

Medical Dissertation

No

EVERYDAY LIFE AMONG NEXT OF KIN OF
HAEMODIALYSIS PATIENTS

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ABSTRACT

Everyday life can be complex when next of kin of haemodialysis patients are preoccupied with taking care of the patient and his/her health, which implies the difficulties and requirements needed. The general aim of this thesis was to explore and describe everyday life among next of kin of haemodialysis patients with focus on the life situation, health, time and professional support. Two perspectives of the thesis was applied: a holistic perspective on the everyday life of next of haemodialysis patient and a social perspective with focus on human communication and understanding of next of kin's experience of everyday life. A qualitative descriptive and explorative design, comprising a phenomenographic and content analysis was used in Studies I-IV. The data collected in the studies consisted of interviews with next of kin to haemodialysis patient and analysis of professional support for next of kin to chronic haemodialysis patients in nursing documentation from two hospitals in Sweden.

The experience of time in everyday life among next of kin of haemodialysis patients demonstrated that time for them is minimised and life space contracted. Next of kin experienced ambivalence towards their own health, especially in cases of patients' spouses. When next of kin of haemodialysis patient's became involved in the patients' care, they experienced arduousness in relation to their own health as well as less uninterrupted time for themselves in everyday life, and their life situation was characterised by confinement and social isolation. They were aware of the prognosis of renal disease and the fact that haemodialysis is a life-sustaining treatment, which forced them to live for the moment. The everyday life among the next of kin changed when the family became involved in the care, which in turn lead to a changed life situation and restrictions in everyday life. Lack of knowledge in nursing documentation of professional support revealed necessity of the readiness of next of kin. It is therefore important to be familiar with this in the nursing process, especially when the patient and their next of kin need support and attention in everyday life.

Keywords: Next of kin, haemodialysis, everyday life, health, time, life situation, professional support, nursing process, qualitativ analysis

Original Papers

This thesis is based on the following papers, which are referred to in the text by their Roman numerals:

- I. Ziegert K. & Fridlund B. Conceptions of life situation among next of kin of haemodialysis patients. *Journal of Nursing Management* 2001; (9) 231-239.
- II. Ziegert K., Fridlund B. & Lidell E. Health in everyday life among spouses of patients on haemodialysis; a content analysis. *Scandinavian Journal of Caring Sciences* (Accepted for publication).
- III. Ziegert K., Fridlund B. & Lidell E. Time in everyday life as experienced by next of kin of haemodialysis patients (Submitted for publication).
- IV. Ziegert K., Fridlund B. & Lidell E. Professional support for next of kin of patients receiving chronic haemodialysis treatment. A content analysis study of nursing documentation. *Journal of Clinical Nursing* (Accepted for publication).

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INTRODUCTION

Next of kin have assumed increasing responsibility for their chronically ill family members, which is particularly true of the next of kin of patients who require haemodialysis as a result of renal disease (National Board of Health and Welfare, 2005). Time in everyday life and the life situation and health of next of kin have received little national or international attention. At the same time, nursing staff often regard next of kin as a resource when dealing with the demands and strains that arise in connection with a serious disease (Aneshensel et al., 1995). In Sweden, recent cutbacks within the public sector have led to a situation where next of kin have to shoulder increasing responsibility for patient care. The National Swedish Board of Health and Welfare (2004) reports that, while next of kin accept the situation, they are tired and in some cases exhausted as a result of demands and expectations in connection with patient care placed on them by healthcare professionals. The exhaustion is mental rather than physical in character. Although next of kin have assumed more and more caring duties, they have received little financial assistance or confirmation from the social welfare system. The people around them may not realise the true extent of their caring, as renal disease is not associated with any functional impairment. The Swedish welfare system has for many years provided necessary support for families afflicted by ill health. However, the level of support has decreased in recent years in line with reduced socio-economic resources, leading to a greater focus on the caring resources of next of kin (Fritzell & Lundberg, 1994; Nordenmark, 2004).

A belief still exists in Sweden that next of kin who need help in everyday life to care for severely ill family members will receive the assistance necessary to do so from the welfare system. Moreover, many next of kin voluntarily assume responsibility for the care of a sick family member, a role that is welcomed but not supported by society. In many cases this leads to strain in a person's life, due to the need to combine the role of employee with the responsibility for running the household and caring for a sick family member (Nordenmark, 2004). In contrast to the welfare systems in the UK and USA where next of kin are responsible for care in the home, the contribution of next of kin in Sweden is not officially acknowledged. One of the cornerstones of post-war Swedish policy has been the belief that responsibility for the care of sick, elderly, and disabled members of society should be assumed by the state (Johansson, 2001).

Chronic renal disease implies a life-long process of change for the patient and his/her next of kin (George & Neilson, 2000). Patients on haemodialysis spend most of their time at home,

which means that their next of kin must be available on a 24-hour basis (Hagren, 2001). Healthcare professionals require extensive knowledge and understanding of aspects that affect next of kin's health and life in order to help them gain the necessary strength to support and assist the patient. By listening to next of kin's experiences of caring for the patient in the home, nursing staff can acquire knowledge about their everyday life situation, thereby making it possible to improve co-ordinated care planning. Next of kin believe it is important to care for and support the patient. Haemodialysis is a highly technological and expensive form of treatment that places great demands on next of kin, as it is essential for them to understand the complexity of the patient's everyday life and how it is affected by the treatment (McGee & Bradley, 1994). When patients are afflicted by end stage renal disease and require haemodialysis treatment, next of kin need professional support at the right time and at an appropriate level. Such support will change over time due to the progression of the disease as well as the individual's need for different types and levels of support (Steward, 1990; Schulz, 2001).

Studies have shown that haemodialysis patients and their next of kin accept the changes in their everyday life, due the fact that the treatment makes it possible for the patient to survive, but that they need a high level of professional support (Baldree, 1982; Calvin, 2004). There are few studies that have investigated next of kin's self-perceived everyday health and life, and those available have concentrated on groups of next of kin other than those of haemodialysis patients (Bergs, 2002; Mant, 2000). Studies focusing on next of kin may provide important knowledge that can improve the planning of treatment and support interventions aimed at reducing the strain in the everyday life of next of kin, thus arresting the development of stress related conditions and protecting their own health.

THEORETICAL FOUNDATIONS

Patients on haemodialysis treatment

End-stage renal disease is a major health problem. Its incidence is increasing in line with the aging population, and it is therefore crucial for health care systems to offer access to renal replacement therapy. However, this represents a significant financial burden for those health care systems that offer renal replacement therapy free of charge, as it accounts for 1-3% of total health care expenditure (Piccoli et al., 2005). Due to the heterogeneous etiology of various kidney diseases, interaction between multiple genetic and environmental factors is

believed to be involved in the progression to end-stage renal disease (Gumprecht, 2003). Diabetic nephropathy, hypertensive nephrosclerosis, chronic glomerulonephritis, hereditary cystic kidney disease, chronic interstitial nephritis and various diseases of the organ systems, such as systemic lupus erythematosus, Wegener's granulomatosis, amyloidosis and myeloma, are the most common renal diseases leading to end-stage renal disease and the need for regular dialysis. Unless treated with active uraemia care such as dialysis or kidney transplant, end-stage renal disease results in death from uraemia (Attman & Alverstrand, 2004). Hospitalisation is deemed necessary when the renal glomerular filtration rate is $<5\text{ml/min}$ (Tomson, 2000). The purpose of haemodialysis is to eliminate toxic metabolites and acids as well as surplus water and electrolytes, mainly potassium and sodium, from the blood.

Semi permeable membranes with a contra flow of fluid are used for dialysis. Diffusion and ultra filtration are the physical transport mechanisms that act on the dialysis membranes. Clinical use of haemodialysis for the treatment of uraemia was common practice in the USA and Europe by the mid 1960s. Today, active uraemia treatment is available in all developed countries, making it possible to treat the majority of end-stage renal disease patients, which means that an increasing number of patients undergo treatment and survive as a result (SRAU, 2004). There are approximately 246,000 haemodialysis patients in the USA, with a population of 297 million (USRDS, 2002). In all countries, the number of men receiving renal replacement therapy exceeds that of women (Abbott et al., 2000). In Europe, with a population of 376 million, the incidence of new end-stage therapy patients was 120 per million with a clear north to south/west divide (69 in Ireland, 131 in Italy and 163 in Germany). The main forms of treatment for new patients with end-stage renal disease are haemodialysis (HD; 81%), peritoneal dialysis (PD; 18%) and renal transplantation (Tx; 1%). However, despite the excellent dialysis technique, the expected survival rate in renal replacement therapy patients is considerably less than that of an individual with healthy kidneys (Berthoux et al., 1999). A demographic study of European countries shows a mean age ranging from 58 years in the UK to 62 years in Italy. On average, there were 10% more male than female patients, while the proportion of black, Asian and Indian people was higher in the UK than in the other European countries (Rayner et al., 2004). In a European comparison, Swedish dialysis patients were the oldest (Bakoush et al., 2001). The incidence of renal replacement therapy in Sweden is approximately 125 patients/million inhabitants. In 1999, 2,300 patients received haemodialysis treatment in Sweden, 38 of whom were resident in the County of Halland. The annual mortality among Swedish patients on haemodialysis

represents approximately 30% of the whole uraemia group. The main cause of death among renal replacement therapy patients is cardiovascular diseases, which account for 14% of deaths (SRAU, 2004). Findings from the US (Owen, 2003) indicate low survival rates in patients in the 70-74 year age group, with only 50% surviving for two years and slightly less than 20% surviving after five years. For middle-aged people (40-45), the survival rate is a great deal higher than for elderly patients. However, when compared to middle-aged people with well-functioning own kidneys, mortality is still high. The overall high mortality rate for patients receiving renal replacement therapy, especially those on haemodialysis, is mainly explained by a simultaneous high prevalence of other chronic diseases such as diabetes and/or cardiovascular disease. Without dialysis treatment, these patients would die due to uraemia within a 60-day period (Bell et al., 2005).

