接近您的感覺的答案。

在過去四星期裏有多少時間：

(每項只圈出一個答案)

		常常如此	大部份時間	相當多時間	有時	偶爾	從來沒有
a.	您覺得充滿活力？	1	2	3	4	5	6
b.	您覺得精神非常緊張？	1	2	3	4	5	6
c.	您覺得情緒低落，以致沒有任何事能使您高興起來？	1	2	3	4	5	6
d.	您感到心平氣和？	1	2	3	4	5	6
e.	您感到精力充足？	1	2	3	4	5	6
f.	您覺得心情不好，悶悶不樂？	1	2	3	4	5	6
g.	您感到筋疲力盡？	1	2	3	4	5	6
h.	您是個快樂的人？	1	2	3	4	5	6
i.	您覺得疲倦？	1	2	3	4	5	6

10. 在過去四星期裏，有多少時間由於您的身體健康或情緒問題妨礙了您的社交活動（比如探親，訪友等）？

(只圈出一個答案)

常常有影響 .....	1
大部份時間有影響 .....	2
有時有影響 .....	3
偶爾有影響 .....	4
完全沒有影響 .....	5

11. 如果用下列句子來形容您，您認為有多正確？

(每項只圈出一個答案)

		肯定對	大致對	不知道	大致不對	肯定不對
a.	您好像比別人更容易生病	1	2	3	4	5
b.	您和所有認識的人一樣健康	1	2	3	4	5
c.	您覺得自己的身體狀況會變壞	1	2	3	4	5
d.	您的健康極好	1	2	3	4	5

### 您的腎病

12. 如果用下列句子來形容您，您認為有多正確？

(每項只圈出一個答案)

		肯定對	大致對	不知道	大致不對	肯定不對
a.	腎病對我的生活有太多的阻礙... ..	1	2	3	4	5
b.	我用了太多時間去打理腎病... ..	1	2	3	4	5
c.	我對打理我的腎病感到氣餒... ..	1	2	3	4	5
d.	我覺得對家庭造成負累... ..	1	2	3	4	5

13. 下列問題是有關您，在過去四星期裏的自我感覺和其他近況。請針對每一問題，選擇一個最接近您的感覺的答案。

請問在過去四星期裏，有多少時間是：

(每項只圈出一個答案)

		從來沒有	偶爾	有時	相當多時間	大部份時間	常常如此
a.	您自己離群獨處？	1	2	3	4	5	6
b.	您對周圍發生的事情反應緩慢？	1	2	3	4	5	6
c.	您對別人表現得暴躁煩厭？	1	2	3	4	5	6
d.	您感到集中精神或思考有困難？	1	2	3	4	5	6
e.	您和別人融洽相處？	1	2	3	4	5	6
f.	您感到神智混亂？	1	2	3	4	5	6

14. 下列情況在過去四星期裏，對您的困擾有多大？

(每項只圈出一個答案)

		毫無困擾	少許困擾	一般困擾	很大困擾	嚴重困擾
a.	肌肉疼痛	1	2	3	4	5
b.	胸口痛	1	2	3	4	5
c.	骨痛	1	2	3	4	5
d.	抽筋	1	2	3	4	5
e.	皮膚痕癢	1	2	3	4	5
f.	皮膚乾燥	1	2	3	4	5
g.	氣促	1	2	3	4	5
h.	頭暈	1	2	3	4	5
i.	血壓不正常	1	2	3	4	5
j.	食慾不振	1	2	3	4	5
k.	疲倦無力	1	2	3	4	5
l.	手 / 腳麻痺	1	2	3	4	5
m.	作嘔作悶	1	2	3	4	5

n.	腳腫	1	2	3	4	5
o.	洗血血管出現問題 (只限血液透析病人作答)	1	2	3	4	5
p.	洗肚導管出現問題 (只限腹膜透析病人作答)	1	2	3	4	5

15. 試針對以下情況，您認為腎病對您帶來的困擾有多大？

(每項只圈出一個答案)

		毫無困擾	少許困擾	一般困擾	很大困擾	嚴重困擾
a.	限制水份	1	2	3	4	5
b.	戒口	1	2	3	4	5
c.	您處理家務的能力	1	2	3	4	5
d.	您消遣娛樂的能力	1	2	3	4	5
e.	您出外遠遊的能力	1	2	3	4	5
f.	對醫生和其他醫護人員的依賴	1	2	3	4	5
g.	因腎病產生的壓力和擔憂	1	2	3	4	5
h.	您的性生活	1	2	3	4	5
i.	您的個人儀容	1	2	3	4	5

