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Excessive Fluid Overload Among Haemodialysis Patients

Prevalence, Individual Characteristics and Self-regulation of Fluid Intake

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Abstract

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This thesis is comprised of four studies and concerns haemodialysis patients' confidence in being able to manage fluid intake between treatment sessions, and whether the fluid intake is influenced by certain modifiable characteristics of the persons in question. The overall aim was to study aspects of excessive fluid overload and haemodialysis patients' self-regulation of fluid allotment from a bio-psychosocial and behavioural medicine perspective.

The extent of non-adherence to fluid allotment was described in **Study I**. National registry data were used. Three out of ten Swedish haemodialysis patients had excessive fluid overload and one out of five was at risk for treatment related complications due to too rapid ultrafiltration rate.

The objective in **Study II** was to develop and psychometrically evaluate a self-administered scale to measure situation-specific self-efficacy to low fluid intake. The measure (the Fluid Intake Appraisal Inventory) was found to be reliable and valid in haemodialysis settings.

Subgroups based on individual profiles of self-efficacy, attentional style and depressive symptoms were explored in **Study III** using a cluster analytic approach. Three distinct subgroups were found and the subgroup structure was validated for clinical relevance. The individuals' profile concerning self-efficacy, attentional style and depressive symptoms has to be taken into account in nursing interventions designed to reduce haemodialysis patients' fluid intake.

In **Study IV**, an intervention designed to reduce haemodialysis patients' fluid intake was introduced and its acceptability, feasibility and efficacy were evaluated and discussed. Acceptability of such an intervention was confirmed. Addressing beliefs, behaviours, emotions and physical feelings is clinically feasible and may reduce haemodialysis patient's excessive fluid overload.

This thesis indicates that there is a potential for improvement in the fluid management care of haemodialysis patients. Behavioural nursing strategies that aim to assist patients to achieve fluid control should be applied more extensively. Cognitive profiles of the patients should be taken into account when targeted nursing intervention aiming to encourage and maintain the patient's fluid control is introduced.

Keywords: Behavioural medicine, fluid overload, adherence, haemodialysis, self-efficacy, attentional style, depressive symptomatology, cluster analysis, tailored treatment, quasi-experimental single-case design, Fluid Intake Appraisal Inventory (FIAI), renal nursing

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List of Papers

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

I Lindberg, M., Prütz, K-G., Lindberg, P., Wikström, B. (2009) Interdialytic weight gain and ultrafiltration rate in hemodialysis: Lessons about fluid adherence from a national registry of clinical practice. *Hemodialysis International*, 13(2):181-8

II Lindberg, M., Wikström, B., Lindberg, P. (2007) Fluid Intake Appraisal Inventory: Development and psychometric evaluation of a situation-specific measure for haemodialysis patients' self-efficacy to low fluid intake. *Journal of Psychosomatic Research*, 63(2):167-173

III Lindberg, M., Wikström, B., Lindberg, P. (2010) Subgroups of haemodialysis patients in relation to fluid intake restrictions: a cluster analytic approach. Accepted for publication in *Journal of Clinical Nursing*

IV Lindberg, M., Wikström, B., Lindberg, P. (2010) A behavioural nursing intervention for reduced fluid overload in haemodialysis patients. Acceptability, feasibility and efficacy. *Manuscript*

Front cover photograph, Klintholm Havn, Mön, Denmark. Photo by Margareta Fredriksson, 2008

Back cover photograph, the author. Photo by Inga-Lill Stenlund, 2009

Contents

Abbreviations

ANOVA	Analysis of Variance
BCM	Body Composition Monitor
BIC	Schwartz Bayesian Criterion
CES-D	Centre for Epidemiological Studies-Depression scale
CFI	Comparative Fit Index
CMIN	Minimum discrepancy
DASH	Dietary Approaches to Stop Hypertension
DOPPS	Dialysis Outcomes and Practice Patterns Study
ESRD	End-Stage Renal Disease
FIAI	Fluid Intake Appraisal Inventory
HD	Haemodialysis
IWG	Interdialytic Weight Gain
IWG%	Interdialytic Weight Gain percent of dry bodyweight
RBV	Relative Blood Volume
RMSEA	Root Mean Square Error of Approximation
SDDB	Swedish Dialysis DataBase
SRAU	Swedish Registry of Active Treatment of Uremia
TMSI	Threatening Medical Situation Inventory
WHO	World Health Organization

Key concepts and their definitions in this thesis

Key concept	Definition
Fluid overload	Ungraded retention of fluid in haemodialysis patients' body fluid compartments (total body water, blood volume, extracellular space, intracellular space, etc.) due to impaired processes in the body that regulate the excretion of water and electrolytes.
Excessive fluid overload	Retention of fluid in haemodialysis patients' body fluid compartments producing weight gain exceeding 3.5% of dry body weight.
Dry body weight	The body weight at which there are no clinical signs of fluid retention.
Fluid allotment	The amount of fluid that the haemodialysis patient is allowed to have daily.
Adherence	The haemodialysis patient's behaviour in relation to approved treatment.
Adherence to fluid allowance	Weight gain less than 3.5% of dry body weight between thrice-weekly dialysis treatments (interdialytic weight gain).

Prologue

When I completed nursing school and became an R.N., my ambition was to develop and become a good clinician in renal nursing. I was not even considering research. A few years went by and after completing in-service training, I applied for a master degree in nursing. I graduated and became the first nurse at the County hospital of Gävleborg with a Master of Science with specialized training in renal medicine. The late Professor Per-Olow Sjödén, my supervisor for the master thesis, energetically encouraged me to continue with graduate studies. Sheer curiosity during clinical work at the Department of Renal Medicine aroused a great many questions and an abundance of clinically relevant research questions were available at the time when I entered the research training program. To choose a pertinent area of current practice for this thesis, a small empirical study was carried out and the longstanding multi-factorial problem of excessive fluid overload designated as the topic. Excessive fluid overload in patients with End-Stage Renal Disease is in many ways related to demanding tasks for both the patient and the health care provider. In particular as excessive fluid overload affects the patient's daily living and treatment outcomes negatively and as it constitute a threat for patient safety during care. Further literature review identified a possible theoretical angle from which the problem could be approached. Although there is a large literature addressing the wellbeing of people with end-stage renal disease in terms of quality of life, stressors, coping and adaptation involved in using renal replacement therapies, less empirical attention has been devoted to the patients' beliefs about their capabilities (self-efficacy) to produce treatment-related self-care activities. Also, few studies have used theoretically rooted measures of self-efficacy to low fluid intake. In this thesis, a bio-psychosocial and behavioural medicine perspective was used to study haemodialysis patients' confidence in being able to manage fluid intake, and whether the fluid intake was influenced by modifiable personality characteristics such as self-efficacy.