Nutritional markers and cardiovascular disease are important predictors of morbidity and mortality in dialysis patients, and trial filtration in chronic haemodialysis is a major risk factor for hospitalization and mortality (Abbott et al., 2003, Combe et al., 2004; Ifudu, 1998).

Renal care is extensive and comprises out-patient haemodialysis treatment, in-patient care if necessary, and care in the home. This means that the need for care continues after the haemodialysis treatment in the form of treatment restrictions affecting the everyday life of both the patient and his/her family. Further, haemodialysis includes 12 or more hours of out-patient treatment per week, intake of supplementary medication, adherence to a prescribed nutritional and fluid balance and a significantly limited fluid intake. It has been shown that 28-78% of haemodialysis patients failed to adhere to certain parts of the treatment regimen (Vlaminck et al., 2001). The dialysis dosage, duration and frequency, type of dialyzer membrane and solute clearance were found to be important for the patient's health during haemodialysis as well as for his/her survival. A properly functioning, surgically created vascular access site is necessary for adequate dialysis. Thrombosis and infection of the vascular access site account for 20 - 40% of all hospitalisations of haemodialysis patients (Ifudu, 1998). Patients with inadequate haemodialysis were afflicted by a range of health and nursing problems, such as nutritional difficulties associated with nausea, vomiting, weight loss, fluid retention in addition to weakness or functional status problems related to peripheral neuropathy, impaired alertness, pericarditis, ascites, hypertension and diarrhoea (Owen, 2003). Haematologic problems, renal osteodystrophy, gastrointestinal and neurological problems highlight the complexity of a haemodialysis patient's health status (Hakim et al., 1994; Owen, 2003, Ehnfors et al., 2002). Due to exhaustion before and after haemodialysis, the patient requires help and support with everyday activities both during his/her hospital stay

and in the home. Exhaustion can also mean that patients take longer to think about and carry out tasks (Winearls, 1999).

The patient on haemodialysis is at risk of suffering many losses as well as a changed everyday life due to reduced physical fitness and dietary restrictions. The treatment is time consuming and mostly takes place at a dialysis unit, which leads to reduced working capacity and thereby lower income. The end-stage renal disease indicates a life-long process of change for these patients as well as for their next of kin (Janes, 1990). Patients with end-stage renal disease who receive haemodialysis treatment experience both depression and a sense of hopelessness despite good relationships with their next of kin, while the latter have feelings of guilt, loss, dejection and resentment in relation to the patient's disease (White & Grenyer, 1999). The patients on haemodialysis need in-patient care due to various acute conditions, which is invariably provided at the renal clinic, regardless of the cause of the condition.

Next of kin

Within health care, the concept of next of kin is first and foremost defined as the immediate family and other close relatives, for example spouse, live-in partner, officially registered partner, children, parents, siblings, grandparents, spouse's child etc. In certain cases, close friends can also be defined as next of kin (The National Swedish Board of Health and Welfare, 2005). The most common concepts found in the scientific nursing literature on the care needs of sick, disabled and elderly people refer to one or several family caregivers, next of kin, relatives and spouses. Sometimes the concept of next of kin is also used synonymously with family member, which is restricted to one's immediate family and relatives (Jeppsson-Grassman, 2001). Thus, next of kin are not only the providers but also the recipients of care and are close to the patient in the course of his or her everyday life. The concept of next of kin has been employed to denote persons close to the haemodialysis patient. The role of next of kin within health care has undergone a transformation during the last 150 years, both socially and demographically. In line with socio-economic changes, care for sick family members has, in recent decades, shifted from a social to an increasingly greater care responsibility for the family concerned (Rolland, 1998).

For several hundred years, the family constituted the fundamental unit of society, characterised by extended families with a strong sense of loyalty and social influence. Over the last hundred years, with the entry of women into the labour market, meaning that both men and women are employed outside the home, care has largely been transferred from the

family to a range of experts. As a result, the core family is in a state of decline, and living alone is becoming increasingly common. This development is more marked in Sweden than in other western countries. The care of elderly and chronically ill people is no longer the concern of the children, as was the case during previous historical eras, but has become a public responsibility (Tornstam, 1998). An increasing number of people in need of care live at home, and sheltered housing and nursing homes are considered a last resort, when their health is so poor that they are unable to carry out everyday activities without personal assistance. In the new millennium, a transition has taken place in Sweden, where the welfare state and the security provided by the healthcare system are in decline, which has consequences for the next of kin of family members in need of care (Korpi & Palme, 1998; Tamm, 2004).

There are studies available that focus on both the positive and the negative aspects of caring for a close relative or family member. Next of kin's sense of satisfaction at providing care has a strengthening effect on their health and helps them provide support (Lynam, 1995; Nolan et al., 1996). Next of kin are knowledgeable about the patient's condition and the influence of the disease on their everyday life together, whereas healthcare professionals possess technical and medical knowledge about the specific diagnosis and treatment – two types of knowledge that should be combined by means of collaboration and a sharing of experience (Mant et al., 2000). Next of kin may only have a very limited knowledge of what it means to be a carer, what help is available, and what the future holds. Nevertheless, there are next of kin who derive great satisfaction from caring for someone close to them. Healthcare professionals must take this into account in order to provide support and minimise the negative aspects and stressors inherent in care (Häggström, 2004). Next of kin are affected by the difficulties caused by the disease in the patient's everyday life. A next of kin takes part in the planning of the patient's care and is thus involved in the care process. Chronic renal disease is classified as a terminal disease that gives rise to crises, instability in everyday life and a sense of loss among next of kin (Welch & Austin 1999; Tossani et al., 2005). When the patient commences haemodialysis treatment, questions and hopes are raised in the next of kin, who subsequently become involved in the patient's disease and care process (Nolan et al., 1996).

Findings show that the mortality rate in haemodialysis patients with poor support from next of kin is approximately three times higher than the estimated mortality of high support patients (Christensen et al., 1994). Satisfaction with the support provided by next of kin is important for the ability of haemodialysis patients to manage their health. The extent to which next of kin are involved in the care and how they handle disease related problems may be linked to

the kind of information the haemodialysis patient has received about the disease and the degree of openness of their next of kin (Pang et al., 2001).

Everyday Life

Everyday life refers to something that forms a regular and basic part of normal life and that is not especially interesting or unusual. How the individual or family can or must function and defines the necessary level of functional ability refers to everyday life. Everyday life focuses on the phenomena that take place in time and space and comprises ordinary activities such as cooking, watching TV, socialising, sleeping, working, and level of mobility as well as social interaction and communication with the surrounding world. The surrounding world means the everyday environment, where a person spends most of his/her time, e.g. the home, workplace, school or outdoor environment (Goffman, 1959; Adrews & Kearns, 2004). Everyday life can be at any level where the individual encounters society through his or her specific social relations and activities. People can also be involved in other areas that occupy their time and space besides work and the home (Bech-Jørgensen, 1994). Another important aspect of everyday life is that security and well-being are linked to family ties and support, which can, when satisfactory, result in greater resistance to insecurity and difficulties. At the same time, the current belief is that every human being should lead an independent life in order to foster their own personal development, which results in a dilemma when a family member becomes seriously ill and dependent on assistance from his or her next of kin (Roepke, 2001).

Everyday life has also been described as an interaction between everyday activities and the life situation with its deeper content or frame of thought. Everyday life is the surrounding environment that is filled with everyday activities, while the life situation is life as a whole that is influenced by several holistic dimensions (Pierret, 2000). Everyday life also includes emotions, driving forces, symbols and their meanings as well as other individual experiences. Most chronic diseases restrict the ability of a human being to lead the everyday life he/she wants, eventually resulting in a changed life situation. The life situation of a human being consists of a biophysical, socio-cultural, emotional, intellectual and spiritual-existential dimension. These five dimensions can be described individually but, for the human being, they constitute the holistic of an individual's driving forces, goals and capacity and how these manifest themselves and develop within the different dimensions (Sarvimäki & Stenbock-Hult, 1993). The conditions of everyday life are those in which people live and are, in most cases, dependent on socio-economic circumstances that provide opportunities for resources

such as trust, education, time, health and togetherness (Christensen, 2004). Everyday life can be problematic, especially for next of kin of patients who are dependent on complex technology, over which they have no influence. Haemodialysis is a high technology treatment and can therefore be difficult to understand for next of kin who live in close proximity to the patient. However, in order to become understandable and normal, this technology must be made a part of the everyday life of next of kin (Roepke, 2001). Furthermore, everyday life can be complex when next of kin of haemodialysis patients are preoccupied with taking care of the patient and his/her health, which implies difficulties and requirements that have to be met. When next of kin devote themselves to the patient's needs, their everyday life becomes narrower, with fewer opportunities to carry out their own activities or change their life situation.