16. 以下三個問題是有關您的性生活，您的答案能夠有助了解及分析腎病對病患者生活的影響。

過去四個星期內，您有沒有性行為？

(只圈出一個答案)

無..... 1 (跳到 17 題)  
有..... 2

在過去四星期裏，您對以下方面有多大困難？

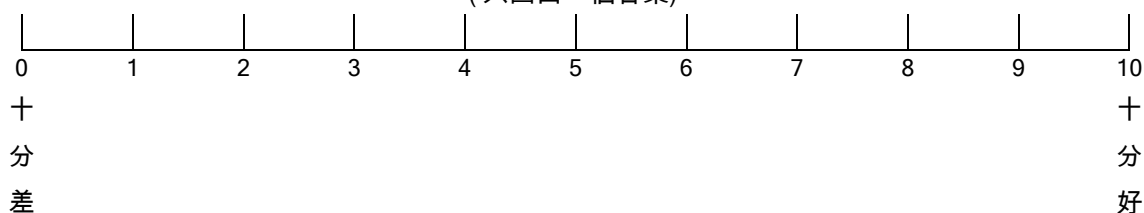
(每項只圈出一個答案)

		毫無困難	少許困難	一般困難	很大困難	嚴重困難
a.	享受性生活	1	2	3	4	5
b.	達致性興奮	1	2	3	4	5

以下問題是有關您對睡眠質素的評估，試在下面的量度尺上圈出一個數字最能代表您的睡眠質素。”0”代表十分差而”10”代表十分好。如果您的睡眠質素是在”十分好”與”十分差”的中間，請圈度數”5”，如果您的睡眠質素是比度數”5”好一度，請圈度數”6”，如果您的睡眠質素是比度數”5”差一度，請圈度數”4”（如此類推）。

17. 整體說，您的睡眠質素是：

(只圈出一個答案)



18. 在過去四星期裏，您有多少時間是：

(每項只圈出一個答案)

		從來沒有	偶爾	有時	相當多時間	大部分時間	常常如此
a.	晚間常醒，很久才可再入睡？	1	2	3	4	5	6
b.	有充足睡眠？	1	2	3	4	5	6
c.	日間有睡意？	1	2	3	4	5	6

19. 以下是關於您對 家庭及朋友 相處方面的滿意程度... ..

(每項只圈出一個答案)

		非常不滿意	少許不滿意	少許滿意	非常滿意
a.	“ 您與家人相聚的時間 ”	1	2	3	4
b.	“ 您與朋友相聚的時間 ”	1	2	3	4
c.	“ 家人給您的支持和鼓勵 ”	1	2	3	4
d.	“ 朋友給您的支持和鼓勵 ”	1	2	3	4

20. 在過去四星期裏，您是否有受薪的工作？

(只圈出一個答案)

有..... 1  
否..... 2

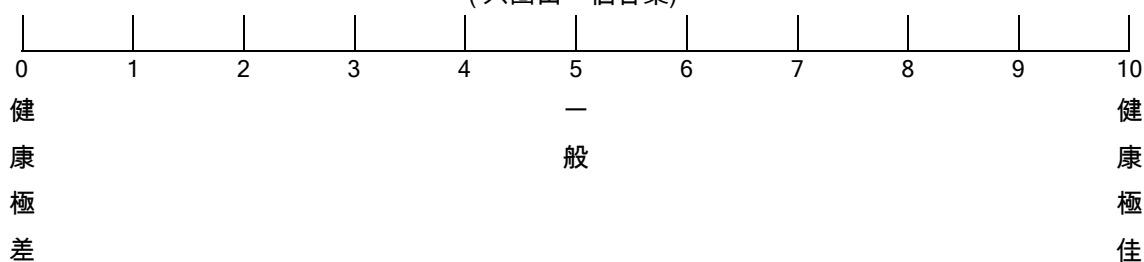
21. 您有否因 健康理由，令您不能擔任受薪的工作？

(只圈出一個答案)