Introduction

The burden of chronic disease on health care services worldwide is growing and the increased development of educational interventions which help patients to better manage their conditions is evident internationally. Such development has been promoted by health policies as patients have to understand and manage their conditions more on their own in order to reduce health services costs (Bag & Mollaoglu 2009, Berzins *et al.* 2009, Coster & Norman 2009). It is not clear what the active ingredients of many successful educational and self-management interventions are (Coster & Norman 2009). Some studies indicate, however, that enhanced self-efficacy particularly helps patients to self-manage problems related to chronic disease (Bag & Mollaoglu 2009, Berzins *et al.* 2009, Clark & Dodge 1999, Dunbar-Jacob 2007, Foster *et al.* 2007, Lorig *et al.* 2001, Richard 2006, Tsay & Healstead 2002).

As a health care profession, nursing has a duty to develop practices that contribute to the health and wellbeing of patients (Forbes & While 2009). To fulfil such responsibility renal nursing requires robust clinical research to show that its interventions do not cause harm, but have a beneficial effect for a sufficient numbers of patients to ensure that they are both clinically and economically worthwhile. Research within renal nursing has developed strongly and rapidly during the past few decades (Hoffart 1995, Molzahn & Sheilds 1997, Molzahn 1993). This makes it possible for renal nurses of today to provide evidence-based nursing practice (Keen 2009), i.e. to use current best evidence when making clinical decisions about patient care (Polit & Beck 2008). Like most patient groups, renal patients' involvement in their care has gradually increased over the decades and self-management has become an important part of renal care (Bag & Mollaoglu 2009, Kaptein *et al.* 2009, Richard 2006, Ricka *et al.* 2002). However, from a behavioural medicine perspective, a focus on self-management is under-represented in studies of patients given renal replacement therapy (Kaptein *et al.* 2009).

Self-management

Self-management encompasses adherence and advocates individuals being partners in their treatment, having the knowledge and skills to care for them selves, making decisions about their own care (Evans *et al.* 2004, Newmann & Litchfield 2005, Ricka *et al.* 2002), identifying problems, setting goals, and monitoring and managing symptoms (Lorig & Holman 2003, Lorig *et al.* 2001, Newmann & Litchfield 2005, Ricka *et al.* 2002). Self-management includes skills such as problem solving, decision making in response to fluctuating signs and symptoms, and taking action, e.g. learning how to change behaviour. The ability to use skills and knowledge, and to apply these to oneself when appropriate, is vital for efficient self-management (Lorig & Holman 2003, Lorig *et al.* 2001). Welch *et.al*. (2003) describes self-management for patients on hemodialysis treatment as a "process of adaptation of particularly relevant behaviours, with the underlying premise being that behaviour change does not usually occur all at once." (p.275). Non-adherence can be seen as a form of self-management deficit (Ricka *et al.* 2002, Simmons 2009) and therefore fostering sustainable strategies for self-management is an important aim for the renal care team (Newmann & Litchfield 2005, Simmons 2009).

Advanced nursing practice

In health care settings the boundaries between medical and nurse clinicians with respect to their clinical work and accountabilities are constantly being challenged due to advancing technologies and increased specialisation (Linda 2009, Merrill *et al.* 2004, Waterhouse 2002). Since the advanced clinical nurse career path was first described in the 1980's, much has been written in the literature with regard to the role of specialist nurses (Bolton 1998, Chamney *et al.* 2009, Macdonald 2007, Pearson & Peels 2002). The advanced nursing practice role is defined by the International Council of Nursing as a registered nurse who has acquired an expert knowledge base, complex decision-making skills and clinical competencies for expanded practice (Schober *et al.* 2006). Specialist nurses across a range of practice settings are a critical link in providing continuity and coordination of care (Chamney *et al.* 2009, Macdonald 2007). There is increasing evidence that specialist nurses provide efficient, cost-effective care that directly influences patient outcomes (Bolton 1998, Davis & Zuber 2009, Holley & McGuirl 2000). The existence and acceptance of expert nursing practice has been evident since Benner (1984) identified five levels of step-wise achievement of nursing competence (novice, advanced beginner, competent, proficient, and expert). Research within renal nursing has, however, reached other conclusions as the nature of expertise acquisition in this profession is made in three steps: non-expert, experienced non-expert and expert. Non-expert renal nurses demonstrate superficial renal nursing knowledge and limited experience, while experienced non-expert nurses have sufficient renal nursing knowledge and adequate experience. The expert nurses demonstrate extensive renal nursing knowledge and exercise advanced renal nursing skills and patient-focused care (Bonner 2003, 2006, 2007, Bonner & Greenwood 2006, Bonner & Walker 2004). The introduction of expert nurses responsible for renal anaemia management (Bennett & Alonso 2005, Davis & Zuber 2009, Macdonald 2007) is an example of successful advanced nursing practice in renal medicine, because it resulted in optimized patient self-management.

Renal nursing

Today, renal nursing is an established speciality directed towards individuals with impaired renal function and their families (Hoffart 2009, Polaschek 2003a). Nursing care of patients with renal failure is described in the nursing literature as early as 1915 (Gillespie 1915), but renal nursing did not emerge as a speciality until dialysis and transplant programs had been established during the 1950s and 1960s. Between 1915 and 1950, treatment was restricted to symptomatic relief and the nursing care was focused on dietary control, providing rest and administration of diuretics and digitalis. Moreover, the care was aimed at promoting extra-renal elimination of waste products as it was the only available treatment (Hoffart 2009).

Contemporary renal nursing involves many situations that require complex decision-making, skilful practice and holistic health care intervention in order to enhance the patients' own disease-management (Chamney *et al.* 2009, Murphy 2006, Ran & Hyde 1999, Richard 2006). Renal nurses work in a number of subspecialty areas including general nephrology, pre-dialysis care, haemodialysis, peritoneal dialysis, and renal transplantation. Renal nursing focuses on the health needs of individuals and their families who are experiencing a progressive decline in renal function or who have lost function completely (Murphy *et al.* 2008). Nephrology necessitates that the nurse focus on teaching self-care, prevention of related illness or complications associated with renal disease, assisting individuals to make informed choices regarding the type and location of therapy, and the provision of renal replacement therapy (Chamney *et al.* 2009, Ran & Hyde 1999).