Health in everyday life

The WHO (1999) defines health as a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. This broad definition applies to developing countries and to both genders. Health is a cumulative state, to be promoted throughout life in order to ensure that the full benefits are enjoyed in later years. Health can be achieved when the preconditions for leading an independent life exist, thus enabling the individual to realise his/her aims in everyday life. Nightingale's definition of health (1859) focuses on the ability and strength of each individual to cope with everyday life. Health is achieved in a healthy environment in the presence of opportunities for meaningful activities and, in the case of those afflicted by illness, by recovering one's strength. This definition emphasises the importance of knowledge about how the environment and everyday habits affect health as well as the fact that monotony and boredom are a hindrance to well-being. Health in everyday life is dependent on taking part in activities that are influenced by the experiences of people in one's immediate environment. It is within the family that a healthy attitude towards food, exercise, abuse, wellness and illness is shaped (Christensen, 2004). According to Nordenfeldt (1991a), well-being exists when a human being is exposed to internal and external stressors, which can be reflected in emotions and bodily complaints, such as depressed mood, sadness and anger. Bodily complaints are manifested as, among other things, nausea, fatigue and sleep disturbances. The definition of well-being is based on pleasurable experiences such as joy, serenity, and harmony, which are transformed into energy and relaxation. Furthermore, Nordenfeldt et al. (1994) argue that health is the ability to maintain one's everyday life, which

includes taking care of oneself and one's family, one's home, work, social relationships and leisure activities. Health is to some extent dependent on the degree to which individuals are able to realise their important goals, satisfy their basic needs and perform ordinary everyday activities, leading to the experience of a minimal level of happiness (Nordenfeldt, 2001).

Next of kin protect family members who are struck by a chronic disease, at the expense of their own health. The burden and lack of freedom in next of kin's everyday life diminish their chances of realising their own important goals, which can lead to emotional strain and has the potential to make them ill (Nordenfeldt, 2001; Schneider, 2004). Next of kin need to feel that there is balance as well as meaning in their everyday life in order to experience well-being and be able to care for the patient in the home (Nolan, 2001). However, knowledge about health among next of kin of seriously ill patients is insufficient. Furthermore, it has been revealed that next of kin of patients on haemodialysis can suffer from fatigue and depressed mood as well as feelings of guilt and hopelessness (Schneider, 2004).

Time in everyday life

Newton (1687) defined time in the following precise manner: "Absolute, true, and mathematical time, of itself, and from its own nature, flows equally without relation to anything external" (Kern, 1983, p. 11). The human being's perspective on time constantly changes in line with relationships between individuals and due to behaviour within the family, in addition to the historical contexts that influence everyday life.

Life is filled with time that encompasses experiences of how individuals live their everyday life. How an individual has lived his or her life cannot be ascertained merely by measuring time or life in a linear manner – life is more complex than that. Everyday life is dependent on changes in the interaction with other people as well as related to processes of time linked to responsibility for the home, work, emotions, creativity and being there for others (Davies, 1996).

According to Heidegger (1927), human existence is characterised by solicitude, human caring and concern. Time is regarded as the horizontal boundary of existence. Solicitude is considered an important aim in an individual's life and can be achieved if time is utilised for the performance of activities. The human time perspective is based on a human existence that is open to the past. People are the carriers of past experiences and decisions. By constantly caring about and being in the present, doing things, and taking action, the human being is at the same time his/her own future. Existence is both a possibility and the future. The

individual's attitude to time is constant throughout life, and the human being can have a specific attitude towards his/her own death. In addition, time is perceived as a relationship between experience and expectation, as knowledge about the future is important for the present. When a loved one is afflicted by a serious disease, the family members deal with everyday life based on past experiences and future expectations. Time increases understanding of events and of an individual's own life.

The structure of life can be found in the life cycle, which consists of a range of time units, which in turn can be related to given points in life, e.g. founding a family, having children, work, illness and death (Rolland, 1998). The time units become the remains of everyday life when the life cycle lacks coherence. This can happen in the case of chronic renal disease and haemodialysis, when next of kin experience that their everyday existence is split and there is uncertainty regarding the patient's survival due to the knowledge that ESRD is associated with high mortality. Each time the patient receives haemodialysis, next of kin are reminded that life is finite (Hagren et al., 2005). Death is constantly present as the ultimate finality, which can be linked to the experience of time as linear, clock and process time, timing and temporality. Time is also associated with movement and events in an individual's life (Rolland, 1998).

An additional perspective on chronic disease focuses on common characteristics that invariably appear during the progression of the condition and about which the next of kin should be aware (Corbin & Strauss, 1991). Furthermore, increased reflection on and understanding of time and codification of reality is needed in order to create a greater awareness of the fact that adapting everyday life to a time-related treatment such as haemodialysis presents a challenge.

Professional support

Social support has been described as a protective factor in crises, illness and social breakdown syndromes (Cobb, 1976). People in one's environment who care and show respect are an important source of effective support. The patient perceives that he/she means something to next of kin and that he/she has something to offer. Social support provides the freedom to take responsibility for one's own problems within the framework of one's ability. Support can be either informal or formal. Informal support consists of family members and friends who have a buffering impact on the harmful effects of stressful situations. A situation is perceived

as a strain when demands arising from a negative everyday event exceed an individual's ability to deal with it, which leads to a sense of reduced control over everyday life. Informal support can minimise these consequences. Formal support in the form of professional assistance to the patient and his/her next of kin consists of information, advice, emotional involvement and encouragement aimed at motivating the patient and next of kin to act in a way that promotes health (Cobb, 1976). Professional support is an important aspect of nursing and can be described in terms of components related to health and caring. These components comprise supportive interventions directed towards both the patient and his/her next of kin (Stewart, 1990). In order to provide support to next of kin that enables them to cope with the demands and strains of everyday life, nursing interventions should include components that make acceptance, recommendations and encouragement possible (Stewart, 1993). When a person falls ill, his/her integrity is threatened by the support of others. Next of kin are an important social support component and have a positive influence on health when the patient's need for professional care is reduced. Healthcare professionals often overlook the fact that next of kin can be a valuable resource for the health of the patient, as they have greater opportunities for personal commitment and communication (Lynam, 1995). Next of kin of haemodialysis patients experience many of the stresses associated with end-stage renal disease, yet are relatively unsupported by healthcare professionals. The patient and his/her treatment is the main focus of the multidisciplinary team in the dialysis unit, yet the main part of the patient's life is spent at home. It is thus important to understand next of kin's need for support in the caring situation (Acaray & Pinar, 2005). Modes of communication need to be developed in order for information to reach next of kin. Professional support is important in order to help them manage their everyday life and give them the strength necessary to assist the patient in the home (Ehnfors & Grobe, 2004). Professional support should focus on physical, psychological, social, spiritual and practical aspects (Kuuppelomäki et al., 2004). Good haemodialysis outcomes depends as much on the efforts and support of next of kin as on professional intervention. Healthcare professionals have to devote more attention to the next of kin of haemodialysis patients. One method is to involve them at an early stage, perhaps at the pre-dialysis meeting, making it clear that their health, symptoms, functional and emotional status are of concern to the healthcare professionals (Klang, 1997; Campbell, 1998). Separate assessment of their needs should be made, possibly involving the dialysis unit's social worker, occupational therapist and hospital chaplain. This assessment could be updated by means of a telephone call in connection with the patient's visits to the clinic. It is important that next of kin are asked how they are coping at a time when they are

free to speak, since some will not admit to problems in the presence of the patient. Many next of kin of haemodialysis patients need permission to feel anger and frustration at their everyday life as well as reassurance that these feelings do not mean that they are bad or selfish. It has been reported that next of kin of haemodialysis patients need a chance to spend time away from their responsibilities, but in reality it is extremely difficult to make them take a proper break (Aswanden, 2002). When respite care is arranged for a patient, either in a nursing home or hospital, the next of kin often visits the patient daily, rather than getting away, relaxing or pursuing his or her own interests. Next of kin of haemodialysis patients need space in order to provide support to their sick relative and avoid being overburdened with care duties.

AIMS OF THE THESIS

The general aim of this thesis was to explore and describe everyday life among next of kin of haemodialysis patients with focus on the life situation, health, time and professional support.

The specific aims of the thesis were:

I: to describe how the next of kin of haemodialysis patients conceive their life situation.

II: to explore experiences of health in the everyday life of spouses of haemodialysis patients.

III: to explore the content of time in everyday life as experienced by next of kin of haemodialysis patients.

IV: to examine the content of nursing documentation with focus on professional support to next of kin of patients receiving haemodialysis treatment.

METHODS

Design and approaches

This thesis had a descriptive and explorative design based on a qualitative approach (Table 1). Two perspectives were applied: a holistic perspective on the everyday life of next of kin of haemodialysis patients and a social perspective with focus on human communication and understanding of next of kin's experience of everyday life (Sarvimäki & Stenbock-Hult, 1993; Cobb, 1976). The qualitative approach was chosen in Studies I-III in order to describe next of kin's conceptions of their life situation, explore their experiences of everyday life, and to structure and organise the interview data to enable reduction, interpretation and the drawing of conclusions (Berg, 2004; Polit & Beck, 2004). The qualitative approach was also chosen in Study IV in order to identify content that describes professional support and the extent to which next of kin are involved in care planning. The analysis of the text aimed at remaining close to the studied phenomenon in order to present the reality as opposed to an interpretation of the emerging content (Graneheim & Lundman, 2004).