有..... 1  
否..... 2

22. 總括來說，您認為自己的健康狀況是：

(只圈出一個答案)



23. 試用以下來評價您對腎病護理服務的滿意程度。

(只圈出一個答案)

很差 .....	1
差 .....	2
一般 .....	3
好 .....	4
很好 .....	5
非常好 .....	6
極好 .....	7

24. 您認為下列的句子有多正確？

(每項只圈出一個答案)

		肯定對	大致對	不知道	大致不對	肯定不對
a.	本中心的醫護人員有鼓勵我盡力自立生活... ..	1	2	3	4	5
b.	本中心的醫護人員有支持我去面對和適應腎病所帶來問題... ..	1	2	3	4	5

**La Monica-Oberst Patient Satisfaction Scale**

Please indicate your level of agreement by marking a ✓ in the corresponding box

For control group

	Items	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
1	The nurse is gentle in caring for me	0	0	0	0	0
2	The nurse helps me to understand my illness	0	0	0	0	0
3	The nurse understands me when I share my problems	0	0	0	0	0
4	The nurse is available when I need support	0	0	0	0	0
5	The nurse gives impression my care is top priority	0	0	0	0	0
6	The nurse makes me feel secure when giving care	0	0	0	0	0
7	The nurse gives complete explanations	0	0	0	0	0
8	The nurse gives directions at the right speed	0	0	0	0	0
9	The nurse appears to enjoy caring for me	0	0	0	0	0
10	The nurse sees that I get physical assistance when I need it	0	0	0	0	0
11	I can share my feelings when I need to talk	0	0	0	0	0
12	The nurse does things to make me more comfortable	0	0	0	0	0
13	Just talking makes me feel better	0	0	0	0	0
14	If I needed nursing care again, I would back to this hospital	0	0	0	0	0
15	The nurse makes me feel like a “case”, not an individual	0	0	0	0	0
16	The nurse does not follow through quickly enough	0	0	0	0	0
17	The nurse should be more thorough	0	0	0	0	0
18	The nurse is not as friendly as she/he could be	0	0	0	0	0
19	The nurse seems more interested in completing tasks than listening to the concerns	0	0	0	0	0
20	The nurse neglects to be sure I understand importance of my treatment	0	0	0	0	0
21	The nurse is impatient	0	0	0	0	0
22	The nurse acts like I cannot understand the medical explanation of my illness	0	0	0	0	0
23	The nurse is not as attentive as she/he should be	0	0	0	0	0
24	The nurse does nothing with information I give	0	0	0	0	0
25	The nurse fails to consider my opinions and preferences regarding plans for my care	0	0	0	0	0
26	The nurse does not keep promises to return to do things for me	0	0	0	0	0
27	The nurse talks down to me	0	0	0	0	0
28	The nurse does not answer my phone call promptly enough	0	0	0	0	0

What will you suggest to improve this service?



**La Monica-Oberst Patient Satisfaction Scale**

Please indicate your level of agreement by marking a ✓ in the corresponding box

For study group

	<b>Items</b>	<b>Strongly Disagree</b>	<b>Disagree</b>	<b>Neutral</b>	<b>Agree</b>	<b>Strongly Agree</b>
1	The case manager is gentle in caring for me	0	0	0	0	0
2	The case manager helps me to understand my illness	0	0	0	0	0
3	The case manager understands me when I share my problems	0	0	0	0	0
4	The case manager is available when I need support	0	0	0	0	0
5	The case manager gives impression my care is top priority	0	0	0	0	0
6	The case manager makes me feel secure when giving care	0	0	0	0	0
7	The case manager gives complete explanations	0	0	0	0	0
8	The case manager gives directions at the right speed	0	0	0	0	0
9	The case manager appears to enjoy caring for me	0	0	0	0	0
10	The case manager sees that I get physical assistance when I need it	0	0	0	0	0
11	I can share my feelings when I need to talk	0	0	0	0	0
12	The case manager does things to make me more comfortable	0	0	0	0	0
13	Just talking makes me feel better	0	0	0	0	0
14	If I needed nursing care again, I would back to this hospital	0	0	0	0	0
15	The case manager makes me feel like a “case”, not an individual	0	0	0	0	0
16	The case manager does not follow through quickly enough	0	0	0	0	0
17	The case manager should be more thorough	0	0	0	0	0
18	The case manager is not as friendly as she/he could be	0	0	0	0	0
19	The case manager seems more interested in completing tasks than listening to the concerns	0	0	0	0	0
20	The case manager neglects to be sure I understand importance of my treatment	0	0	0	0	0
21	The case manager is impatient	0	0	0	0	0
22	The case manager acts like I cannot understand the medical explanation of my illness	0	0	0	0	0
23	The case manager is not as attentive as she/he should be	0	0	0	0	0
24	The case manager does nothing with information I give	0	0	0	0	0
25	The case manager fails to consider my opinions and preferences regarding plans for my care	0	0	0	0	0
26	The case manager does not keep promises to return to do things for me	0	0	0	0	0
27	The case manager talks down to me	0	0	0	0	0
28	The case manager does not answer my phone call promptly enough	0	0	0	0	0