End-Stage Renal Disease and treatment

End-Stage Renal Disease (ESRD), also known as Stage 5 Chronic Kidney Disease (Levey *et al.* 2005), is incurable and afflicts individuals of all ages, ethnic groups and socioeconomic strata. The underlying etiology is most commonly due to advanced complications of other medical conditions such as diabetes mellitus and hypertension. Other etiological factors for renal disease are for instance glomerulonephritis and polycystic kidney disease (Mallick & Gokal 1999, Meldrum 2000, Schön *et al.* 2004, Swedish Renal Registry 2009). Whatever caused the disorder, all ESRD patients face a life-threatening loss of renal functions and the patients have to face the burdens of long-term illness and numerous treatment or disease-associated stressors (Jablonski 2007, Murphy 2006). Consequently, ESRD is marked by an extreme loss of personal control, an array of acute and chronic stressors, emotional distress, and the challenge of lifelong behavioural change (Christensen & Ehlers 2002, Kara *et al.* 2007).

Upon the cessation of renal function, fluid, metabolic toxins, and electrolytes accumulate in blood and body tissue and for the preservation of life these substances must be removed by alternative means. The treatment of ESRD concentrates therefore on replacing the lost renal functions and consists of several components: a dietary prescription composed of fluid, mineral and foodstuff restrictions (Ash *et al.* 2006, Mallick & Gokal 1999); an extensive use of medications (Lindberg *et al.* 2007, Manley *et al.* 2004); and dialysis treatment (Couchoud *et al.* 2009, Mallick & Gokal 1999). Dieticians describe the renal diet as the most restrictive for any patient group, and many of the restrictions contradict current recommendations for healthy eating (Hollingdale *et al.* 2008). Current renal replacement therapies include a number of dialysis treatment alternatives or renal transplantation. In general, the choice of a particular treatment is substantially influenced by non medical factors such as patient and provider preferences and judgements about which modality is likely to be most favourable for the patient's adherence, quality of life (Christensen & Moran 1998, Lee *et al.* 2008), and at the lowest cost (Nissenson *et al.* 1997). Although a successful renal transplant is undoubtedly advantageous in terms of patient quality of life, a shortage of donor organs will result in dialysis becoming the dominating treatment. Thrice-weekly haemodialysis (HD), for four to five hours, is the most common strategy (Couchoud *et al.* 2009, Murphy *et al.* 2008) and 66 % of the Swedish incident patients (125 per million inhabitants) started with HD as their first renal replacement therapy in 2008 (Swedish Renal Registry 2009). There are an estimated 920, 000 patients on dialysis throughout the world, and this figure increases by approximately 7% per year (Chamney *et al.* 2009). In Sweden, there were 3,567 patients on dialysis on December 31, 2008 and the number of prevalent dialysis patients increases by 4-5% annually (Swedish Renal Registry 2009).

Adherence to effective treatments is an important issue in most chronic illnesses (Dunbar-Jacob *et al.* 2000, Sabaté 2003) and in the ESRD population non-adherence to treatments is a pervasive problem (Baines & Jindal 2000, Denhaerynck *et al.* 2007, Hailey & Moss 2000, Quinan 2007).

Adherence for an HD patient has been divided into three comprehensive domains consisting of a various number of subareas. Firstly, adherence to medication regimens includes subareas such as antihypertensive medication, drugs to control calcium-phosphate balance, and drugs to manage renal anaemia. Secondly, the dietary adherence domain includes subareas such as protein intake, mineral (sodium, potassium and phosphate) intake, and fluid intake while the third domain, dialysis treatment, includes subareas of attendance and completion of scheduled HD session (Kaveh & Kimmel 2001, Lamping & Campbell 1990a, b). In addition, physical activity is suggested as a forth treatment domain as it is evident that renal patients benefit from increased activity but it has not yet been adopted in treatment guidelines (Painter 2009). People undergoing treatment for ESRD are required to follow a multifaceted and comprehensive treatment that is complex and difficult to comprehend (Kaveh & Kimmel 2001, Lamping & Campbell 1990a, b). Consequently, the individual patient might be adherent in one domain (e.g. following prescribed medication) but not in another. The individual's adherence may also fluctuate within a domain (e.g. following anaemia management treatment but not calcium-phosphate treatment), which makes the magnitude of adherence complex to measure (Kaveh & Kimmel 2001, Lamping & Campbell 1990a). As a consequence, at least 50% of the HD patients are estimated to be non-adherent to some of the equally important parts of the treatment (Baines & Jindal 2000, Kaveh & Kimmel 2001, Quinan 2007). Adherence to fluid restrictions is considered the most difficult to accomplish (Johnstone & Halshaw 2003, Mallick & Gokal 1999, Newmann & Litchfield 2005, Pace 2007, Sagawa *et al.* 2003, Sharp *et al.* 2005a, Sharp *et al.* 2005b).

Fluid intake behaviour

The intake of fluids may be related to physical needs, habits, customs, social rituals, or disease. People drink to alleviate mouth dryness; to match the ingestion of food (Abuelo 1998, McKinley *et al.* 2004); or to enjoy the taste or experience the psychotropic effect of the liquid (Abuelo 1998). Fluid intake may also occur as a way to take prescribed medication and it could be a strategy to handle medication-related problems (Lindberg & Lindberg 2008). Some reports indicate that the season of the year may affect fluid consumption, with higher intake in the winter season than in summer. The reason for this variation is, however, not apparent (Cheung *et al.* 2002, Hwang *et al.* 2007, Manley & Sweeney 1986, Tozawa *et al.* 1999). Moreover, fluid intake is foremost a regulatory reaction to thirst (Abuelo 1998, Mistiaen 2001, Porcu *et al.* 2007, Sarkar *et al.* 2006), which is a physiological response to physical deficit of fluid, or to systematic hypertonicity (Charra 2007, Lindley 2009, McKinley *et al.* 2004, Raimann *et* *al.* 2008b). The sensation of thirst often results in behavioural activities such as drinking (Aarts *et al.* 2001, Abuelo 1998, Mistiaen 2001) whereas the onset of drinking results from various motivational and cognitive processes that elicits the behaviour (Aarts *et al.* 2001). Because sodium intake constitutes the main cause of osmometric thirst sensation in HD patients (Lindley 2009, Raimann *et al.* 2008b, Sarkar *et al.* 2006), an anuric patient will consume one litre of water for every 8 g salt consumed to regain haemostasis. Research findings indicate that a majority of the HD patients are drinking in response to osmometric thirst (Abuelo 1998, Lindley 2009). Consequently, sodium intake is an important part of an HD patient's fluid intake behaviour (Charra 2007, Lindley 2009, Sarkar *et al.* 2006, Tomson 2001).