Table 1 Overview of the design, approaches, participants and methods in the thesis

Study	Design/Approaches	Selection/Sample	Method of data collection	Method of data analysis
I	Descriptive/Conceptions of the life situation of next of kin of haemodialysis patients	Strategic sampling/12 next of kin from two dialysis units in the same county	Interview	Phenomenographic analysis
II	Descriptive/Experiences of health in everyday life of spouses of haemodialysis patients	Purposive sampling/13 spouses from two dialysis units in the same county	Interview	Manifest and latent content analysis
III	Descriptive/Experiences of time in everyday life of next of kin of haemodialysis patients	Purposive sampling/20 next of kin from two dialysis units in the same county	Interview	Manifest and latent content analysis
IV	Descriptive/Focus on content of professional support to next of kin of chronic haemodialysis patients	Total sample (N=50) of nursing records from one dialysis unit of patients receiving chronic haemodialysis over a five-year period between 1998-2002.	Text analysis of nursing Documentation	Manifest and latent content analysis

Ethical considerations

The studies were approved by the operations managers at two selected hospitals in south-western Sweden as well as the Ethics Committee at Lund University, Sweden.

The names of the participants in Studies I-III were supplied by the nurse in charge of dialysis. Qualitative research focuses on the experiences, meanings and understanding of the informants. As findings originate in data and not in tested hypotheses, it is important that the researcher informs the participants about the study design, how the data will be processed and that abstraction of data and use of short quotations eliminate the risk of identification (Sim, 1991). The participants were fully informed about the voluntary nature of participation, how their data would be treated and the procedures that would be used to ensure confidentiality. Informed written consent was obtained from all participants and they were told that they could withdraw at any time. The main researcher then introduced herself and explained the purpose of the study to the next of kin. The interviews took place at the participants' convenience in their homes without the presence of the patient. Codes were used to identify the participants. The transcripts, audio-tapes and consent forms were stored in a locked cabinet. Study IV investigated the haemodialysis patients' nursing records. Prior to the study, the research nurse removed all personal details from the nursing records that could identify the informants, and the entire material was treated in accordance with the Data Protection Act (1998). Ethical issues were reflected on and harm minimised, through following the ethical guiding principles of the World Medical Association's Helsinki Declaration 1964 (The Swedish Medical Research Council, 2000).

Setting and context

The studies were carried out at two hospitals in a county of south-west Sweden during 1999 (Study I), 2002 (Study IV), and from July 2003 to April 2004 (Studies II-III). The two hospitals served approximately 270,000 inhabitants, of whom 38 were haemodialysis patients (SRAU, 2004).

Patients undergoing chronic haemodialysis treatment had access to a dialysis unit at each of the two hospitals. Haemodialysis is a high technology treatment consisting of continuous out-patient care and sometimes in-patient care in a hospital ward. Haemodialysis provided in both out-patient and in-patient care amounted to an average of 215.6 days, which was broken down

into 182 days haemodialysis out-patient treatments and 33.6 days of in-patient care per patient annually. The out-patient care consisted of frequent, regular visits throughout the year. Each treatment session lasted between four and six hours, depending on the patient's condition and the distance between his/her home and the dialysis unit. Palliative care due to uraemia was the main reason for in-patient care, the other reasons being graft complication and hypotension (Ziegert et al., 2004).

Nurses and physicians with specialist competence in nephrology were responsible for the patients' care on the basis of a strategy in line with the diagnosis and treatment guidelines. The Swedish Nephrology Group's guiding principles for the care of patients with end-stage renal disease were followed (2001). Prior to the start of renal replacement therapy, the patient and next of kin received medical information as well as an invitation to take part in renal education with focus on four themes. This education, which was led by a nephrologist and a dialysis nurse, was provided to patients and their next of kin and encompassed end-stage renal disease and renal replacement therapy in addition to psycho-social factors that affect the everyday life of the patient and next of kin. A social worker, a physiotherapist and a church representative gave a talk during the final renal education session and described their work and the support interventions available to patients and their next of kin. The haemodialysis treatment was adapted to the needs of the individual, and patients could opt for either three hours of dialysis five times per week or five hours three times per week, provided during office hours seven days a week. The decision was taken in consultation with the nephrologist. A nephrologist and a dialysis nurse with nursing responsibility monitored the patient's health and the progress of his/her disease during and after the haemodialysis in accordance with an individual nursing plan. The same nurse and nephrologist were responsible for the patient for the entire period during which he/she received haemodialysis or other forms of renal replacement therapy. The organisation of renal care in a renal medical unit promoted a care partnership initiated and maintained by the dialysis nurse, thus leading to a relationship with the patient's next of kin, which may last for the duration of the treatment.

Participants

In Study I, strategic sampling was used in line with the phenomenographic method in order to obtain the maximum amount of variation in terms of subjects with different background characteristics, such as relationship to the patient, gender, age, education, type of housing and

number of years of experience as a next of kin of a haemodialysis patient (Burns & Grove, 2001). The sample consisted of 12 respondents.

In Studies II and III the participants were selected by purposive sampling based on the inclusion criterion of having at least one year's experience as next of kin of a patient on haemodialysis. Study I was conducted during a 4-month period in 2004 with 38 patients who were undergoing haemodialysis and who were from the same county. In all, 38 next of kin were identified in the patient records, but due to the purposive selection, the sample was reduced to 20 next of kin, 13 of whom were spouses. All selected next of kin agreed to participate.

Table 2 Characteristics of next of kin of haemodialysis (HD) patients in Studies I-IV

	Study I (N=12)	Study II (N=13)	Study III (N=20)	Study IV (N=50)
Mean Age	52	56	58	48
Wife	4	11	11	12
Husband	1	2	2	5
Daughter	4		4	16
Son	1		1	4
Sibling				6
Friend				4
Parent	2		2	
No next-of-kin				3
Education				
Primary	2	4	4	
Secondary	9	8	13	
University	1	1	3	
Spatial closeness				
Living with	7	13	13	21
Living near by	3		6	17
Living far away	2		1	9
Duration of HD				
>1 year	5	9	12	12
2-6 years	3	3	6	31
6-10 years	4	1	2	4

The participants in Study IV were selected according to the following criteria: all patients with chronic haemodialysis from one dialysis unit were included. All nursing records of patients on chronic haemodialysis (N=50) for the 5-year period 1998-2002 were included in this study. Each patient record contained a huge amount of annotations, as some patients had received haemodialysis for 10 years or more. In most cases, information about next of kin including family circumstances could be found under all aspects of the nursing process and not merely under the search word support.

Table 3 Characteristics of the haemodialysis patients in Study IV (N=50)

Characteristics	Number
Mean Age	65
Sex	
Male	37
Female	13
Duration of haemodialysis	
<2 years	15
2-6 years	31
6-10 years	4

Data collection

Interviews

The data collection in Study I was based on semi structured interviews. An interview plan was used with opening questions leading to a number of delimited areas that described the life situation of next of kin from a holistic perspective. The following areas were focused upon: emotional, behavioural, work, biophysical, existential and family situation (Sarvimäki & Hult, 1993). The opening questions were intended to establish the basic facts about the participants' life situation as thoroughly as possible. Two pilot interviews were conducted in order to test the validity of the questions, resulting in a minor modification. The interview took place after an informal conversation, the purpose of which was to create a comfortable atmosphere.

Table 4 The content of the questions used in the interviews in Study I

What are the implications of your next of kin's renal disease for your life situation?
How do you perceive your own life situation due to your next of kin's need for haemodialysis treatment?
How do you perceive that your family and closest friends are affected by the sick person's haemodialysis treatment?
How has your future been affected by the treatment?
How do you perceive that information you have received from the healthcare professionals regarding the patient's haemodialysis treatment?
How can the health care sector influence your future?

The interviews, which were conducted in the informants' homes, lasted between 20 and 40 minutes and were audio-taped and transcribed verbatim in order to not to lose any information.

Studies II and III employed a content analysis approach to data collection that remains close to the original material and does not paraphrase the reality (Polit & Beck, 2004). The main focus of the interviews in Studies II and III was the next of kin's experiences of everyday life. In the interviews in Study II, the researcher was free to engage in a conversation that focused on the main questions regarding spouses' views and experiences of their everyday life in terms of their own health. The research questions in Study III concerned the everyday life of the next of kin and how they viewed their own time in relation to caring for the patient, with focus on the past, present and future. The first interview question in both studies was broadly formulated as "Can you describe your everyday life?" The interviews lasted between 30 minutes and 2 hours.

Patients' records

Study IV included data collected from the patients' nursing records for the 5-year period 1998-2002. Each record consisted of approximately 100 pages and was documented by means of the VIPS keywords (Well-being, Integrity, Prevention, Safety) from the nursing documentation model by Ehnfors et al. (2002). The VIPS model is based on the nursing process, and the key words are identified and described in the model manual. The key word of significance in this study on the subject of support was defined in the nursing plans as nursing

intervention with focus on communication in conjunction with diagnosis, prognosis, dialogue with next of kin and difficult decisions (Ehnfors et al., 2002). Significant parts of the nursing record text referring to support to next of kin were identified and copied. The focus of the data collection was text identified in the nursing documentation concerning professional support to next of kin of patients on haemodialysis.

