CHAPTER 1

INTRODUCTION

Background and Significance of Research Problem

Chronic renal failure (CRF) is a permanent, irreversible condition characterized by a progressive and generally irreversible decline in glomerular filtration rate (GFR) (Bennett & Plum, 1996). Hemodialysis is one of the revival therapies for CRF patients. The incidence rate of CRF is 50-100/1,000,000 of the population in the world (Wang, 1996). Ιn the United States, over 220,000 individuals had end-stage renal disease (ESRD) (McCarley & Lewis, 1996), and there were over 113,000 individuals receiving hemodialysis (Gurklis & Menke, 1995). In China, the incidence rate of CRF is 100/1,000,000 of the population (Wang, 1996). Since the beginning of hemodialysis in 1960s, the number of chronic hemodialysis patients in China has been increasing. There were 4,028 CRF patients receiving hemodialysis in 1989, and the number increased to 14,661 in 1992 (Institute of Organ in China). According to an annual record of the Second Teaching Hospital of Hunan Medical University, about 120

patients have regularly received hemodialysis (Annual Report of the Second Teaching Hospital of Hunan Medical University, 1996).

dysfunction causes multiple pathologic situations including disruptions in the glomerular filtration rate, abnormalities of urine production and electrolyte imbalances, and metabolic water excretion, abnormalities (Ignatavicius, Workman, & Mishler, 1995). If renal function gradually decreases until the healthier kidney tissue can no longer compensate for the loss of nonfunctional nephrons, the patient will ultimately progress to end-stage renal disease (ESRD) (LeMone & Burke, 1996).

Hemodialysis is one of several therapies for the treatment of renal failure. With the initial dialysis in 1940, ESRD patients were given a second chance of life. Over time, there has been significant improvement in dialysis techniques and patient care (Tell, Mittelmark, Hylander, Shumaker, Russell, & Burkart, 1995). Even though hemodialysis can improve some physical functions, patients have to face much treatment-associated stress (Baldree, Murphy, & Powers, 1982). Most patients are not able to return to their normal life and need other therapeutic modalities. Dialysis patients commonly experience a wide

range of disorders that negatively influence their holistic well-being (Bjorvell & Hylander, 1989; cited in Tell et al., 1995). The patients will face some complications from undergoing hemodialysis as well as problems from disease. problems found include developing some systemic complications during or after the hemodialysis procedure such as hypotension, bleeding, infection, and dialysis dementia (LeMone & Burke, 1996). Other complications are not feeling well after dialysis, nausea, vomiting, decreased mobility, bone pain, and having too much fluid removed during hemodialysis (Gurklis & Menke, 1995). Some patients have to face many symptoms including muscle cramps, fatigue, and itching which were the top three kinds of stress (Eichel, 1986). Boredom and uncertainty about the future were also ranked as the high stress (Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988). All of these could eventually affect physical, psychological, and social aspects of these patients.

With regards to the physical aspect, the general health function of hemodialysis patients is decreased including limitation of activity of daily living (Gurklis & Menke, 1988; Lok, 1996). In addition to physical problems, psychological problems of hemodialysis patients occur including loss of control, depression, anxiety, impaired

body image, and helplessness (Courts & Vacc, 1994; Folkman, Lazarus, Gruen, & DeLongis, 1986, cited in Courts & Vacc, 1994; Gurklis & Menke, 1988). Social aspects of their life are affected including restriction of travel, decrease in participation in both family and social activities, unemployment and financial burdens (Gurklis & Menke, 1988; Lambert & Lambert, 1985). All of these aspects could affect the patients' quality of life.

Quality of life is the degree to which a person's life experiences are satisfying in four aspects including life satisfaction, self-concept, health and functioning, and socio-economic factors (Zhan, 1992). This concept could cover all dimensions of individual life experiences of hemodialysis patients which include physical, psychological and social aspects. Ferrans and Powers (1993) studied the quality of life of hemodialysis patients by using the Ferrans and Powers' Quality of Life Index (1990) which was categorized into four subscales including health functioning, social and economic, psychological/spiritual, and family subscales. Quality of life of the patients was found to be relatively high. The patients also reported that they had to restrict their participation in many activities or give them up entirely because of poor health and medical regimen.

