

CHAPTER 1

INTRODUCTION

Background and Significance of the Study

Chronic renal failure (CRF) is a major concern of health care professionals. The World Health Organization (WHO) reported that in 1999 there were approximately 8,429,000 CRF patients worldwide (WHO, 1999). In Indonesia, the number of CRF patients is quite high. Moniaga (2002) reported that there were approximately 200 patients per million of the population that suffered from CRF nationwide in 2002, giving a total of potential people suffering from CRF of up to 40,000 people.

Chronic renal failure is a progressive, irreversible deterioration in renal function in which the body's system ability to maintain metabolic and fluid and electrolyte balance fails, resulting in uremia or azotemia (Ulrich, 1989). The toxic effects of uremia are manifested in virtually all body systems and can lead to organ systems disturbances (Baldree, Murphy, & Powers, 1982; Ulrich, 1989). Chronic loss of function causes progressive scarring all parts of the kidneys. In time, the Glomerular Filtration Rate (GFR) will decline to levels of less than 10 cc/min (Verreli, 2002). To sustain life, patients with renal failure need to undergo renal replacement therapy.

Hemodialysis is one of the most widely used renal replacement therapies for patients with renal failure. In Indonesia, although there are many CRF patients who need hemodialysis, most can not afford the treatment; only approximately 4000 patients are able to undergo hemodialysis regularly (Roesli, 2002). In Bandung, Indonesia, with a population of approximately 2,000,000 people, there were 413

patients who regularly underwent hemodialysis in the year 2001 (Nursing Department of Mrs. Habibi Hospital, 2002).

The technologies of hemodialysis have been of great benefit in sustaining the life of patients with renal failure. This technique improves comfort, allows patients to eat a reasonable diet, helps maintain tolerable blood pressure, prevents progression of uremic neuropathy, and improves the survival rate as well as the level of quality of life (Oberley & Schatell, 1995). However, the patients still experience problems of certain specific disease symptoms, which impacts on multiple stress factors (Ferrans & Power, 1993). Stressors that can be caused by hemodialysis treatment include hypotension, nausea, vomiting, muscle cramps, headache, chest pain, and disequilibrium syndrome. In addition, patients also suffer other problems from CRF such as a reduction in physical functioning, diminished working capacity, and difficulties in coping with family and social responsibilities (Suet-Ching, 2001).

CRF also introduces an added stress dimension to the already enormous demands placed on the contemporary family system. Family dynamics can change drastically and role reversal is inevitable (Flaherty & O'Brien, 1992). Family members, especially the spouse, are acknowledged to be important in the patient's response to the illness and related treatment. The spouse shares many problems which face the patient, including change in role, life-style, and the marital relationship (White & Grenyer, 1999). The unending demands of hemodialysis and renal failure require major adjustments in living patterns of patients and families, particularly spouses.

Regarding the multiple impacts of chronic renal failure and hemodialysis treatment on physical, psychological, economic, and social relationships, the quality

of life becomes an important issue for hemodialysis patients and their spouses (Ferrans & Power, 1992). Lok (1996) investigated the quality of life of dialysis patients in Australia; he found that the quality of life of hemodialysis patients was below average. A study of dialysis patients in Hong Kong showed that patients with worsening health conditions, lower level of income, and lack of family as well as social support, had a lower quality of life (Suet-Ching, 2001). Compared with continuous ambulatory peritoneal dialysis (CAPD) patients, hemodialysis patients had a lower quality of life (Lok, 1996). In addition, it was found that spouses who acted as a care giver for hemodialysis patient had poorer health, more frequent chronic diseases, particularly depression, and greater use of medication. These all resulted in a lower quality of life than in the general population (Belasco & Sesso, 2002). Spouses of hemodialysis patients also had poorer quality of life than spouses of CAPD and renal transplant (Lindqvist, Carlsson, & Sjoden, 2000). In order to provide appropriate nursing care, information regarding the quality of life of patients as well as their spouses is needed. Quality of life is an important outcome of health care intervention as well as of nursing care (Anderson & Burckhardt, 1999).

