

CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL/THEORETICAL FRAMEWORK

Literature review

In this section, the review of literature includes the following categories:

1. Chronic renal failure with hemodialysis
2. Quality of life
3. Family support
4. The relationship between family support and quality of life among hemodialysis patients.

Chronic renal failure with hemodialysis

Chronic renal failure (CRF) is a functional diagnosis characterised by a progressive and generally irreversible decline in glomerular filtration rate (GFR). It is caused by a large number of diseases. Diabetes and hypertension are now recognized as the leading causes of CRF in the United States (Bennett & Plum, 1996). Renal disorder such as glomerulonephritis, chronic pyelonephritis, urinary tract obstruction, and kidney tumours and stones may result in chronic renal failure (Scherer &

Timby, 1995).

Chronic renal failure results in many multisystem manifestations including neurological, cardiovascular, respiratory, hemotologic, gastrointestinal, integum and musculoskeletal manifestations. The symptoms found include apathy, lethargy, headache, insomnia, hypertension, anemia, anorexia, nausea, vomiting, pruritus, bone pain, and so on (LeMone & Burke, 1996).

Chronic renal failure usually begins slowly. At first, symptoms may be vague and nonspecific and include lethargy, headache, anorexia, and dry mouth. As the disease progresses, symptoms include pruritus, dry skin, metallic taste, uremic odor to the breath, diarrhoea or constipation, edema, anemia, tendency to bleeding muscle cramps, and mental changes. Oliguria or anuria may be present; however, the volume of urinary output may be near normal even in late stage of the disease. There are many complications in CRF patients, such as fluid and electrolyte imbalances, hemorrhage, cardiac and respiratory failure, infection, and severe hypertension (Scherer & Timby, 1995).

The clinical signs and symptoms of end-stage renal failure are known as the "uremic syndrome". Unfortunately, patients often seek medical attention only when their

disease has progressed to the uremic stage. Normally, the adult patient is unaware of advancing renal failure until the GFR has decreased to less than 15 ml per minute. The uremic syndrome results from functional derangements of many organs, and the prominence of specific symptoms may vary from patient to patient. Uremia refers to the final stages of progressive renal insufficiency when the multiorgan system derangements become clinically manifest. Uremia generally results from the accumulation of such metabolites and from the progressive failure of renal catabolic and endocrinologic processes.

The management of patients with CRF can be divided conveniently into three separate categories: treatment of aggravating factors, treatment of specific complications of uremia, and consideration of optimal diet and general principles in the long-term care of patients with CRF. Aggravating factors include volume depletion, drugs, obstruction, infection, toxins, hypertensive crisis and metabolic factors. Patients with CRF are highly susceptible to these factors and they may cause a deterioration of renal function. These must be treated immediately so that the underlying renal failure will not be worsened permanently. An appropriate diet can be crucial in managing patients in CRF. Using an appropriate diet, uremic symptoms

and the consequences of renal insufficiency can be controlled for most patients (Bennett & Plum, 1996).

Treatment of irreversible renal failure includes dialysis and renal transplantation. The development of dialysis as a therapeutic modality during the late 1960s and early 1970s owes much of its widespread dissemination to the development of an effective dialysis membrane (Henrich, 1994). Dialysis involves the movement of fluid and particles across a semipermeable membrane. It is a treatment that can help restore fluid and electrolyte balance, control acid-base balance, and remove waste and toxic materials from the body. This treatment can sustain life successfully in both acute and chronic renal failure. There are two basic types of dialytic therapy: hemodialysis and peritoneal dialysis. Hemodialysis involves shunting the patient's blood from the body through a dialyzer in which diffusion and ultrafiltration occur and back into the patient's circulation (Phipps, Cassmeyer, Sands, & Lehman, 1995).

Although hemodialysis can solve some problems caused by CRF, the rest of problems continue to affect their lives and need other therapeutic modalities, such as anemia, tendency to bleeding peripheral neuropathy, osteoporosis etc. From undergoing hemodialysis, the

patients will face many problems such as losing their freedom concerning diet and fluid intake (Stone & Rabin, 1983); developing some systemic complications during or after the hemodialysis procedure including hypotension, bleeding, infection, dialysis dementia (LeMone & Burke, 1996). Some patients have to face much stress including muscle cramps, fatigue, and itching which were the top three causes of stress (Eichel, 1986). Other causes of stress included boredom, frequent hospitalization, and uncertainty about the future (Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988). Limitation of activity and decrease in social life were also the highly ranked causes of stress as identified by Lok (1996). Threatened loss of body functions, threat of death, inability to plan a future, a decrease in available energy for coping and dependency were very stressful to the patients (Schlebusch & Levin, 1982; cited in Hoothay, Leary, DeStefano, & Foley-Hartel, 1990). All of these could eventually affect physical, psychological, and social aspects of these patients.