What will you suggest to improve this service?

## 病人滿意調查表 (對照組用)

請在最合適答案的空格上填上✓

	項目	非常不同意	不同意	中立	同意	非常同意
1	護士很細心地照顧我					
2	護士令我明白到我的病況					
3	士明白我傾訴的難題					
4	當我需要支持時，護士總會接觸我					
5	護士令我感覺到我所受到的照顧是佔首要的					
6	護士在照顧我時，給予我安全感覺					
7	護士給我完整的解釋					
8	護士能以合理速度提供清晰的指引					
9	護士令我感覺到他們很樂意照顧我					
10	當我有需要時，護士能給予協助					
11	當我需要傾訴時，護士能分享我的感受					
12	護士所做的工作，使我更覺得舒適					
3	護士單是談話，便能令我感覺好些					
14	如果我再需要護理服務時，我會再找護士					
15	護士令我覺得自己只是一個「個案」，而不是一個「個體」					
16	護士未能及時跟進我的情況					
17	護士所做的，應該可更深入徹底					
18	護士不夠友善					
19	護士似乎熱衷於完成工作多於聆聽我的需要					
20	護士沒有肯定我是否已經明白治療的重要性					
21	護士的舉動似乎認為我並不明白我自己的病況					
22	護士對我提供的資料沒有做到什麼					
23	護士計劃護理時，沒有考慮我的意見及喜好					
24	護士未能及時地回應我的來電					

你對此服務有何意見？

\_\_\_\_\_

\_\_\_\_\_

## 病人滿意調查表 (研究組用)

請在最合適答案的空格上填上✓

項目		非常不同意	不同意	中立	同意	非常同意
1	專責護士很細心地照顧我					
2	專責護士令我明白到我的病況					
3	專責護士明白我傾訴的難題					
4	當我需要支持時，專責護士總會接觸我					
5	專責護士令我感覺到我所受到的照顧是佔首要的					
6	專責護士在照顧我時，給予我安全感覺					
7	專責護士給我完整的解釋					
8	專責護士能以合理速度提供清晰的指引					
9	專責護士令我感覺到他們很樂意照顧我					
10	當我有需要時，專責護士能給予協助					
11	當我需要傾訴時，專責護士能分享我的感受					
12	專責護士所做的工作，使我更覺得舒適					
13	專責護士單是談話，便能令我感覺好些					
14	如果我再需要護理服務時，我會再來此醫院					
15	專責護士令我覺得自己只是一個「個案」，而不是一個「個體」					
16	專責護士未能及時跟進我的情況					
17	專責護士所做的，應該可更深入徹底					
18	專責護士不夠友善					
19	專責護士似乎熱衷於完成工作多於聆聽我的需要					
20	專責護士沒有肯定我是否已經明白治療的重要性					
21	專責護士的舉動似乎認為我並不明白我自己的病況					
22	專責護士對我提供的資料沒有做到什麼					
23	專責護士計劃護理時，沒有考慮我的意見及喜好					
24	專責護士未能及時地回應我的來電					

你對專責護士服務有何意見？

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### *The Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ)*

1.1 How many days during the past 14 days didn't you follow your diet guidelines? .....

1.2 To what degree did you deviate from your diet guidelines?

No deviation	Mild	Moderate	Severe	Very Severe
0	1	2	3	4

(Please circle the appropriate answer)

2.1 How many days during the past 14 days didn't you follow your fluid guidelines?

2.2 To what degree did you deviate from your fluid guidelines?

No deviation	Mild	Moderate	Severe	Very Severe
0	1	2	3	4

(Please circle the appropriate answer)