Data analysis

Phenomenographic analysis

In phenomenography, the focus of research is variation in the way of experiencing a phenomenon, which embodies two phases (Marton, 1999). The first phase is concerned with describing how the phenomenon is experienced and answers the question: “What are the different ways of experiencing the phenomenon?” The second phase scrutinises variation corresponding to the critical aspects of the phenomenon, i.e. the dimensions of variation, as characterised by the, experiences or conceptions within the framework of the structure of awareness. In this phase, critical aspects of the phenomenon concerned are identified and focused upon simultaneously, thereby resulting in conceptions with an ontological status. Variation is present in certain conceptions of a phenomenon due to different ways of seeing it, and these conceptions are illuminated by the researcher (Marton, 1999). In pheomenography, the participants’ thoughts about a given phenomenon are more important than their number. The phenomenographic method allows conceptions of a phenomenon contained in collected data to be explored by means of analysis and interpretation and sorted into descriptive categories based on referential and structural meanings (Marton, 1981; 1999)

The phenomenographic method was used for the analysis in Study I (Marton, 1981; 1999). The first step of the analysis involved focusing on the differences and similarities in the conceptions of the life situation among next of kin of haemodialysis patients identified in the transcribed interview texts. The analysis was carried out in four steps in line with Ågren (1992). The first step involved each interview text being read several times to obtain a holistic view of the material. The texts were read through and reflected upon, and eventually 612 statements that were directly related to the aim of the study were selected.

In the next step, the individual statements were placed in relation to each other in order to identify characteristics of the conceptions.

A further step was to distinguish the main conception from the twelve that had emerged. The text was read through once again to identify a main conception in each interview.

The final step consisted of a back and forth movement between the 24 conceptions, after which a final pattern emerged in terms of content, which resulted in six main categories and 18 subcategories describing the phenomenon. For example, “loss of life companion”, “lack of visions of the future”, “having to adapt themselves”, “carrying a greater work load” and “a changed relationship” resulted in the main conception “perception of a changed life world”. The variation in Study I was due to the fact that the sample and the data collection method resulted in a rich variety of statements that provided a wide range of information about the phenomenon of the life situation. The descriptions of the life situation that exhibited variation in background variables were selected with the aim of achieving variation in conceptions. Depth was achieved due to the nature of the questions and the multidimensional description of the life situation.

Content analysis

Qualitative content analysis, a technique aimed at providing an objective, systematic description of the manifest content of texts or interviews, was chosen in order to better understand the perspectives of the subjects as revealed by the interview texts. Furthermore, qualitative content analysis identifies concealed messages and reveals whether or not certain characteristics are present in the statements, which can take the form of texts or interviews. This method is considered an innovative means of collecting and analysing data such as those found in nursing records (Berg, 2004; Polit & Beck, 2004).

In Studies II and III, data were analysed in accordance with the principles of content analysis, the selection criterion and the steps of analysis (Berg, 2004). The analysis began by forming an impression of the content of the transcribed interview texts, which were read several times in order to ascertain the manifest meanings. The analysis continued with coding, in which step the texts and annotations were reread and subsequently condensed into text units, after which the meanings emerging from the categories were labelled. In accordance with Granheim & Lundman (2004), the steps set out below were adhered to:

1. **Impression.** The analysis began when the transcripts were read and compared to the audio-taped interviews in order to check the accuracy of the text and to gain an initial impression of the transcribed interview texts.
2. **Rereading.** The transcribed interview texts were reread. Emergent meanings that revealed the content of the texts were continually noted.

3. Coding. While reading the transcripts of each interview, notes were made in the margin indicating the content and emerging ideas. The entire text was then read through once again, and text units that corresponded to the aim were coded.
4. Inductive process. In this step, the units were condensed in order to filter out irrelevant information. An inductive process was initiated by the main researcher deeply absorbing herself in the written material with the aim of identifying dimensions or themes that appeared meaningful in relation to how the information was presented.
5. Reduction. The condensed texts were read and coded into broad categories in a so-called category list. The analysis continued with another reading of the texts to identify different nuances in the broad categories, which were then reduced to new, more nuanced ones (Table 4).
6. The validation process was concluded by selecting quotations from each category that corresponded to the category description.
7. The final categories were determined. The most important meanings were marked and brought together. Each coded main quotation was cut out and placed in a pile. An examination was made to ensure consistency between the category and quotations selected to illustrate it. Consensus between the researchers (KZ & EL) was achieved when the result categories were established and the quotations belonging to them selected.
8. Writing process. The texts were re-read in order to link the original material to the category descriptions. The main researcher then selected the most relevant text from each category and abstracted the meaningful information.
9. Quantification. Finally, the analysis was concluded by quantifying the quotations in order to establish which category accounted for the largest number (Polit & Beck, 2004).

Table 4 Examples of coding by condensing text from the interviews

Extracts from interviews	Condensing	Category
My life is bound up with my husband. It really is. People tell me that I don't need to look after him so much, but I am afraid to leave him on his own.	Mutual dependency was a source of worry and tension.	Arduousness
My day became quite different. I can't stay away from home for more than an hour at a time, as there is nobody here	Time was devoted to the patient's needs, and there were few possibilities to get away.	Fragmented

In Study IV the nursing documentation was mainly analysed by means of manifest content analysis (Polit & Beck, 2004; Berg, 2004) in order to describe the content of professional support to next of kin of haemodialysis patients as revealed by the records. The content analysis focused on what was found in the nursing documentation on the subject of professional support to next of kin of haemodialysis patients. The analysis started with repeatedly reading the records in order to acquire a sense of the nursing process as a whole and to apprehend essential features. Significant parts of the records referring to support to next of kin were identified and copied. This text was read and re-read and sentences describing support to next of kin were marked. Single words or short sentences were used for coding. Codes with a similar content were grouped together and sub themes formulated. The sub themes were then coded in order to reduce them into themes describing support to next of kin as expressed in the nursing documentation. As a means of verifying the relevance of the themes and sub themes, they were linked to the data from which they were derived (Berg, 2004). They were then analysed using latent content analysis in order to illustrate that professional support is a process, which the findings had succeeded in capturing. Finally, the

words related to the theme were indexed to show their frequency within the themes (Polit & Beck, 2004).

SUMMARY OF FINDINGS

Life situation (I)

The next of kin of haemodialysis patients generally expressed high commitment to and concern for the patient. In spite of their life situation having been dramatically changed, the next of kin exhibited an ability to adapt. Confinement and social isolation, together with the constant worry about death, may lead to next of kin not having the strength to support and encourage the patient in the long term. This finding thus revealed a marked change in the next of kin's life situation and comprised the following areas:

Confinement focused on variation in aspects of next of kin's life situation. The next of kin expressed an emotional affinity with the disease. Confinement was experienced as burdensome and as dominating their life situation, which revolved around the patient's needs, the necessity of always being available, constantly having to plan and being permanently preoccupied with the disease.

Social isolation covered a number of problems experienced by those who had to care for a patient: less leisure time, reduced social contacts, a restrictive time-table and a sense of "missing out on the good times". The next of kin described how opportunities for leading an active social life are reduced due to the patient's haemodialysis.

Changed life-world described how the next of kin's life situation is altered when a family member falls ill. Next of kin made efforts to adapt themselves to their perceived lack of visions of the future, to a heavier workload, and coping with a changed relationship.

Security in life focused on how the next of kin perceived the Swedish medical care system and how their financial situation was unaffected by the patient's need for haemodialysis. The next of kin appreciated the medical competence and continuity of renal care. They reported that the patient received good and safe care, which provided them with a sense of security.

Threatening future referred to the next of kin's constant preoccupation with the worry of losing their sick family member and fear of death. The next of kin perceived this as a failing on their part, which led to a feeling of insecurity about the future due to uncertainty about the patient's prognosis.

Promoting health described how the next of kin are committed to improving the patient's health and well-being. By means of different activities and initiatives, they endeavoured to make the haemodialysis patient feel better in everyday life. It emerged that next of kin are knowledgeable and anxious to promote the patient's health.

Health in everyday life (II)

Physical and mental complaints were manifestations of the fact that spouses' everyday life was taken up by caring for the patient at the expense of their own health. Spouses were worried about the patient's everyday life and burdened with responsibility, a situation that can become strenuous for both the patient and his/her next of kin. They found it arduous and trying to be present for the patient, which constituted an obstacle to their health. Spouses exhibited stamina and neglected their own health when they focused on the patient's condition and minimised their own illness. Spouses put the patient's health first, thus neglecting their own, and their everyday life was filled with activities that were centred on the patient's needs. Independence in everyday life could protect spouses' health when it led to the experience of happiness and relaxation. Cultural activities and the countryside were positive for spouses' health, as were experiences of calm and an escape from their arduous situation.

The content of health in everyday life could be described as follows: *arduousness*, *stamina* and *independence*.

Arduousness referred to the spouses' burden and strain when taking care of the patient in the home. Arduousness was expressed as a range of emotions as well as physical and mental complaints. The spouses' unwillingness to share their own health problems with the patient was described as a burden and source of distress.

Stamina consisted of descriptions of the ability to withstand difficulties. Stamina reflected neglect of one's health as well as diminished ability to consider oneself and one's own health problems. Stamina was an expression of willpower that was mobilised in order to cope with everyday life. Spouses' stamina helped them to conceal their own suffering and feelings in order to appear happy with their life.

Independence comprised experiences that are beneficial to health. The spouses experienced situations that afforded them happiness and leisure and thus had a beneficial effect.

The spouses thrived on autonomy in their everyday life when they were free to decide what to do.

Time in everyday life (III)

The experiences of time in the everyday life of next of kin of haemodialysis patients demonstrated that time for themselves was minimised and that life space was contracted.