Drinking considerably more fluid than recommended is, however, a familiar experience for many dialysis patients (Hecking *et al.* 2004, Ifudu *et al.* 2002, Kara *et al.* 2007, Kugler *et al.* 2005, Quinan 2007). Although patients are aware of the need to be adherent to fluid allotment despite the desire to drink normally, to not be allowed creates an uncomfortable state of ambivalence regarding drinking (Fisher 2004, Sinclair & Parker 2009, Sussmann 2001). In addition, a prescription that restricts fluid intake often generates a treatment-related stressor (Baldree *et al.* 1982, Gurklis & Menke 1988, Krespi *et al.* 2004, Mok & Tam 2001, Quinan 2007, Welch & Austin 1999, Yeh & Chou 2007) and non-adherence to permissible fluid volume is used as a strategy to reduce such stress experiences in an attempt to gain some control (Krespi *et al.* 2004, Quinan 2007, Welch & Austin 1999). The evolving tension between treatment-related constraints and the individual's effort to maintain a sense of autonomy has been described as a 'compliance independence tight rope' (Curtin *et al.* 1997, Kutner 2001, Sussmann 2001). This tension has also been associated with loss of social interaction and HD patients describe fluid management as a constant struggle, regardless if the outcome is successful or not (Sinclair & Parker 2009). Fisher (2004) has conceptualized such struggle in order to describe the psychological processes contributing to excessive fluid intake in dialysis patients. Her model assumes that there is a tension between the need to restrict fluid intake and the desire to drink. Focusing on the notion of thirst will lead to an increased sense of being thirsty. Furthermore, encountering triggers e.g. to see others drink, will start processes of monitoring the degree of thirst or other somatic sensations, which could all result in feelings of powerlessness to resist the urge to drink i.e. poor self-efficacy to fluid restriction. *Figure 1* displays an adapted description of Fishers model.

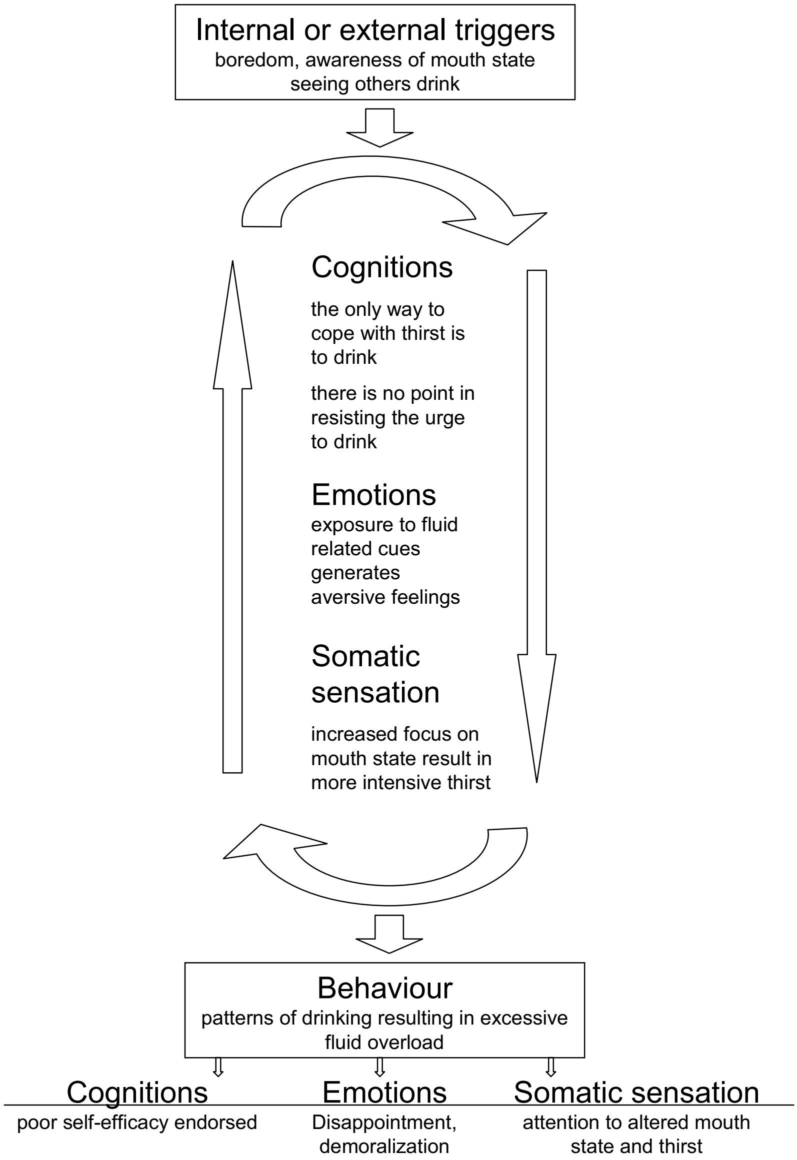

Figure 1. Adapted model from Fisher (2004) of suggested psychological processes involved in an increased perception of thirst and unhelpful drinking patterns in HD patients on a fluid restriction.

Fluid overload

Fluid retention and associated fluid surplus is a major clinical problem in individuals with ESRD (Abram *et al.* 1971, Abuelo 1998, Charra 2007, Newmann & Litchfield 2005). The urine production usually falls to insignificant amounts (Abuelo 1998) and patients with oliguria or anuria will experience weight gain between two consecutive dialysis sessions (Abuelo 1998, Davenport 2009, Tomson 2001, Welch *et al.* 2006). Fluid and food intake during the interdialytic period will increase extracellular water volume because the decreased or ceased renal function can not maintain homeostasis. Consequently, the body weight might increase by several kilograms and typically the greatest fluid overload is developed during the longer interval between treatments (Abuelo 1998, Davenport 2009, Welch *et al.* 2006). Owing to the intermittent nature of HD, the patient oscillates between a high-weight before a dialysis session starts and a low weight at the end of the session. A schematic illustration of such bi-diurnal variation of fluid status is presented in *Figure 2*.