3.1 How many days during the past 14 days didn't you follow your medication guidelines?

3.2 To what degree did you deviate from your medication guidelines?

No deviation	Mild	Moderate	Severe	Very Severe
0	1	2	3	4

(Please circle the appropriate answer)

4.1 How many days during the past 14 days didn't you follow your dialysis guidelines?

4.2 To what degree did you deviate from your dialysis guidelines?

No deviation	Mild	Moderate	Severe	Very Severe
0	1	2	3	4

(Please circle the appropriate answer)

Modified from: The Dialysis Diet and Fluid Non-adherence Questionnaire (DDFQ). Vlaminck, H., Maes, B. & Evers, G.

## 腎病患者行為遵從問卷

這份問卷一共有 8 條題目，全部都係問你最近一星期治療方面的問題。

1.1 過去七日內，你總共有幾多天沒有跟隨正確飲食指示? \_\_\_\_\_ 天

1.2 請形容沒有跟隨正確飲食指示的偏差程度。以下有五個形容詞。(請✓正確數字)

0 \_\_\_\_\_ 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
全無偏差 少許偏差 中等偏差 嚴重偏差 極嚴重偏差

2.1 過去七天日內，你總共有幾多天沒有跟隨液體飲量指示? \_\_\_\_\_ 天

2.2 請形容沒有跟隨正確液體入量的偏差程度。以下有五個形容詞。(請✓正確數字)

0 \_\_\_\_\_ 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
全無偏差 少許偏差 中等偏差 嚴重偏差 極嚴重偏差

3.1 過去七天日內，你總共有幾多天沒有跟隨服藥指示? \_\_\_\_\_ 天

3.2 請形容沒有跟隨服藥指示的偏差程度。以下有五個形容詞。(請✓正確數字)

0 \_\_\_\_\_ 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
全無偏差 少許偏差 中等偏差 嚴重偏差 極嚴重偏差

4.1 過去七天日內，你總共有幾多天沒有跟隨腹膜透析指示? \_\_\_\_\_ 天

4.2 請形容沒有跟隨腹膜透析的偏差程度。以下有五個形容詞。(請✓正確數字)

0 \_\_\_\_\_ 1 \_\_\_\_\_ 2 \_\_\_\_\_ 3 \_\_\_\_\_ 4 \_\_\_\_\_  
全無偏差 少許偏差 中等偏差 嚴重偏差 極嚴重偏差

<i>Personal Information</i>
-----------------------------

(Please ✓ the correct box)

- 1) Patient code \_\_\_\_\_
- 2) Age : \_\_\_\_\_
- 3) Gender : 1.  Male 2.  Female
- 4) Marital Status : 1.  Single 2.  Married  
3.  Divorced 4.  Widowed
- 5) Peritoneal Dialysis : Length of time receiving Peritoneal Dialysis  
\_\_\_\_\_year(s) \_\_\_\_\_month(s)
- 6) Cause of Renal Failure :
  1.  Unknown
  2.  Hypertension
  3.  Diabetics mellitus
  4.  Polycystic kidney disease
  5.  Chronic glomerulonuphritis
  6.  Chronic pyelonephritis
  7.  Systemic lupus erythmatosus
  8.  Others (please specify)
- 7) Education Level :
  1.  No-schooling
  2.  Primary or Below
  3.  Secondary
  4.  Tertiary or Vocational Training
  5.  University or above
- 8) Employment status :
  1.  Full-Time
  2.  Part-time
  3.  Unemployed
  4.  Retired
  5.  Studying
  6.  House-keeping
- 9) Do you suffer other chronic disease(s)?
  1.  None
  2.  Cancer
  3.  Diabetic Mellitus
  4.  Cardiac Disease
  5.  Systemic lupus erythematosus
  6.  Respiratory Disesase
  7.  Mental Disroder
  8.  Hematologic Disorder (Hemophilic)
  9.  Others (Please Specify) \_\_\_\_\_

10) Are you the financial support of the family?

1.  Yes      2.  No

11) How do you consider your financial status at present?

1.  More than enough                      2.  Barely enough for daily expenses  
3.  Not enough for daily expenses      4.  Very insufficient

12) Do you receive financial support from the government?