In summary: chronic renal failure is a slow, progressive decrease in kidney function with irreversible damage to the kidney nephrons. It is caused by a large number of diseases. The symptoms of the disease are

extremely unpleasant. The patients have physical, psychological and social responses and face much stress. Treatment such as hemodialysis can diminish some physical problems but also contributes to some alterations in physical and psychosocial aspects that negatively influence hemodialysis patients' quality of life. The literature about quality of life of hemodialysis patients will be presented as follows.

Quality of life

Concept of Quality of Life

The concept of quality of life can be traced back to the ancient western philosopher Aristotle. He described "happiness" as a certain kind of virtuous activity of soul (Mckeon 1947, cited in Zhan, 1992). The phrase "quality of life" has meant different things at different periods during this century. It entered the vocabulary of the United States towards the end of the Second World War and implied the "good life", or material affluence evidenced by possession of cars, houses and other consumer goods such as household appliances. Spare time and spare money for leisure activities and holidays also became part of the equation (Fallowfield, 1990).

Quality of life is a multi-disciplinary term in

current use. Today the term quality of life is not only used in everyday speech, but also in the context of research where it is linked to various specialized areas such as sociology, medicine, nursing, psychology and so on (Farquhar, 1995). An assessment of quality of life came into the research field in the early 1960s, and the health-related quality of life assessment became popular a decade later (Flanagan, 1982).

In Farquhar's (1995) view there are three major types of definitions of quality of life: the first is global definitions, the second is component definitions, and the third is focused definitions. The global characterization usually includes physical function; symptoms from disease and/or treatment; occupational and social interactions; and psychological parameters, including mood and some overall assessment of well-being, such as happiness or satisfaction (Smart & Yates, 1987). An example of a component definition is George and Bearon's definition (1980, cited in Farquhar, 1995). They defined quality of life in terms of four underlying dimensions, two of which are objective and two of which are reflected in the personal judgement of the individual. The objective dimensions are general health and functional status, and socio-economic status. The dimensions reflecting the

personal judgement of the individual, or subjective evaluations, are life satisfaction and related measures, and self-esteem and related measures. Focused definitions are those definitions which refer to only one or a small number of the components of quality of life. The most common form of this definition refers only to the components of health/functional ability (Farquhar, 1995). Thus quality of life is a multi-faceted phenomenon and any measures taken during treatment purporting to improve the quality of life must address the impact that disease and its treatment has on a variety of dimensions, not simply physical functioning (Fallowfield, 1990).

Quality of life is conceptualized as a multidimensional term with three main dimensions: physical well-being, emotional well-being, and social well-being. Physical well-being includes perceptions of self as healthy or ill, self-ratings of difficulty with daily activities, health satisfaction, and number of nights hospitalized. Emotional well-being includes self-esteem, happiness, and life satisfaction. Social well-being includes vocational rehabilitation, sexual adjustment, and marital and family adjustment (Simmons & Abress, 1990).

Zhan (1992) defined quality of life as the degree to which a person's life experiences are satisfying. This

includes four aspects: life satisfaction; self-concept; health and functioning; and socio-economic factors. Life satisfaction refers to life as a whole rather than to specific domains of life experience. Because of its global nature, domain-specific measures of satisfaction are an alternative approach to the use of global measures. Self-concept is defined as the composite of beliefs and feelings that one holds about oneself at a given time. It focuses on the individual's assessment and evaluation of himself or herself as an object in the life experience. Concept of health and functioning has been operationalized in terms of activity in daily life, mobility or absence of disease. Socio-economic factors have been assessed subjectively in terms of perceived adequacy of income and satisfaction with financial resources.

In summary, quality of life is a multidimensional construct which has been commonly defined as happiness or satisfaction. Quality of life is defined differently in different studies. In this study, quality of life was based on Zhan's concept which will cover all dimensions of individual life experience including physical, psychological, and social aspects of the quality of life of Chinese hemodialysis patients. Quality of life will be assessed as self evaluation of the individual's

satisfaction with their life in four aspects including life satisfaction, self-concept, health and functioning and social-economic factors.