Hemodialysis patients have to face physical, psychological and social problems that often result in increased need for social support. Social support, particularly support from family members, will patients to adequately deal with these problems. Social support was identified as the main factor that has both stress buffering and direct effects on a wide variety of outcomes including physical health, mental well-being and social functioning (Courtens, Stevens, Crebolder Philipsen, 1996)

Family support is considered the primary social support group which plays an important role in promoting and protecting health (Pender, 1987). Clerk (1983, cited Pender, 1987) found that the more individuals participated in family activities, the fewer individuals experienced ill-health. Procidano and Heller (1983) defined family support as the extent to which an individual perceives that his/her needs for support, information, and feedback are fulfilled. They indicated family support as social support which an individual received from family members. Results from some studies indicated that family support appeared to be a major factor that can protect people in crisis from a wide range of health problems including arthritis, tuberculosis, cancer, depression and

so on (Berkman, 1969; Koski, Ahas, & Kumento, 1976; cited in Caldwell, 1988).

Therefore, family support could be one of the major supports for hemodialysis patients because the patients have to handle some stressful events and receive long-term care throughout their life. Patients need continued physical and psychosocial support. For many chronically ill patients, having a supportive family during times of illness is one of the most important aspects of their care (Black & Matassarin-Jacobs, 1993).

A study by Webb, Wrigley, Yoels and Fine (1995) indicated that family support improved the quality of life of patients with traumatic brain injuries indirectly by increasing functional independence. Patients with strong family support had fewer physical impairments which directly improved their quality of life and indirectly improved their quality of life through increased likelihood of employment and by reducing the need for rehabilitation and improving functional independence.

The First, Second, and Third Teaching Hospitals of Hunan Medical University, and Hunan People Hospital are the largest teaching hospitals in Changsha, Hunan Province. They are government-operated general hospitals. The hemodialysis units in these hospitals provide treatment for

both inpatients and outpatients. Most of patients are CRF patients who need to be hospitalized for medical treatment. Although there is some information regarding relationships between social support and quality of life in hemodialysis patients in western countries, little is reported in China. The results from western countries may not be generalized Chinese hemodialysis patients because of different cultural background, family networks, and socio-economic In China, traditionally, the family structure is an extended family. Almost all of the family members are tied by blood relationships and the relationship between each member is very tight. Family members are concerned about each other. Most Chinese consider family as most important source of support, especially when they are ill (Tong, 1990). However, by the end of 1970s, the family structure in China changed rapidly from the extended family to the nuclear family due to the developing process of industrialization, economic growth, and family planning policy. This might bring some changes to the family network which used to be strong in China. In addition, hemodialysis patients may have to face economic burdens because of the high cost of hemodialysis treatment, between 30,000 to 50,000 yuan a year per patient (Hemodialysis unit record, 1997). These points could affect the quality of life of

hemodialysis patients. Therefore, this study is designed to describe family support and quality of life and to ascertain the relationship between family support and quality of life of Chinese hemodialysis patients.

Objectives of the study

The study had three objectives:

- 1. To describe the quality of life of Chinese hemodialysis patients.
- 2. To describe the family support of Chinese hemodialysis patients.
- 3. To ascertain the relationship between family support and quality of life among hemodialysis patients in China.

Hypothesis

There was a positive relationship between family support and quality of life among hemodialysis patients.

Definition of terms

Quality of life Self evaluation of individual's satisfaction with his or her life in four dimensions including life satisfaction, self-conception, health

and functioning and social-economic factors, measured by a quality of life questionnaire, developed by Uppalabut (1994) based on Zhan's concept. The questionnaire was modified by the researcher to fit with CRF patients who receive hemodialysis.

Family support Perceived needs for support, information and feedback fulfilled by family members including parents, siblings, spouse, children and close relatives. measured by the Modified Perceived Social Support from Family (MPSS-Fa) Scale which Zhang (1997) modified from the Perceived Social Support from Family (PSS-Fa) Scale developed by Procidano and Heller (1983). Hemodialysis Chinese persons aged 18 years old or oldrt patients who have been diagnosed as CRF by a Physician, and currently receive hemo-

dialysis treatment.