1.  No  
2.  Comprehensive Social Security Assistant (CSSA)  
3.  Old Age Allowance  
4.  Disability Allowance (\$1260/month)  
5.  High Disability Allowance (\$2520/month)  
6.  Others (please specify) \_\_\_\_\_

13) Accommodation status:

1.  A flat                                      2.  A room  
3.  Cage home                                4.  Others \_\_\_\_\_

14) Who is responsible for the daily living task in the family?

1.  Myself      2.  Spouse                      3.  Co-habitat  
4.  Maid      5.  Domestic Helper      6.  Others \_\_\_\_\_

15) If you are ill, who will be responsible for the daily living tasks?

1.  Myself                      2.  Spouse                      3.  Maid  
4.  Domestic Helper      5.  Others \_\_\_\_\_

16) Whom you are living with?

- |   |   |
|---|---|
| 1. <input type="checkbox"/> Nil                           | 2. <input type="checkbox"/> Father                                  |
| 3. <input type="checkbox"/> Mother                        | 4. <input type="checkbox"/> Parent in-law                           |
| 5. <input type="checkbox"/> Spouse                        | 6. <input type="checkbox"/> Elder brother _____person(s)            |
| 7. <input type="checkbox"/> Elder sister _____person(s)   | 8. <input type="checkbox"/> Younger brother _____person(s)          |
| 9. <input type="checkbox"/> Younger sister _____person(s) | 10. <input type="checkbox"/> Son _____person(s)                     |
| 11. <input type="checkbox"/> Daughter _____person(s)      | 12. <input type="checkbox"/> Daughter-in-law _____person(s)         |
| 13. <input type="checkbox"/> Son-in-law _____person(s)    | 14. <input type="checkbox"/> Grandson/grand-daughter _____person(s) |
| 15. <input type="checkbox"/> Others _____                 |   |

17) Who will take care of you?

- |  |  |
|--|--|
| 1. <input type="checkbox"/> Yourself       | 2. <input type="checkbox"/> Father                   |
| 3. <input type="checkbox"/> Mother         | 4. <input type="checkbox"/> Parent in-law            |
| 5. <input type="checkbox"/> Spouse         | 6. <input type="checkbox"/> Elder brother            |
| 7. <input type="checkbox"/> Elder sister   | 8. <input type="checkbox"/> Elder sister             |
| 9. <input type="checkbox"/> Younger sister | 10. <input type="checkbox"/> Son                     |
| 11. <input type="checkbox"/> Daughter      | 12. <input type="checkbox"/> Daughter-in-law         |
| 13. <input type="checkbox"/> Son-in-law    | 14. <input type="checkbox"/> Grandson/Grand-daughter |
| 15. <input type="checkbox"/> Friend        | 16. <input type="checkbox"/> Neighbors               |
| 17. <input type="checkbox"/> Volunteer     | 18. <input type="checkbox"/> Maid                    |
| 19. <input type="checkbox"/> Others _____  |  |

18) The care available to you is :

- |  |  |
|--|--|
| 1. <input type="checkbox"/> Any time when needed | 2. <input type="checkbox"/> Occasionally |
| 3. <input type="checkbox"/> At night only        | 4. <input type="checkbox"/> None         |
| 5. <input type="checkbox"/> Others _____         |  |

19) Do you receive any community support services?

- |  |  |
|--|--|
| 1. <input type="checkbox"/> Renal Disease Supporting Services<br>(Renal Patient support group 、 Community Rehabilitation Networks) |  |
| 2. <input type="checkbox"/> Home Helpers   | 3. <input type="checkbox"/> Community nursing services |
| 4. <input type="checkbox"/> Others (Please specify) _____  | 5. <input type="checkbox"/> None                       |

20) Reason of current admission : \_\_\_\_\_



個人資料
------

(請✓上合適的)