Renal disease and its treatment played a central role in the everyday life of next of kin, due to their worries about the patient's symptoms, which could influence the next of kin's rhythm and give rise to the experience of time being negatively affected.

The next of kin described how their own time was drastically reduced when they prioritised the patient's needs, thus allowing themselves no opportunity for relaxation and activities of their own. The next of kin were also aware of the prognosis of renal disease and the fact that haemodialysis was a life-sustaining treatment, which forced them to live in the present. They also had to live with fear, due to their knowledge that haemodialysis can fail, which made them unable to plan for the future. They felt wellness when they experienced a break from everyday life and followed their own intuition in the choice of activities.

The content of time in everyday life can be described as follows: *fragmented time*, *vacuous time* and *uninterrupted time*.

Fragmented time contained descriptions of restricted and divided time. Fragmented time dominated the everyday life of next of kin, as their whole attention was focused on the patient's disease, health and haemodialysis, which meant that they had no time for themselves. The next of kin planned their time to coincide with the patient's everyday activities in order to give priority to his/her needs. Fragmented time mainly consisted of time focused on the patient at the expense of their own unbroken time.

Vacuous time comprised descriptions of the present as vacuous, empty and without a future of one's own, as the patient's haemodialysis treatment prevented the planning of long-term goals. The strict vision of time contributed to the vulnerability of the next of kin, as they had a feeling that time was running out for the patient, which resulted in an emotional void due to uncertainty about the future. Time was measured from day to day and they lived in the present.

Uninterrupted time comprised descriptions of the next of kin's private time, which they could devote to themselves, their own activities and needs, and feel free. Uninterrupted time implied having time to themselves, which they spent on various pastimes that they found enjoyable or relaxing. Uninterrupted time thus had the potential to be beneficial, as they could relax from their role of supporting the patient.

Professional support (IV)

Notes related to support to next of kin were identified in all parts of the nursing documentation and included: assessment on admittance, status sheet, care plan with nursing diagnosis, nursing goals, nursing interventions and outcome description, which showed that contact with next of kin was more frequent during certain periods due to fluctuations in the patient's health status. The content of professional support revealed that the nurse mainly focuses on facilitating the care of the patient in the home. This study showed that next of kin are a supportive resource in the nursing care of patients with chronic haemodialysis and that professional support to next of kin focused on planning their participation in the care of patients in the home. The study also revealed that descriptions of professional support in the nursing documentation lack a linguistic content. Professional support had to be continuous in order to meet the needs of next of kin and to be appropriate to their level of communication. However, in most cases, information about next of kin in relation to their home situation could not be found using a single search word (Table 5).

Table 5 Frequency of the VIPS model keywords (Ehnfors et al., 2002) in nursing documentation where professional support to next of kin of patients receiving chronic haemodialysis treatment was described (N=50)

The nursing process	Keywords	Frequency
Assessment	Nursing history/status	109
	Reason for contact	1
	Health history/care experience	2
	Social history	31
	Social service	14
	Lifestyle	2
	Communication	3
	Cognition/development	9
	Breathing/circulation	4
	Nutrition	5
	Elimination	1
	Psycho-social	42
	Well-being	18
Diagnosis	Nursing diagnosis	19
Planning	Nursing goal	6
	Nursing intervention	49
	Information/education	11
	Support	12
	Observation	3
	Special care	4
	Coordination	19
Intervention	Nursing outcome	27
Evaluation	Nursing transfer report	39

Professional support could be described within the framework of the following themes: *to explore next of kin's supportive resources, to enable next of kin's readiness for the care of the patient and to co-operate with next of kin in the care of the patient in the home*, captured by the core theme which described professional support as an ongoing process.

To explore next of kin's supportive resources consisted of a description of facts about their abilities to be a supportive resource for the patient. The sub-themes that emerged contained

descriptions of the type of relationship to the next of kin, type of accommodation, the family's financial situation, next of kin's care capacity, need for support and spatial closeness, i.e. whether they lived far away from, nearby or together with the patient. The description of the next of kin's relationship, type of accommodation and the family's financial resources provided a picture of their care capacity and availability for continued care. The quantitative analysis revealed a predominance of words describing the relationship between patient and next of kin as well as the latter's spatial closeness, while descriptions of their financial resources and need for support were scarce.

To enable next of kin's readiness for the care of the patient focused on a description of supportive nursing actions aimed at facilitating discharge and supporting the patient in the home. The sub themes contained information about the patient's health status, co-ordination of discharge to the home and information about nutrition. Support took the form of factual information to next of kin to enable their participation in the care. The quantitative analysis revealed a preponderance of words describing information to the next of kin about the patient's health status and co-ordination of discharge to the home while information about nutrition occurred less frequently.

To co-operate with next of kin in the care of the patient in the home included different forms of co-operation between next of kin and the nurse. Sub themes that emerged comprised descriptions of the nurse providing advice in acute care situations in the home, next of kin seeking advice in such situations and the nurse supporting next of kin by means of conversations. The support focused on co-operation with next of kin by means of dialogue, where they could raise questions and discuss their reflections when the patient's condition deteriorated while at home. The quantitative analysis revealed a marked preponderance of words describing the nurse's supportive conversations with next of kin, while words describing the nurse's advice in care situations in the home occurred less frequently.

DISCUSSION

Methodological considerations

The aim of this thesis was to explore and describe everyday life among next of kin of haemodialysis patients. Investigations of everyday life among this group of next of kin raised various questions about life situation, health, time, and professional support. A qualitative descriptive and explorative design comprising phenomenographic and content analysis was

used in Studies I-IV in order to capture experiences of everyday life among next of kin of haemodialysis patients with focus on health and time. Accordingly, the findings were supported by different types of data such as patient records and interviews, which were suitable for phenomenographic and qualitative content analysis, leading to a deeper understanding of the next of kin's everyday life over time (Marton 1981; 1999; Berg, 2004). The method was deemed suitable for these studies, due to the fact that it reflects human communication and preserves information from the original material (Berg, 2004; Granheim & Lundman, 2004). In order to ensure quality in the data collection and analysis, the qualitative approach in this study will be discussed in terms of the four criteria of trustworthiness: credibility, transferability, confirmability and dependability of findings and methods used (Polit & Beck, 2004).

Credibility was achieved by the use of phenomenographic and qualitative content analysis. The implementation corresponds to the aim and the data collection and analysis procedure are structured. The sample and collection method should offer the greatest potential for providing maximum information. Furthermore, the data collection was carried out in agreement with the informants, and there was an atmosphere of trust between the researcher and participants. The next of kin of haemodialysis patients were a carefully chosen, well defined group of men and women living in a specific area of Sweden. In order to obtain variation, strategic sampling was used in line with the phenomenographic tradition (Marton, 1981). This was the reason for choosing twelve next of kin with as diverse background variables as possible with regard to age, gender, education, experience of RRT, relationship to patient and type of housing. The purposive sampling in Studies II and III, which focused on experiences of being a spouse or next of kin of a patient on haemodialysis for a period of at least a year contributed to improving the understanding of health and time in everyday life. Surprisingly, the education level was relatively high, indicating the possible failure of the analysis to capture the experiences of less well educated people. In study IV data were collected from patient records with focus on key words such as support, as defined in the VIPS model (Ehnfors et al., 2004). The keywords of significance to this study on the subject of professional support were found in all parts of the nursing documentation.

Dependability in qualitative research corresponds to reliability in quantitative studies.

Furthermore, dependability was ensured by the fact that the same researcher conducted all the interviews. The researcher was not involved in the patients' care, thus bias in the results was avoided. The follow-up questions probed how next of kin reflected over their life situation. The use of a tape recorder and verbatim transcripts as well as referring back to and rereading

the interview transcripts during the analysis process allowed the researcher to remain close to the content of the interviews.

Confirmability refers to objectivity and can be understood in terms of several researchers with different perspectives on and knowledge of objectivity which, in this study, was ensured by the involvement of several researchers with different perspectives and knowledge. In phenomenographic analysis, the collected information is processed by identifying similar and dissimilar patterns and characteristics. It was thus possible to identify variation in the six main categories. In line with Marton (1981, 1999), variation emerged during the analysis. Moreover, moving back and forth between the main categories and sub-categories of the phenomenon, in this case the life situation among next of kin of haemodialysis patients, leads to variation in the findings. Qualitative content analysis is a tool for drawing valid conclusions based on verbal data for the purpose of describing and evaluating a specific subject (Berg, 2004). The point of departure in the analysis in Studies II-IV was the manifest meaning. The formulation of result categories, as well as the understanding of the result category structures, was based on the latent meaning captured by the main categories. This was achieved by regular discussions between the supervisor and co-assessor in order to ensure conformity between data and theory in all steps of the analysis in studies I-IV. The use of textual analysis in Study IV was suitable for exploring documented annotations, where the aim was to provide a clear picture of a specific aspect of the documentation.

Transferability corresponds to validity and transferability of findings. The findings in Studies I-III were limited to the unique situation of next of kin of haemodialysis patients, but it is for the reader to judge the applicability of the data to other contexts. Although samples in qualitative studies are small, they are nevertheless important for highlighting next of kin's experiences of their life situation. The text analysis in Study IV could be transferred to other contexts concerned with issues of nursing documentation and similar keyword models. Clear and distinct descriptions of culture, context, participants, data collection and analysis are also important for facilitating transferability (Graneheim & Lundman, 2004).