There are many terms similar to quality of life such as life satisfaction, well-being, health, happiness, self-esteem, adjustment, value of life, meaning of life, and functional status (Zhan, 1992). Sarvimaki and Hult (2000) identified factors which influence a person's quality of life, including health, functional capacity, coping mechanism, environment, work, housing conditions, and social network. Among those factors, coping was significantly associated with quality of life (Ketelaars, et al. 1996; Meifen, 1997; Coelho, Amorim, & Prata, 2003).

Living with CRF, patients and spouses have to cope with many problems such as uncertainty about the future, loss of freedom, dependence on the care giver, and disrupted marital, family and social life (Lindquist, Carlsson, & Sjoden, 2000; Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001). Coping strategies have an important role in maintaining the patient's physical and psychological well-being when dealing with some difficulties (Coelho, et al., 2003). Effective coping helps the patients and spouses to lessen stresses, resolve uncomfortable feelings, and preserve the ability to function effectively in relationships, and maintain a positive self-concept that promotes quality of life (Miller, 1992). In addition, the way an individual uses coping methods is influenced by the nature of their belief system, culture, psychological well-being, perception of illness, previous experience using varied methods, and cognitive capacity (Miller, 1992).

Although CRF is currently an incurable disease, promoting optimal function and well-being is a major aim of nursing care. Many previous studies on hemodialysis patients have investigated either stressors and coping, or quality of life of dialysis patients separately. For example, Baldree, et al. (1982) studied stress identification and coping patterns in patients on hemodialysis, Mok & Tam (2001) investigated stressors and coping methods among chronic hemodialysis patient in Hong Kong, Suet-Ching (2001) studied quality of life of Hong Kong dialysis patients, and Welch & Austin (2001) studied stressors, coping and depression in hemodialysis patients. There are no reported studies on the relationship between coping strategies and quality of life of hemodialysis patients as well as their spouses, particularly in Indonesia. Therefore, this study aimed to investigate coping strategies and quality of life of patients with CRF undergoing hemodialysis and their spouses, and also to

examine the relationships between coping strategies and quality of life of patients with CRF undergoing hemodialysis and their spouses.

Objectives of the Study

The objectives of this study were as follows:

- (1) To identify coping methods frequently used by patients with chronic renal failure undergoing hemodialysis and their spouses
- (2) To investigate the level of the quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses
- (3) To examine the relationship between coping strategies and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses

Research Questions

This study attempted to answer the following questions:

- (1) What are the coping methods frequently used by patients with chronic renal failure undergoing hemodialysis and their spouses?
- (2) What are the levels of quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses?
- (3) Is there a relationship between the coping strategies and the quality of life of patients with chronic renal failure undergoing hemodialysis?
- (4) Is there a relationship between the coping strategies and the quality of life of spouses of patients with chronic renal failure undergoing hemodialysis?

Theoretical Framework of the Study

This study aimed to explore coping strategies and quality of life as well as trace the relationship between coping strategies and quality of life of hemodialysis patients and their spouses. Previous studies have found that coping strategies are significantly correlated with quality of life in chronically ill patients, such as breast cancer patients and diabetic patients (Meifen, 1997; Coelho, et al., 2003).

To explore coping in this study, Lazarus and Folkman's (1984) theory of stress, appraisal, and coping was used as a framework. Lazarus and Folkman (1984) defined coping as the constantly changing cognitive and behavioral efforts used to manage specific external and/or internal demands that are appraised as taxing and that exceed the resources of the person. The coping process may include a two-staged cognitive process of primary and secondary appraisals (Lazarus & Folkman, 1984). In the primary appraisal, the individual determines whether the conditions or stimuli are a threat, and the secondary appraisal includes a review of choices of action if a threat is perceived. Lazarus and Folkman (1984) also divided coping strategies into problem focus coping and emotion focus coping. Problem focus coping strategies are directed to manage or alter a problem, whereas emotion focus coping strategies are directed to reduce or regulate emotional distress. Although Lazarus and Folkman (1984) did not specifically mention "quality of life", they used the term "morale" to describe how people feel about themselves and their condition of life, relating to happiness, satisfaction, and subjective well-being. In the concept, appraisal and coping processes affect positive and negative emotions, or subjective well-being and there are relationships between well-being in short-run encounters and morale (life satisfaction) over the long run.