Quality of Life of Hemodialysis Patients

A review of the literature indicated that there were a few studies on quality of life of hemodialysis patients. Ferrans and Powers (1993) studied quality of life of hemodialysis patients by using the Ferrans and Powers's Quality of Life Index. Quality of life was found to be relatively high, with family domain having the highest score and health and functioning having the lowest score. Patients had to restrict their participation in many activities or give them up entirely because of poor health and medical regimen.

Most studies have been concerned with comparison of quality of life between hemodialysis patients and patients treated with other treatment modalities. Bihl, Ferrans and Powers (1988) compared quality of life of hemodialysis patients and continuous ambulatory peritoneal dialysis patients by using the Quality of Life Index (QLI) which was developed by Ferrans and Powers. They measured overall quality of life and four aspects of quality of life including satisfaction with health and functioning, socioeconomic aspects of life, psychological/ spiritual

and family. The results showed that the overall scores of the two groups were not significantly different. Hemodialysis patients were more satisfied with family aspects of life than with health and functioning, socioeconomic aspects, and psychological/-spiritual aspects.

Lok (1996) studied quality of life among dialysis patients by using the Quality of Life Index developed by Padilla et al. (1983) which measured quality of life in three subscales including physical activity, social activities and satisfaction with life. Findings showed that quality of life was perceived as below average in both hemodialysis and continuous ambulatory peritoneal dialysis (CAPD) patients. However, CAPD patients were experiencing a higher quality of life than hemodialysis patients. They reported that they could do normal tasks and they felt that their life was satisfyingly higher than the hemodialysis patients. In the hemodialysis group, sixty four percent of the patients were experiencing pain and 57 percent were experiencing nausea. Only 21 percent reported that they were able to do normal tasks and 28.6 percent and 28.5 percent reported that they could sleep well, and were satisfied with their life respectively.

In summary, hemodialysis patients have to face many

problems from renal dysfunction and from undergoing hemodialysis which could affect their quality of life. Family support might contribute to enhance patients' motivation to perform their health promoting behaviors.

Family support

Concept of Family Support

An interest in the concept of social support began in the 1970s with the theory that the environment had an influence on physical and psychological health. Social support is considered as information leading the subject to believe that he is cared for and loved, esteemed, and a member of a network of mutual obligations. As life progresses, support is derived increasingly from other members of the family, then from peers at work and in the community. As life's end approaches, social support is again derived mostly from members of the family. He defined family support as information leading the family member to believe that he/she is cared for, loved, and valued (Cobb 1976). House (1981) defined social support as four subconcepts : emotional support (esteem, affect, trust, concern, listening), appraisal support (affirmation, feedback, social comparison), informational support (advice, suggestion, directions, information), and

instrumental support. Perceiving support may increase a person's feeling of control and self-esteem. Such feelings may influence health through enhanced motivation to perform health behaviors or through suppression of neuroendocrine responses and enhance immune function (Cohen, 1988).

While research on social support has expanded rapidly, the social support construct has been plagued by conceptual vagueness. Therefore, clarifying the distinctions between social network characteristics and perceived social support is one way of refining the social support construct. Social networks refer to "the social connections provided by the environment and can be assessed in terms of structural and functional dimensions" (Marsella & Snyder, 1981; cited in Procidano & Heller, 1983, p.2). Structural network characteristics include size, density, multiplexity, etc. while network functions include the provision of information, comfort, emotional support, material aid, etc. "Perceived social support refers to the impact networks have on the individual. If networks provide support, information and feedback, then perceived social support can be defined as the extent to which an individual believes that his/her need for support, information, and feedback are fulfilled" (Procidano & Heller, 1983, p.2). In order to adequately deal with

threats, information or help that one perceives to be available within one's support network is needed (Procidano, & Heller, 1983).

The support system represented an enduring pattern of continuous or intermittent ties that played a significant role in maintaining psychological and physical integrity of the individual over time. Five types of social support systems relevant to health have been identified and described including natural support system, peer support systems, religious organizations, organized support systems of care-giving or helping professionals, and organized support groups not directed by health professionals (Pender, 1987).