General discussion of the findings

Experiences of time and health in everyday life

The experience of time in everyday life among next of kin of haemodialysis patients demonstrates that time for themselves is minimised and life space contracted. They are aware of the prognosis of renal disease and the fact that haemodialysis is a life-sustaining treatment, which forces them to live for the moment. The existential knowledge that one cannot live forever was constantly in focus, which can create insecurity in everyday life and the feeling that time is running out, especially as haemodialysis takes up so much of it. According to Heidegger (1927), human existence is characterised by solicitude, human caring and feeling needed. The human time perspective is based on a human existence that is open to the past. People are the carriers of experiences and decisions. The role of next of kin changes when they become involved in the care, which in turn can lead to a change of lifestyle and restrictions in everyday life and the life cycle (Rolland, 1998). However, a serious illness such as end-stage renal disease not only shortens life but also places everyday life on a thin line (Hagren et al, 2001; 2005). Next-of kin's perspectives on everyday life are based on their knowledge of the patient's previous personality and the time spent together (Johansson et al., 2002). They have to live with uncertainty, as they know that haemodialysis can fail, which makes it impossible to plan for the future. Time in the everyday life of next of kin is vacuous when they are unable to think solely in terms of clock and linear time, due to the fact that they have to concentrate on the present, their life being a complicated web of different temporal structures, which is in line with Davies (1996).

The findings also showed that everyday life among next of kin of haemodialysis patients can be characterised by ambivalence towards their own health, especially in cases where the next of kin is a spouse of the patient. Spouses experienced a great deal of arduousness in terms of their health due to trying to keep up appearances and concealing their own condition from the patient. In line with Goodman & Shippy (2002) spouses in poor health experienced caring as a greater burden, have more family conflicts, poorer self-efficacy and were more likely to feel depressed. Although the purpose of this thesis was not to investigate marital breakdown after serious illness, it is nevertheless important for healthcare professionals to routinely enquire about the quality of the marital relationship and whether it has remained stable after serious illness. Marital breakdown is more likely to occur in relationships characterised by previous difficulties (Taylor-Brown et al., 2000). The spouses exhibited stamina when they set their

own diseases aside. However, the lack of proper care for themselves can constitute an emotional pain that prevents them from experiencing good health. According to Aneshensel et al. (1995) spouses play an important role in the practical and emotional aspects of patient care as well as in decision making at the end of life. Although spouses may carry a significant burden as a result of care-giving, they can nevertheless find sustenance and meaning in their own work (Rabow et al, 2004). Next of kin of patients on chronic haemodialysis exist in a state of constant uncertainty and have to reconcile themselves to a series of losses as the patient becomes weaker both physically and mentally (Dingwall, 2003). Health is to some extent dependent on the degree to which individuals are able to realise their important goals, satisfy their basic needs and perform ordinary daily activities, which leads to the experience of a minimal level of happiness (Nordenfeldt, 2001). The spouses described autonomy, being in harmony with oneself, thinking positive thoughts, being grateful for what one has and finding peace as important aspects of their own health.

Perception of life situation

Next of kin of haemodialysis patients generally expressed a high degree of commitment to and concern for the patient. In spite of the fact that their life situation had changed dramatically, they had the ability to adapt. The illness and its treatment impose sexual, marital, psycho-social, financial, work and holiday restrictions on the patients. The thesis reveals how next of kin demonstrated a determination to manage their everyday life while their family member was on haemodialysis, eventually resulting in their whole life situation being changed. The life situation of next of kin includes a relationship with the surrounding world through the care environment, family and friends, work and society (Fridlund, 1997). Everyday life can be complex when next of kin of haemodialysis patients are preoccupied with taking care of the patient (Valderraño et al., 2001). Despite their difficult life situation, the next of kin in this thesis reported an ability to adapt and take each day as it comes. Their commitment to the patient can be regarded as a loss of freedom, which implies that next of kin are unable to live their lives as they wish. Patients in receipt of haemodialysis and their next of kin suffer from strain not only due to the illness, but also because of the change in their social and financial circumstances. Next of kin need support and supervision from the renal care professionals to help them sustain their driving force. It emerged that next of kin take initiatives, that they care and show concern as well as being knowledgeable.

Planning of professional support

Professional support to next of kin should focus on planning their role in caring for the patient in the home. The qualitative analysis of nursing documentation revealed a lack of knowledge about how to document professional support. One possible explanation for the fact that details about support to next of kin were identified in different parts of the nursing process is that contact with next of kin was more frequent during certain periods due to fluctuations in the patient's health status. Consequently, it can be difficult to fully ascertain the amount of professional support provided to next of kin, although the results are nevertheless transferable to documentation of similar situations. It is possible that the nursing documentation was governed by the VIPS-model (Ehnfors et al., 2002), which could have hindered the nurse in describing support to next of kin, due to lack of knowledge and training in the area of key words and their content. The VIPS-model is intended as a support for the nurse in sorting and describing the content of care based on the nursing process and using suitable key words. More descriptions of support to next of kin could perhaps have been found without key words or if the next of kin perspective within the nursing documentation had been accommodated within a key word. The ethical aspects of nursing documentation may influence the extent to which encounters between nurse and next of kin are entered in the record, thus explaining the sparse documentation of support provided to next of kin. The professional healthcare has to enable the next of kin to provide competency care. Furthermore, the nurse has an obligation to keep abreast of new nursing research findings, such as those pertaining to communication, in order to understand the importance of dialogue for assisting reflection together with the next of kin on the care situation (Ehnfors & Grobe, 2004). Stewart (1990) describes professional support in terms of components related to both health and nursing. These components emphasise support, such as the nurse's ability to listen to patients and their families. Most of the documentation concerns the assessment of the home situation, to a lesser extent, the support provided to next of kin how to manage the selfcare situation (Bevall. 2000; Söderhamn et al., 2000). In the clinical setting, nursing interventions are focused on medical care and activities associated with the implementation of the physician's orders and medical treatment. The nurse's role also includes patient monitoring, administration and observation of AV access, supervision of the nephrologist, assisting in the treatment and recovery, and patient discharge (Merill et al., 2004). Therefore, emotional and informational support to the next of kin of haemodialysis patients should receive priority in the nursing plans, with special consideration given to communication patterns.

Main considerations

The everyday life among the next of kin changes when the family becomes involved in the care, and lead to a change of lifestyle and restrictions in everyday life. It is therefore important to be familiar with the nursing process, especially when the patient and their next of kin need support and attention in everyday life. Next of kin of patients on haemodialysis exist in a state of constant uncertainty and have to reconcile themselves to a series of losses as the patient becomes weaker both physically and mentally. A nursing process model describing next of kin of patients receiving haemodialysis was constructed in order to capture their experiences of everyday life (Figure 1). The concept of nursing process mapping is a structural way of helping to views relationships among clinical data and to apply scientific data (Potter et al., 2004).

As illustrated in Figure 1, there may be a linkage between the findings of Studies I-IV. When next of kin of haemodialysis patients become involved in the patients' care they experience arduousness in relation to their own health as well as less continuous time for themselves in everyday life (Nursing assessment), and their life situation is characterised by confinement and social isolation (Nursing diagnosis) . They also become more aware of the complexity of the patient's disease, which demands not only stamina in order to manage everyday life but also vacuous time to be able to concentrate on the present (Nursing assessment). When next of kin receive professional support in their everyday life (Nursing intervention), independence and uninterrupted time become possible (Nursing outcomes). In summary, the thesis has generated a model adapted to the nursing process and the nurse's communication with next of kin of patients on haemodialysis. The model is focused on individual, holistic planning of the everyday life of next of kin who want to participate in the patient's care. The model is based on nursing diagnostics and builds on the results of this thesis, such as next of kin's experiences of time and health, co-operation, competence, communication as well as participation, the nursing staff's attitude and behaviour, and consequences of involvement in the patient's care in the home. The developed model contributes to the nurse's use of a comprehensive nursing assessment, where next of kin's wishes and everyday life can be made visible in nursing diagnoses. Both short and long-term nursing interventions with a more obvious focus on communicative support to next of kin can be planned and initiated. The model can also be employed in patient and nurse traini