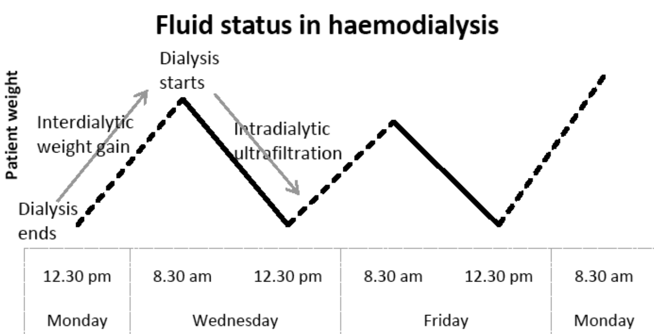

Figure 2. Illustration of the variability of fluid changes in anuric haemodialysis patients. Fluid retention between two dialysis sessions is reflected by interdialytic weight gain, which is removed via intradialytic ultrafiltration.

Fluid overload is the normal condition in most HD patients while excessive fluid overload on the other hand is linked to an increased morbidity (Holmberg & Stegmayr 2009, Leggat *et al.* 1998, Lopez-Gomez *et al.* 2005, Stegmayr *et al.* 2006) and high mortality (Banerjee *et al.* 2007, Kalantar-Zadeh *et al.* 2009, Leggat *et al.* 1998, Movilli *et al.* 2007, Ozkahya *et al.* 2006, Saran *et al.* 2003, Stegmayr *et al.* 2006). Cardiovascular disease is the leading cause of mortality with overhydration as a major contributing factor (Banerjee *et al.* 2007, Raimann *et al.* 2008b). To avoid excessive weight gain, most HD patients are recommended a strict diet and limited fluid intake in contrast to the importance of good nutrition to maintain health (Abuelo 1998, Ash *et al.* 2006, Lopez-Gomez *et al.* 2005, Testa & Plou 2001). Based on evidence and best practice, the HD patient is advised a daily fluid allowance of 500 ml plus the volume equal to daily urine output (Ash *et al.* 2006, Dietitians special interest group 2002). Consequences of excessive fluid intake and associated chronic fluid overload include intradialytic cramping and hypotensive episodes, treatment related fatigue and dizziness, lower-extremity oedema, ascites, left ventricular hypertrophy and congestive heart failure, hypertension, shortness of breath, and pulmonary vascular congestion or acute pulmonary oedema (Abuelo 1998, Charra 2007, Leggat 2005, Leggat *et al.* 1998, Mallick & Gokal 1999, Movilli *et al.* 2007, Saran *et al.* 2003). The intermittent scheduling of thrice-weekly HD treatment that most European dialysis patients receive (Couchoud *et al.* 2009) is a major contributor to such fluid overload problems (Charra 2007). A more frequent dialysis would reduce the fluid overload (Fagugli *et al.* 2006, Palmer 2009, Rayment & Bonner 2008).

Adherence to treatment

Two terms are commonly used to describe patients' engagement in their self-management of chronic disease and accompanying treatment. *Compliance* is the first and most common term for describing the phenomenon of how patients follow their treatment regimen as prescribed (Sackett & Snow 1979). This term is, however, associated with a traditional paternalistic and unequal relationship between the patient and the health care professional (Bissonnette 2008, Chin 2002, Quinan 2007, Trostle 1988) and depicts the patient as a passive responder who should obey the authorial advice. According to this designation, non-compliance may be interpreted as refusing orders or showing deviant behaviour (Bissonnette 2008).

The alternative and less censorious term is *adherence*, which according to the World Health Organization (WHO) (Sabaté 2003) is defined as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle change, corresponds with agreed recommendations from a health care provider."(Sabaté 2003, p. 17). Both compliance and adherence refer therefore to the patient's behaviour in relation to treatment requirements, although the interpretation of adherence indicates that the patient is free to decide whether to adhere to the treatment regimen or not. The failure to adhere should not solely be blamed on the patient because adherence is the product of the patient's behaviour in relation to the treatment; the health care provider's behaviour in relation to the treatment; as well as the environmental conditions under which the patient and provider operate individually and together. Adherence should be seen as the end product of a relationship that is built on respect, active participation and partnership between the patient and the health care professional, which does not involve coercion or manipulation from either party (Kugler *et al.* 2005, Morgan 2001, Richard 2006). Nevertheless, in a comprehensive concept analysis of adherence by Bisonnette (2008) no distinct differentiation between the concepts of adherence and compliance could be revealed in the nursing, medicine, psychology or pharmacy literature. This finding implies that researchers need to more carefully define what they mean when using the concepts. The terms compliance and adherence are, however, used interchangeably within research covering the treatment of ESRD although they have a different content (Hailey & Moss 2000, Morgan 2001, Richard 2006). In this thesis, the terms adherence and non-adherence will be used to describe patients' behaviour in relation to approved treatment as they relate to patient choice. The focus will be within the dietary domain concentrating on adherence to fluid allowance.

Adherence to fluid allowance

The computation of interdialytic weight gain (IWG) is claimed as a valid and objective measure of fluid restriction adherence in ESRD patients with reduced urinary output (Kugler *et al.* 2005, Leggat *et al.* 1998, Manley & Sweeney 1986, Sarkar *et al.* 2006, Wolcott *et al.* 1986) and therefore widely used as an outcome measure (Christensen *et al.* 1997a, Christensen *et al.* 2002, Kimmel *et al.* 2000, Lee & Molassiotis 2002, Pang *et al.* 2001, Sharp *et al.* 2005b, Tsay 2003, Welch *et al.* 2006).

There are two principal methods for assessing IWG (Richard 2006). The first method is mean *IWG expressed in kilograms* (Brady *et al.* 1997, Casey *et al.* 2002, Christensen *et al.* 2002, Christensen & Smith 1995, Evans *et al.* 2004, O'Connor *et al.* 2008, Sevick *et al.* 2005, Sharp *et al.* 2005b, Tsay 2003). The advantages of this computation are that it is simple to perform; the number of days between treatments is accounted for; and it allows for normal fluctuation in fluid intake during the interdialytic period. The primary disadvantage of this method is that dry weight is not considered in the calculation. The alternative method is mean *IWG expressed as percent above dry weight* (Argiles *et al.* 2004, Fisher *et al.* 2006, Holmberg & Stegmayr 2009, Ifudu *et al.* 2002, Kimmel *et al.* 2000, Santos *et al.* 2003, Saran *et al.* 2003, Sarkar *et al.* 2006, Wolcott *et al.* 1986). Some consider this a poor measure because dry weight can only be estimated, while others consider it a better alternative to measure fluid adherence because individuals with a large body mass can tolerate larger fluid weight gains than persons with a smaller body mass. There seems to be an increasing consensus that IWG should be defined as a percentage of dry weight

(Argiles *et al.* 2004, Holmberg & Stegmayr 2009, Santos *et al.* 2003, Sarkar *et al.* 2006) and this method is applied in this thesis (Table 1).