Pender (1987) described family as a natural support system which constitutes the primary support group. Family relationships were frequent sources of support, enabling the young adults to manage different aspects of the family as it increased. The greatest support came from the family, especially from the mother (Enskar, Carlsson, Golsater & Hamrin, 1997). Families, in order to provide appropriate support, must be sensitive to the needs of family members. Families must establish effective communication, respect the unique needs of members, and establish expectations of mutual help and assistance

(Pender, 1987). Clerk (1983, cited in Pender, 1987) hypothesized that family involvement may buffer stress, provide a distancing mechanism through which stress is put in perspective, or provide security that increases ability to cope. Therefore, the quality and availability of family support may be an important role in the recovery process following major illness.

The concept of family includes interactions, relationships, and functional and organizational patterns that strive to effectively meet the needs of family members and the expectations of society. Family functions include economic cooperation, procreation, child rearing (including socialization and enculturation), and the growth and development of family members (Pasquali, Arnold, Debasio & Alesi, 1985). The primary function of family is to maximize coping and motivation (Meister, 1984). Family is the most important unit for the individual and for society. For an individual, family provides the critical unit for development and interactions. In society, family provides new members and socialization of members (Johnson, 1986).

Meister (1984) stated that much of what the family contributes to members can also be called social support. Each of these forms of support describes what the family, or some of its members, might contribute to another member

in need. This statement is based on two assumptions: one is that the family is not wholly divorced from the egocentric social network. Another is that holding a familial form of membership in the social network does not necessarily preclude the ability to offer social support (Meister, 1984).

Brillhart's (1988) definition of family support included four aspects: physical care, economic support, emotional support, and social support. Social support was defined as the communication, response, and sense of belonging. In this study, family support is defined as perceived needs for support, information, and feedback fulfilled by family members.

Family Support in Hemodialysis Patients

A review of the literature indicated that there have been no studies on family support in hemodialysis patients, but there were some studies on social support in hemodialysis patients and social support or family support in some chronic patients.

Gurklis and Menke (1995) conducted a study to describe perceived social support of chronic hemodialysis patients. The convenience sample consisted of 129 hemodialysis patients aged 20 to 87 years at two hospital-based and two outpatient hemodialysis centers. The result

showed that over 90 percent of the subjects perceived one or more of the immediate family members as providing social support. Spouses or significant others, adult children, siblings, parents, friends, dialysis nurses and technicians were main sources of support. Positive feelings about support provided by relatives and friends were expressed by 115 (89%) subjects. They were thankful and happy for their assistance in times of need. This support enabled subjects to make it through times of serious illness.

Some studies have been done to show the significance of family support. Family support appears to protect people in crisis from a wide range of health problems including arthritis, tuberculosis, cancer, depression and so on. Loss of supportive family relationships could increase the risk of mortality and morbidity (Berkman, 1969; Koski, Ahas, & Kumento, 1976; cited in Caldwell, 1988). The giving and acceptance of support in the family network is a central factor in individual and family health (Caldwell, 1988).

Some studies indicated that social support, particularly support from family members could be of crucial importance for well-being, adjustment, and perhaps survival of cancer patients. In this context, spouses played a special role because they are the closest kin in responding to the patients' social and emotional needs (Chaitchik, Kreitler,

Rapoport & Algor, 1992). Cancer patients who received minimal family support clearly experienced more difficulty in adjustment (Jassak, 1992).

Palsson and Norberg (1995) studied the emotional support from the family of breast cancer patients. The findings showed that emotional support led to feelings of safety and security. The study also indicated that adequate information, confirming relationships and emotional contact are important factors for the sense of control in women with breast cancer. The presence of a supportive husband, sister, child, friend, or colleague was said to be an important factor for most of the women, and was said to help them in coping with the illness. They talked about the need for open communication and for others to give them hope and help with practical things in everyday life (Palsson & Norberg, 1995). Emotional support was the factor most frequently identified by husbands as helping them to cope with their wives' illness (Northouse, 1989).

In the study of Brillhart (1988) on family support of 143 disabled adults, parents, especially mothers were very supportive to disabled adult family members. Most support offered was focused on meeting economic, emotional, social, and physical care needs. Parents of patients was identified as key persons for patient-family educational

sessions, support or discussion groups, and family counseling. Positive family support for the disabled were re-established roles, empathy, and support for identified needs. The disabled person often relied on family members for physical care, social contacts, emotional support, and financial aid (Brillhart, 1988).

In China, Zhang (1997) studied family support in Chinese breast cancer patients by using Modified Perceived Social Support from Family Scale modified from the PSS-Fa Scale developed by Procidano and Heller (1983). The results showed that husbands and close family members were primary sources for support of breast cancer patients. Assistance in daily life activities, love, understanding, and concern from husbands and children may contribute to the patient's perception of being supported.