- 1) 病人編號 : \_\_\_\_\_
- 2) 年齡 : \_\_\_\_\_
- 3) 性別 : 1. 男 2. 女
- 4) 婚姻狀況 : 1. 未婚 2. 已婚 3. 離婚  
4. 喪偶
- 5) 腹膜透析 : 已洗肚\_\_\_\_\_年\_\_\_\_\_月
- 6) 腎病起因 : 1. 不知道 2. 高血壓 3. 糖尿病 4. 多囊腎  
5. 慢性腎小球炎 6. 慢性腎盂炎 7. 紅斑狼瘡  
8. 其他 (請註明) \_\_\_\_\_
- 7) 教育程度 : 1. 沒正式受教育 2. 小學或以下 3. 中學  
4. 大專或專業資格 5. 大學或以上
- 8) 職業 : 1. 全職 2. 兼職 3. 待業 4. 退休  
5. 在學 6. 主理家務
- 9) 是否患有其他疾病: 1. 無 2. 癌症 3. 糖尿 4. 心臟病  
5. 紅斑狼瘡 6. 呼吸系統疾病 7. 精神病  
8. 血液病(血友病) 9. 其他(請註明)\_\_\_\_\_
- 10) 你是否家庭的經濟支柱?  
1. 是 2. 否
- 11) 你覺得你的經濟狀況如何? 1. 足夠有餘 2. 剛剛足夠應付日常開支  
3. 不足夠應付日常開支 4. 十分不足夠
- 12) 你現時有否接受任何社會福利金錢上的援助?  
1. 無 2. 綜合援助 3. 高齡津貼 4. 傷殘津貼 (\$1260/月)  
5. 高傷殘津貼 (\$2520/月) 6. 其他 (請列明) \_\_\_\_\_

- 13) 你現在的居所是:  
 1.  整個單位      2.  一房間      3.  籠屋      4. 其它\_\_\_\_\_
- 14) 家庭的起居飲食是由誰人照顧?  
 1.  自己    2.  配偶    3.  與同居者分工    4.  傭人    5.  家務助理  
 6.  其他 \_\_\_\_\_
- 15) 若你有病時，家庭的起居飲食會由誰人照顧?  
 1.  自己    2.  配偶    3.  傭人    4.  家務助理    5.  其他 \_\_\_\_\_
- 16) 你現在與那些家庭成員居住?  
 1.  獨居  
 2.  父    3.  母    4.  配偶父母  
 5.  配偶    6.  兄 \_\_\_\_\_ 人    7.  姊 \_\_\_\_\_ 人    8.  弟 \_\_\_\_\_ 人    9.  妹 \_\_\_\_\_ 人  
 10.  子 \_\_\_\_\_ 人    11.  女 \_\_\_\_\_ 人    12.  媳婦 \_\_\_\_\_ 人    13.  女婿 \_\_\_\_\_ 人  
 14.  孫 \_\_\_\_\_ 人    15.  其他\_\_\_\_\_
- 17) 有那些人會照顧你?  
 1.  自己  
 2.  父                  3.  母                  4.  配偶父母  
 5.  配偶              6.  兄                  7.  姊                  8.  弟                  9.  妹  
 10.  子              11.  女              12.  媳婦              13.  女婿  
 14.  孫              15.  朋友              16.  鄰居              17.  機構義工    18.  傭人  
 19.  其它\_\_\_\_\_
- 18) 所得到的照顧是：  
 1.  隨時    2.  間中到訪 / 幫助    3.  只在晚上    4.  完全無其他人幫助  
 5.  其他 \_\_\_\_\_
- 19) 你現時有否接受下列各種社區支援?  
 1.  腎病支援服務 (腎友會、社區復康網絡)      2.  家務助理  
 3.  社康護理服務      4.  其他 (請列明) \_\_\_\_\_      5.  無
- 20) 今次入院原因： \_\_\_\_\_

### Symptom control and complication management

Name \_\_\_\_\_

Research code \_\_\_\_\_

<b>Biochemical indicators</b>	<b>Blood chemistry</b>	<b>T1</b>	<b>T2</b>	<b>T3</b>
	Urea			
	Creatinine			
	Sodium			
	Potassium			
	Phosphate			
	Albumin			
	Kt/V			
	Calcium			
	Haemoglobin			
	<b>Other indicators</b>	Oedema 0=0 / 1=+ / 2=++ / 3=+++		
Peritonitis 0=No/1=Yes				
Exit site condition 0=normal / 1=abnormal				
Body weight (kg)				

Exact values are to be recorded for blood chemistry results.

從來沒有

None of the time

偶爾

A little of the time

有時

Some of the time

相當多時間

A good bit of the time

大部份時間

Most of the time

常常如此

All of the time