The cut-off defining fluid adherence varies through out the literature (Denhaerynck *et al.* 2007). In order to lower the risk of volume overload between thrice-weekly dialysis, IWG should be less than 2.5 kg or 3.5% of dry body weight (Holmberg & Stegmayr 2009). The cut-off used in this thesis is IWG 3.5% of dry body weight for thrice-weekly dialysis, which corresponds to a mean daily IWG % of 1.75%. A hypothetical case is described in Table 1 as an illustration of the procedure to calculate IWG% and mean daily IWG% respectively.

Table 1. *An example of the procedure used in this thesis to calculate interdialytic weight gain % of dry body weigh (IWG%) and mean daily IWG%*

Assessed weight before dialysis		88.5 Kg
Subtract postdialytic weight from previous dialysis session		86.0 Kg
Divide by dry weight		86.0 Kg
	∑	0.029
Multiply by 100	=IWG%	2.9 %
Sum IWG% for the whole week and divide by 7 (e.g. provided IWG% other days of the week is 3.2 and 4.1)		2.9+3.2+4.1=10.2 / 7
	=Mean daily IWG%	1.5 %

The role of the nurse in hemodialysis settings

Nurses involved in the dialysis process often provide care to the same patient for a lengthy period of time. This period can be as long as the patient remains in HD, for some nurses and for single patients it can be longer than thirty years (Otsubo *et al.* 2007). Consequently, the dialysis nurse has regular and frequent interactions with the HD patient and thereby the possibility to provide ongoing assessment of medical, social, and psychological concerns (Murphy 2006). Such long-term professional relationships are also ideally suited for teaching or training the patients, as well as for providing encouragement, support and preventive care (Barnett *et al.* 2008, Davis & Zuber 2009, Kovac *et al.* 2002, Yokoyama *et al.* 2009). The responsibilities of a nurse caring for a patient with a chronic disease is summarized in clinical activities were the nurse can take on several roles: an educator, an interpreter, a monitor, a modulator, and a referrer (Forbes & While 2009). More specifically, Ran and Hyde (1999) emphasize that the primary role of renal nurses is to strengthen the coping resources of dialysis patients and by such means assist the patient to achieve balance and optimal quality of life. In addition, Chamney (2007) highlights six essential nursing areas in HD settings: 1) to observe clinical signs of fluid and hydration status; 2) to educate the patient and relatives about fluid management and assist adaptation and management of nutritional needs; 3) to perform routine observations e.g. monitoring weight, blood pressure and body temperature; 4) to give psychological support and ease the social and behavioural consequences of end-stage renal disease; 5) to care for and teach the patient self-care of vascular access, i.e. their lifeline; and 6) to monitor or carry out the administration of drugs.

In Swedish dialysis units, the nursing care is generally organized in accordance with a primary nursing care model, i.e. one nurse is primarily responsible for the planning, evaluation, and care of a patient throughout the course of illness and convalescence (Ilumin 2003). The "true content" of primary nursing is, however, difficult to describe because it can be defined in many ways. According to Molzahn (1989), it is likely that there have been as many interpretations of the concept as there are dialysis units using primary nursing but the major components of autonomy, authority and accountability can be found in most of them. Nevertheless, the primary nurse plays an integral role in planning the care and coordinating the multidisciplinary collaboration among physicians, pharmacists, social workers, dieticians, physiotherapists (Carver *et al.* 2008, Ilumin 2003, Murphy 2006, Rastogi *et al.* 2008) and specialist nurses such as those dealing with anaemia (Macdonald 2007), vascular access (Waterhouse 2002), and renal bone and mineral metabolism (Limrick & McNichols-Thomas 2009).

Nursing care during dialysis

A nephrologist will administer the dialysis prescription and consultation (Daugirdas 2008, Newmann & Litchfield 2005), but the day-to-day dialysis management including execution of a safe and evidence-based treatment is the responsibility of the nurse (Ballantine & Barcellos 2004, Murphy 2006). The aim of nursing care during ongoing HD treatment is to monitor the treatment and prevent the occurrence of complications through comprehensive assessments and planning (Chamney 2007, Dasselaar 2007). Nevertheless, unplanned events will happen (Abuelo 1998, Davenport 2006, Davenport *et al.* 2008) and the role of the nurse is then to ensure early recognition and prompt intervention to protect the patient from harm (Ballantine & Barcellos 2004, Dasselaar 2007, Murphy 2006). The nurse has to complete several predialysis assessments of the patient, including weight, blood pressure, pulse, and clinical signs of dehydration (e.g. dizziness, postural hypertension and decreased skin turgor) or fluid overload (e.g. headache, dry cough, and oedema) as well as to complete an additional machine check before commencing dialysis treatment (Chamney 2007).

Removal of excess fluid during dialysis by intradialytic ultrafiltration is the cornerstone of volume management in HD patients (Abuelo 1998, Machek *et al.* 2010). This implies that the nurse performing the treatment has to ensure that the patient comes off dialysis normovolemic, which is at the dry weight. The term dry weight (also known as ideal weight or target weight) refers to the body weight at which there is no clinical evidence of fluid overload (Charra 2007, Raimann *et al.* 2008a, Raimann *et al.* 2008b, Twardowski 2009). Initial determination of the dry weight is mostly performed by the nephrologist whereas regular assessment of its accuracy is assessed by the nurse and the patient (Charra 2007, Newmann & Litchfield 2005). The dry weight is essential to enable the nurse to determine the amount of fluid removal required during dialysis. One kilogram is equal to one litre of body fluid, meaning that patient weight is a simple and accurate measure of fluid gain between dialysis treatments (Welch *et al.* 2006). The formula

actual weight – dry weight = weight gain + fluid intake during treatment = total fluid to remove during dialysis

is used to calculate the required fluid removal (Table 2). Thus, the amount of fluid that is ultra-filtrated during the subsequent HD session is equivalent to the magnitude of weight gain between treatments with supplying fluids during the treatment session added. A hypothetic clinical case is described in Table 2 as an illustration of the process of calculating required fluid removal and fluid removal rate during dialysis.