In summary, family support is considered as the primary social support group which plays an important role in hemodialysis patients. In China, family members are tied by blood relationships and the relationship between each member is very tight. Most Chinese consider family as their most important source of support, especially when they are ill. Due to the change of family structure by the developing process of industrialization, economic growth, and family planning policy, family networks which used to

be strong might have been affected. In this study, family support was described as perceived needs for support, information, and feedback which are fulfilled by family members.

The relationship between family support and quality of life among hemodialysis patients

A review of the literature indicated that there have been no studies on the relationship between family support and quality of life of hemodialysis patients, but there are few studies on social support and quality of life of dialysis patients and cancer patients.

Tell, et al. (1995) studied the social support and health-related quality of life in 256 black and white dialysis patients. They used a 6-item version of the Interpersonal Support Evaluation List which developed by Cohen, Mermelstein, Kamarck, and Hoberman (1985) to measure social support and used the five measures to assess health-related quality of life and measure global quality of life. The five measures included patients' feelings about life as a whole (one 6-point item), patients' life satisfaction (one 10-point item), Karnofsky's Scale on Physical Functioning rated by the patients, Karnofsky's scale rated by a nurse familiar with the patient and patients' reports

of any limitations in leisure time activities that they attributed to renal disease (one item). Among the participant group, 186 patients (73%) received incenter hemodialysis, 12 (5%) home hemodialysis, 58 (22%) peritoneal dialysis. The results showed that social support was positively correlated with the Karnofsky scale rated by a nurse ($r=0.16$, $p<0.012$) and by patients ($r=0.19$, $p<0.037$). The higher the perceived social support, the better the reported and observed functional level. Good social support was associated with less limitations in leisure time activities, with better life satisfaction. A larger social network was related to better feelings about life and to better life satisfaction.

In general, positive effects of social support were expected on the indicators of quality of life. Although no definite statement can be made about causality, the results from some studies of social support in cancer patients indicated, as Ros(1990, cited in Courtens, et al., 1996) expected, a positive relationship between perceived emotional support and illness indicators of quality of life. Patients with fewer symptoms and better global evaluation of life perceived more emotional support. It may be that emotional support enhances a better quality of life. The perceived emotional support of significant

others, the perception of being cared for or loved and appreciated, can contribute to a positive feeling of health. On the other hand, it is possible that a better quality of life leads to more emotional support. Another study by Courtens, et al. (1996) also support the face that cancer patients who perceived a decrease in emotional support reported an increase of physical symptoms and a decrease of global well-being; patients who perceived a decrease of practical support reported a decrease of psychological symptoms and an improvement of global well-being.

Summary

Hemodialysis is one of the revival therapies for CRF patients. It can solve some problems caused by CRF. But hemodialysis patients have to face much threat-associated stress which could affect their quality of life. Family support is helpful enhancing patients' motivation to perform their health behaviors which could eventually influence the patients' quality of life. In China, there have been few studies on family support in breast cancer patients. Base on a review of the literature, there have been no studies of family support and quality of life of hemodialysis patients in China. Results from western studies may not be generalized to Chinese hemodialysis

patients because different countries have different cultural backgrounds and family networks. Therefore, this research will ascertain the relationship between family support and quality of life of hemodialysis patients.

Conceptual framework

Hemodialysis patients have to face many problems from undergoing hemodialysis and from the disease itself. Impact from the disease and hemodialysis treatment could impair patients' physical, psychological, and social function, and could further reduce their quality of life. According to Zhan (1992), quality of life was defined as the degree to which a person's life experiences are satisfying. It is influenced by personal background factors, health-related factors, and social, cultural, and environmental factors. There are four essential aspects for assessing quality of life: life, life satisfaction, self-concept, health and functioning, and socio-economic factors.

Social support was identified as the main factor that has both stress buffering and direct effect on a wide variety of outcomes including physical health, mental well-being and social functioning (Courtens, Stevens, Crebolder, & Philipsen, 1996). Family is considered as a natural support system which could be considered as a major

environmental factor that supports family members in order to deal with threats (Procidano & Heller, 1983). It can be considered as the primary social network in the environment that could help hemodialysis patients by providing support, information and feedback. Therefore, family support could be considered as one aspect of the social environment which could improve patients' quality of life. So, this study is designed to describe family support and quality of life and ascertain the relationship between family support and quality of life of Chinese hemodialysis patients.