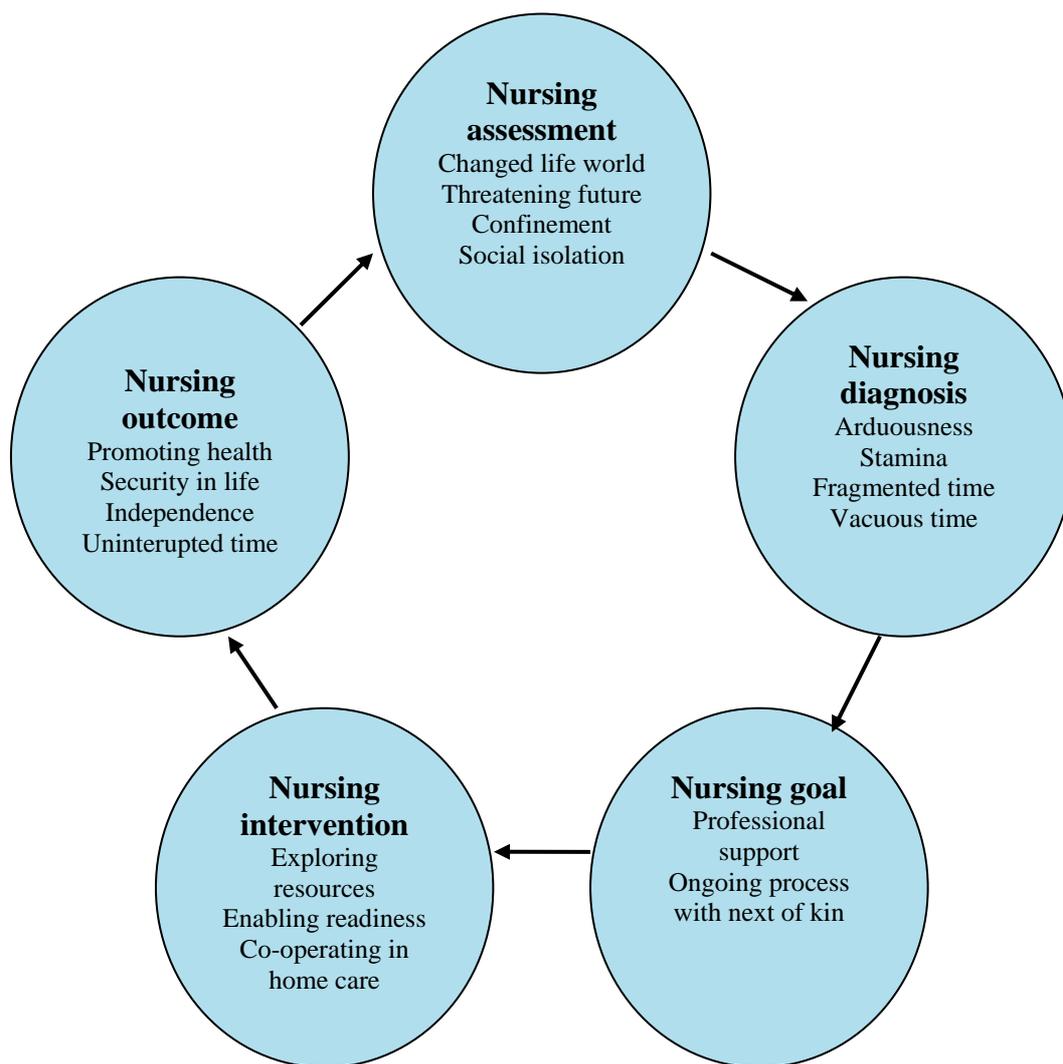


Figure 1 Illustration of the nursing process in everyday life among next of kin of haemodialysis patients

CONCLUSIONS

* Next of kin of haemodialysis patients express a high degree of commitment to and concern for the patient. In spite of the fact that their life situation had changed dramatically, they were capacity to adapt.

* Next of kin perceived their life situation as difficult, due to restrictions in their everyday life and concerns about the patient's condition and chances of survival.

* Next of kin experienced ambivalence towards their own health, especially in cases of patients' spouses. Their experience of health fluctuated between arduousness, stamina, and independence.

* Next of kin demonstrated that time for them was minimised and common life space contracted.

* Next of kin were a supportive resource in the nursing care of patients on haemodialysis. Lack of knowledge in nursing documentation of professional support revealed necessity of readiness of next of kin.

IMPLICATIONS

Clinical implications

* Next of kin should be provided with supervision in order to enable them to take decisions in everyday life that allow them more time for themselves, which can benefit their health. .

* Nurses' assessment of the next of kin's everyday life should focus on the time aspect, so that the nursing care plan takes account of the time required for the patient's care, and whether or not the next of kin have sufficient time for relaxation and recovery.

* Professional support for next of kin should be specified in family focused nursing diagnoses, thus making it possible to linguistically deepen the search for the specific key word.

* Follow-up information to next of kin about the haemodialysis patient's health is of mainly important area. Additional modes of communication should be developed by means of IT, in order to facilitate the information flow as well as providing a meeting point for next of kin.

Implications for future research

* A future study could be done with a grounded theory method on this population to determine relationships between elements of social process of arduousness, stamina and/or independence in the context of having a spouses experiencing haemodialysis.

* The development of an instrument contributing to improved assessment of the ability of next of kin to care for the patient in the home as well as assessment of whether or not time can be made available for next of kin to spend as they wish, thus promoting their well-being is of importance.

* Continued research into next of kin's need for professional support and whether or not they wish to be involved in the care can contribute knowledge about how best to support this group.

* A future area of research might be to intervene new technology of how to develop nurses' and next of kin's communication ways in the nursing process.

SUMMARY IN SWEDISH

Kunskapen om anhörigas eget liv och deras livssituation är uppmärksammas både nationellt och internationellt. I samhället idag tar anhöriga allt större ansvar vilket i hög grad gäller kroniskt njursjuka med hemodialys. Dessutom betraktar vårdpersonal anhöriga vanligast som resurs för att hantera krav och påfrestningar som uppkommer i samband med svår sjukdom. Det finns få studier som visar på hur anhöriga upplever sin hälsa och vilka möjligheter de har till ett självständigt liv. Socialstyrelsen visar på att anhöriga är nöjda men också att de är trötta och ibland utmattade. Tröttheten utgörs snarare av psykisk belastning än av fysisk. Patienter med kronisk njursjukdom och hemodialys kan drabbas av en rad hälsoproblem som påverkar deras vardag och som även kan upplevas belastande för de närmast anhöriga. Anhöriga utför oftast ett omfattande arbete när de hjälper patienten, då kan det innebära arbete dygnet runt. Dessutom är hemodialysbehandling livsnödvändig och tidskrävande vilket oftast förändrar vardagen för patienten men även för de närmast anhöriga. För att anhöriga ska vara de personer som har kraft att ge stöd till de berörda behövs det kunskap om och förståelse för hur livssituationen påverkas när anhöriga till patienter med hemodialys engageras i vården av patienten. Få studier har undersökt anhörigas självupplevda hälsa och tid. De genomförda studierna har varit koncentrerade på andra anhöriggrupper. Övergripande syfte med avhandlingen var att utforska och beskriva vardagen hos anhöriga till patienter med hemodialysbehandling med fokus på livssituation, hälsa, tid och professionellt stöd. Studiernas design var explorativ och deskriptiv med kvalitativa analyser som baserades på de närmast anhöriga till patienter med hemodialys i Halland, Sverige. Studie I byggde på uppfattningar från 12 intervjuer med närmast anhöriga till patienter med kronisk hemodialys. Studie II och III baserades på upplevelser som kom fram i intervjuer med 13 makar/makor samt 20 närmast anhöriga till patienter med hemodialysbehandling. Studie IV grundade sig på innehållsanalys av omvårdnadsdokumentation i 50 patientjournaler till patienter med kronisk hemodialysbehandling under femårsperiod.

Studie I visade att kronisk njursjukdom med hemodialysbehandling uppfattades belastande av anhöriga men även att anhöriga var kunniga och stödjande mot patienten trots den osäkra livssituationen. Anhörigas livssituation var förändrad med tanke på bundenhet, social isolering

och rädslan för döden men det framkom att njursjukvården var tryggheten i anhörigas livssituation. Studie II påvisade att makarnas upplevelse av sin egen hälsa återspeglades i mödosamhet vid belastning på hälsan som stördes av all oro och påfrestningar när de inte vågade lämna ansvaret för den sjuke till någon utomstående. Vidare visade makarna uthållighet i hälsan när de ville klara vardagen själva för att framstå som starka individer för att skona och skydda patienten. Makarna upplevde att deras hälsa skonades när patientens beroende kunde avlastas och de kunde vara självständiga och komma ifrån både själsligt och kroppsligt. I studie III framkom att anhörigas egen tid i vardagen var begränsad till dialysfria dagar vilket hindrade dem att planera tidskrävande aktiviteter men även skapade en vardag som var anpassad till patientens behandlingstider. Tiden var utmätt till en dag i taget och till att leva i nuet. Den utmätta tiden var även kopplad till vetskapen om att sjukdomen kunde leda till döden vilket stärkte den anhöriges band till den sjuke men även hämmade de anhöriga i planering av sin egen framtid. Det förelåg behov av oavbruten tid i anhörigas vardag som var hållbar och med möjligheter till återhämtning. Studie IV identifierade innehållet i beskrivningar av professionellt stöd i omvårdnadsdokumentationen. Det framkom att stödet var fokuserat på samordning av fortsatt vård av patienten hemma och att anhöriga utgjorde en resurs när specifika omvårdnadsåtgärder planerades. Dessutom var dialogen med anhöriga nästan osynlig i omvårdnadsdokumentationen liksom att frågor om anhöriga vill vara involverade i omvårdnaden fanns inte dokumenterade. Professionellt stöd behöver dokumenteras mera samlat i omvårdnadsjournalen med ett innehåll som motsvarar beskrivningen av stöd i omvårdnad.

Sammanfattningsvis framkom i denna avhandling att när de närmast anhöriga till patienter med hemodialysbehandling blir involverade i patienternas vård upplever de mödosamhet i sin vardag med reducerad sammanhängande tid för sig själva. Vidare blir anhöriga mer medvetna om komplexiteten med patientens sjukdom vilket kräver en uthållighet i att hålla tillbaka sina egna hälsoproblem för att fokusera all tid och kraft på patientens behov. Livssituationen uppfattas av anhöriga som bunden och osäker men det finns ett engagemang hos dem för patientens hälsa och en vilja att samarbeta med njursjukvården. Professionellt stöd bör fokuseras på dialog med anhöriga angående möjligheter och hinder som finns i deras vardag när de engageras i patientens vård.

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