Table 2. *An example of calculated fluid removal required during haemodialysis*

Actual weight		88.5 kg
Dry weight	−	86.0 kg
Weight gain	∑	2,5 kg
Add any additional fluid intake during treatment including IV drugs	+	400ml
Total fluid to be removed	∑	2900 ml
Divide by total number of hours (e.g. 4)	⁄	725 ml/h
Divide by dry weight	⁄	86.0 kg
Ultrafiltration rate	∑	8,4 ml/kg/h
Verify if ultrafiltration is below recommended max rate (10ml/h/kg dry weight)		yes

Although thrice-weekly intermittent HD is considered a routine outpatient treatment, a common complication is intradialytic hypotension, which has been reported to occur in 16-30 % of dialysis sessions (Ballantine & Barcellos 2004, Davenport *et al.* 2008, Yung 2008). Intradialytic hypotension is defined as a fall in systolic or mean arterial pressure of 20 mmHg or greater, in combination with clinical symptoms requiring intervention (Davenport *et al.* 2008). Such hypotension event will occur if the rate of fluid removal in the dialyser exceeds the plasma refilling rate in the patient (Charra 2007, Dasselaar 2007, Twardowski 2009). Intradialytic hypotension leads to chronic overhydration and inadequate dialysis as the ultrafiltration needs to be stopped routinely. In these circumstances patients are often unable to achieve the desired ultrafiltration goal and are regularly sent home above their current dry weight, i.e. fluid overloaded (Ballantine & Barcellos 2004, Dasselaar 2007, Yung 2008). In addition, repeated episodes of intradialytic hypotension may cause cardiac fibrosis and cerebral ischemia developing lacunar infarcts (Davenport 2009). For a safe and evidence-based haemodialysis treatment, the rate of fluid removal at dialysis should be less than 10 ml/h/kg dry body weight. A higher rate is associated with an increased risk of both intradialytic hypotension and mortality (Movilli *et al.* 2007, Palmer 2009, Saran *et al.* 2006) and will be termed "inadequate ultrafiltration rate" in this thesis.

Technological aids during intradialytic ultrafiltration

Technological aids have been developed to facilitate fluid removal during dialysis. The use of ultrafiltration profiling can decrease the need of nursing interventions due to hypotension because it enhances a continuous balance between ultrafiltration rate and plasma refilling rate (Ballantine & Barcellos 2004, Davenport 2009, Palmer 2009, Yung 2008). Specially-designed dialysis profiles could deliberately use a high ultrafiltration rate in the initial part of the treatment session and then either gradually reducing the rate over the session, or sequentially use a step-down or rapid pulsating ultrafiltration and refilling mode in alternating segments. Ultrafiltration at a high initial rate (up to maximum of two litres/hour), steadily reduced during the first half of the dialysis session and then continued at a lower constant rate for the remainder of the treatment session often allows a large volume removed without inducing hemodynamic instability (Davenport 2009, Palmer 2009). A constant rate of ultrafiltration during the whole session is, however, the most common (Yung 2008). Efficient technological aids are available but used in a limited extent.

Modern HD machines with incorporated relative blood volume (RBV) monitor have increased the ability of dialysis nurses to monitor vascular refilling during dialysis and to observe the effects of nursing interventions on refilling capability (Ballantine & Barcellos 2004, Dasselaar *et al.* 2007, Lindley 2007, Lindley 2006). The values of blood volume change (in percent) at which individual patients develop hypotension vary markedly, however, from patient to patient because the measure is influenced by several physiological and medical factors (Dasselaar *et al.* 2007, Lindley 2007, Lindley 2006). Using the device is therefore quite time consuming and requires knowledge about the condition of each treated patient, which makes it rather expensive (Charra 2007, Davenport 2009). Other modern technology, such as the Body Composition Monitor (BCM), can assist nurses to determine the normohydration target. Thus patients who present intradialytic adverse events due to dehydration could have their fluid status improved by an increase of the dry weight while overhydrated patients could have their fluid overload, hypertension and antihypertensive medication reduced by slow gradual reduction of the dry-weight (Charra 2007, Machek *et al.* 2010).

Ethical aspects of haemodialysis treatment

Nephrologists and renal nurses have struggled with ethical concerns surrounding the life sustaining treatment of HD for as long as the treatment has been available. One of the overriding issues has been appropriate utilization and dialysis prescription. Technological advances, economical limitations and the annual increase of the dialysis population lead to ethical problems that are getting more complex (Hashmi & Moss 2008, Shapiro 1999, 2000). Although the majority of ethical conflicts experienced by renal nurses seem to be left unresolved (Redman *et al.* 1997), the use of interprofessional ethics rounds could extend perspectives and the awareness of reaching a solution (Svantesson *et al.* 2008). Recently, Hermsen & van der Donk (2009) asked renal nurses to describe moral problems on HD units. Ethical concerns regarding stopping or continuing dialysis were the most prominent. However, the second most common concern which involved approximately 25 % of all the expressed cases was related to patient non-adherence.

Haemodialysis is a rigorous undertaking because of what the treatment demands of the patients. It does not merely include the sacrifice of time for treatment and travel, and constant threats of morbidity and mortality, but it also demands that patients give up certain behaviours such as dictated by limited fluid allowance. To many patients, the consequences of rigid adherence could include suffering of constant thirst and sacrifice of social activities involving diet and fluid. Thus, maintaining adequate fluid intake is an extraordinary challenge that drastically changes the normal social pleasures of eating and drinking (Kara *et al.* 2007, Krespi *et al.* 2004, Newmann & Litchfield 2005, Sussmann 2001). Excessive fluid intake could contribute to impaired staff-patient relationships as well as the patient's perception of care (Fisher *et al.* 2006). Renal nurses practice under both personal and professional values (Hashmi & Moss 2008) and those who feel responsible for securing patient adherence are often frustrated in their inability to do so. It often seems that they are left with only two alternatives- either to harangue fluid restriction adherence out of patients or to ignore them (Shapiro 1999, 2000)- but these alternatives are not consistent with evidence-based practice (Keen 2009). Dedicated renal professionals will, however, try to help the patient understand and emotionally accept fluid allotments and try to improve the quality of their lives, but some patients never show any interest in treatment adequacy. In addition, some patients find it to difficult to make the sacrifices and behavioural changes required to achieve adequate dialysis. To support the patients, it is imperative to understand the personal meaning of disruptive behaviour and how they experience living with ESRD (Hashmi & Moss 2008). HD patients perceive few immediate positive effects of fluid restrictions and the only tangible effects are on their physical state (Krespi *et al.* 2004, Sinclair & Parker 2009). Consequently many patients regard the fluid restriction as an externally imposed constraint and their reaction is to "disobey" the advice (Krespi *et al.* 2004). Nursing staff tend, however, to make their own assumptions about the life experiences of those for whom they provide care and they often underestimate health status, functional status, support, and outlook (McSharry 1996, Molzahn *et al.* 1997, Sinclair & Parker 2009).