The World Health Organization Quality of Life (WHOQoL) concept was used as a framework to explore levels of quality of life in this study. According to the WHOQoL Group (1994), quality of life is an individual's perception of his/her position in life in the context of the culture and value system in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. The definition, based on the constitution of the WHO, defines health as "a state of complete physical, mental and social well being and not merely the absence of disease or infirmity" (WHO, 1994). It follows that the measurement of health and the effects of health care must include not only an indication of change in the frequency and severity of diseases, but also an estimation of well-being. In addition, the meaning of quality of life arises from the transaction between the person and the environment, which is influenced by personal background, health, social situation, culture, and age (Zhan, 1992). A broad definition seems preferable since quality of life can mean different things to people of different cultural backgrounds.

Drawing on this work, four domains of quality of life comprising a total of 24 facets were identified as a behavior, a state of being, a potential capacity, and subjective perception or experience (WHOQoL Group, 1994). Those four domains of QOL are physical health, psychosocial health, social relationships, and environment. Physical health is the domain of closely approximating the outcome measures traditionally used, including pain and discomfort, dependence on medical treatment, energy and fatigue, mobility, sleep and rest, activities of daily living, and work capacity. Psychological health refers to positive effects, spirituality, thinking, learning, memory and concentration, body image and appearance, self-esteem, and negative effects. Social relationship comprises personal relationships, sexual activity,

and social support, and environment consists of physical safety and security, physical environment, financial resources, opportunities for acquiring new information and skills, participation in and opportunities for recreation/leisure activities, home environment, accessibility of quality of health and social care, and transportation (WHOQoL Group, 1994).

In this framework, chronic renal failure and hemodialysis treatment is perceived by patients and their spouses as stressors that affect the level of their quality of life. In the primary appraisal, the patient or spouse's cognition and perceptions is used to appraise the stressors as either threatening or nonthreatening. If the patient or spouse identifies the stressors as threatening, her or his response is manifested as a coping strategy (secondary appraisal). The responses are reflected into either a problem solving coping strategy or an affective coping strategy. The coping results may influence the patients' and/or spouses' perception of their quality of life. The association of coping and quality of life can be conceptualized as in the following figure:

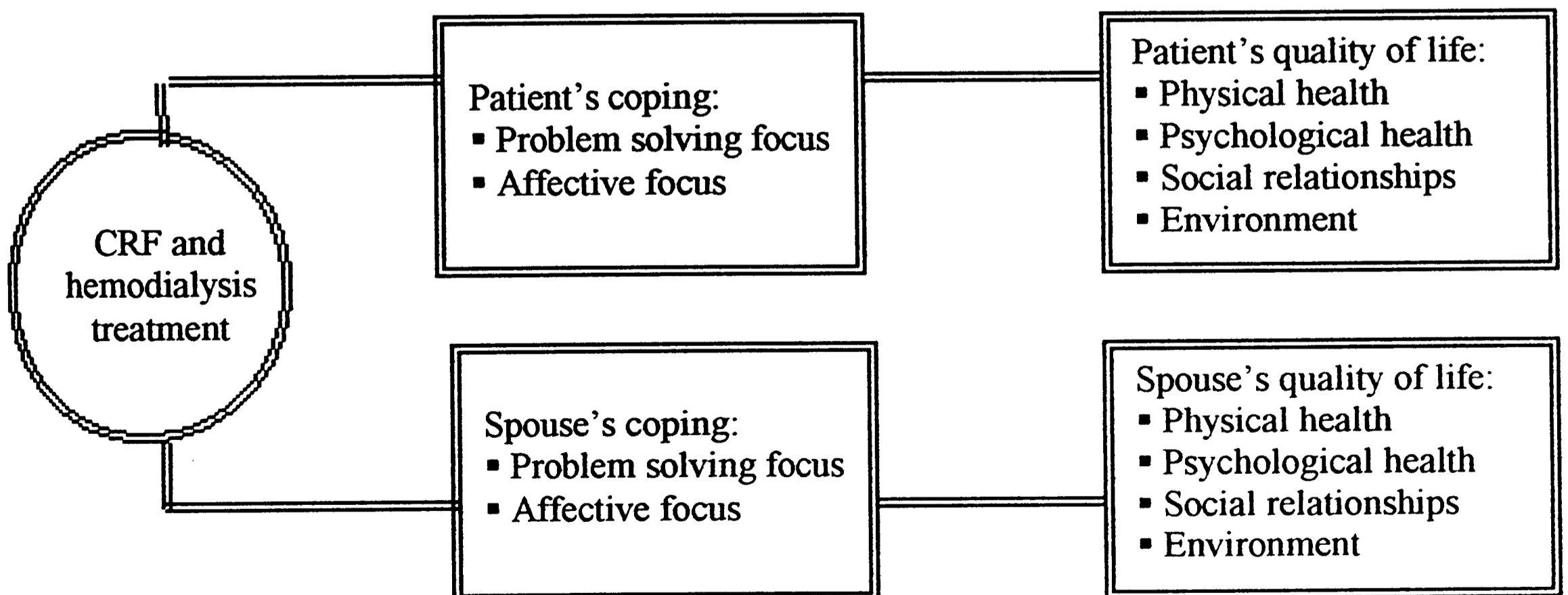


Figure 1 The framework to study the relationship between coping strategies and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses

Hypothesis

The hypotheses of the study included:

- (1) There is a relationship between affective focus coping and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses.
- (2) There is a relationship between problem focus coping and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses.
- (3) There is a relationship between total coping score and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses.

Definition of Terms

In this study, **coping** is defined as a method that the hemodialysis patients and their spouses use when they encounter with a stressful situation regarding chronic renal failure and hemodialysis treatments. Coping of patients with hemodialysis and their spouses is measured by using the Jalowiec Coping Scale (JCS) (Jalowiec, 1987).

Quality of life is a perception of hemodialysis patients and their spouses to the degree of satisfaction with their current level of functioning compared to what they perceive to be possible or ideal. This is reflected in each dimension of the quality of life assessment including physical health, psychological health, social relationships, and environment. The quality of life of hemodialysis patients and their spouses is measured by using the WHO Quality of Life BREF (WHOQoL-BREF, 1994).

Patient with chronic renal failure undergoing hemodialysis is defined as a patient who was diagnosed with CRF and had been receiving hemodialysis treatment at least one month before data collection began. **Spouse** is defined as one who is legally recognized as either wife or husband of the patient.

Benefits of the Study

The findings of this study can provide contributions to nursing practice, nursing education and development of further research as follows:

- (1) For nursing practice, the research findings provide useful information which can enable nurses to better understand coping strategies and quality of life of patients with chronic renal failure undergoing hemodialysis and their spouses, thus helping them to develop appropriate nursing interventions.
- (2) For nursing education, the knowledge gained from the study is beneficial for developing knowledge, especially coping methods that are frequently used by hemodialysis patients and their spouses and their relationship with quality of life, as a teaching material for nursing students.
- (3) For nursing research, the research findings can be used as baseline data for further research related to hemodialysis patients and their spouses regarding coping strategies and quality of life.

Scope of the Study

This study took place in three inner city hemodialysis units in Bandung Indonesia, and involved 91 couples of hemodialysis patients and their spouses. The patients involved in this study were limited to only those who still lived with their spouse.