Because fluid restriction has to be applied day and night, HD patients must learn to assess their own physiological, psychological and functional state and consume fluids within the agreed allowance (Hashmi & Moss 2008, Newmann & Litchfield 2005, Richard 2006). The renal care team and the renal patients must play complementary roles in assuring patient competency to perform inevitable self-management. To succeed, the renal care team has to allow and encourage the patient to be an active, preferably proactive, member of the team as the patient's role is the most important in the team's efforts to achieve adequate dialysis (Hashmi & Moss 2008, Newmann & Litchfield 2005). An unethical behaviour is evident, however, when renal professionals are of the opinion that they have limited responsibility to provide information as part of care, and when all of the responsibility to adhere to the prescribed treatment is unreasonably transferred to the patient (Hashmi & Moss 2008, Kirk 2005, Newmann & Litchfield 2005). Friedman's position, however, is that repeated refusal to adhere to the treatment is sufficient reason to dismiss a patient, providing that evidence of mental competence and extensive efforts to explain the need for adherence have been documented (Friedman 2001). Nevertheless, guided by ethical principles renal care has to be delivered with respect for autonomy, non-maleficence, beneficence, and justice (Hashmi & Moss 2008, Kirk 2005).

Determinants of non-adherence to fluid allotments

The problem of fluid overload is multi-factorial and much attention has been focused on fluid adherence issues. In order to understand the factors associated with non-adherence to fluid restrictions and thus develop interventions to optimise adherence, previous studies have explored associations with demographical, psychological, medical and social factors. As an illustration, characteristics such as sex, ethnicity, age, educational status, and income have been investigated (Bame *et al.* 1993, Kara *et al.* 2007, Kugler *et al.* 2005, Lee & Molassiotis 2002, Morduchowicz *et al.* 1993, Pang *et al.* 2001, Richard 2006, Saran *et al.* 2003). Similarly, several personality traits (Christensen & Smith 1995, Christensen *et al.* 1996, Christensen *et al.* 1997b, Pang *et al.* 2001), important medical factors such as glycaemia status (Brady *et al.* 1997, Cvengros *et al.* 2004, Kugler *et al.* 2005), dialysis vintage and cause of ESRD have been studied in addition to psychosocial factors (Kimmel *et al.* 1998, Kutner *et al.* 2002, Pang *et al.* 2001, Saran *et al.* 2003, Sensky *et al.* 1996) such as cognitions (Evans *et al.* 2004, Sagawa *et al.* 2003, Sensky *et al.* 1996) self-efficacy (Brady *et al.* 1997, Ghaddar *et al.* 2009, Welch *et al.* 2003, Zrinyi *et al.* 2003) and social support (Kara *et al.* 2007, Kovac *et al.* 2002, Kugler *et al.* 2005, Patel *et al.* 2002, Yokoyama *et al.* 2009). Furthermore, several empirical studies have evaluated theoretical assumptions. As suggested by the Health Belief Model, HD patients' beliefs about costs of excessive drinking and benefits of fluid restriction predict subsequent changes in fluid adherence (Cummings *et al.* 1981, Ghaddar *et al.* 2009, Welch 2001, Welch *et al.* 2003). Similar findings are revealed for the somewhat similar Common Sense Model of Illness (Chilcot *et al.* 2010, O'Connor *et al.* 2008). While most HD patients are categorized in a precontemplation stage (Molaison & Yadrick 2003, Welch 2001, Welch *et al.* 2003), interventions based on the Transtheoretical Model of Health Behaviour Change do not achieve any effects on reduced fluid overload (Molaison & Yadrick 2003, Welch & Thomas-Hawkins 2005). Knowledge about dietetics and complications of non-adherence do not predict fluid non-adherence (Durose *et al.* 2004, Lamping & Campbell 1990b, Lee & Molassiotis 2002, McCloskey *et al.* 1997, O'Connor *et al.* 2008) but dietary sodium intake, dialysate sodium concentration, and other treatment-related use of sodium have a negative impact on fluid overload (Lindley 2009, Raimann *et al.* 2008b, Ritz 2006, Ritz *et al.* 2006). Furthermore, depression is found as one of the permissive factors for non-adherent behaviour in HD patients and thus related to a negative impact on health status (Christensen & Moran 1998, Cukor *et al.* 2009, Kaveh & Kimmel 2001, Pang *et al.* 2001, Taskapan *et al.* 2005).

Individuals can be characterized by distinctive cognitive styles in how they select, encode, and manage threatening health information. Some people ("attention seekers") have a tendency to search out information and focus on health treats, whereas others ("attention distracters") have a tendency to avoid information (Christensen *et al.* 1997a, Miller 1989, van Zuuren *et al.* 1996). Compared to "attention distracters", "attention seekers" report greater negative expectations about the severity, causes and consequences of medical threats (Miller 1987), which mean that "attention seekers" exhibit higher levels of distress in response to threatening health information. Thus, "attention distracters" are found less adherent and less distressed because of their low attentiveness to threat from the outside (Miller *et al.* 1996a, Miller *et al.* 1996b). On the other hand Christensen *et al* (1997a) demonstrate that HD patients judged to be "attention seekers" were less inclined to be adherent to fluid allotments. To summarize, cognitive factors may be better predictors of adherence to fluid allotment than emotional variables. Younger people, people with diabetes, people with depression, people perceiving low self-efficacy and especially people with high sodium intake are at greater risk for excessive fluid overload.

Promotive strategies for adherence to fluid allotments

Preventive measures directed to help HD patients achieve fluid control and reduce fluid overload is a more long-term undertaking than the day-to-day duty of fluid removal by ultrafiltration. Prevention or reduction of excessive fluid overload constitutes a nursing problem of interest amongst nursing researchers in Australia (Barnett *et al.* 2008), Belgium (Vlaminck *et al.* 2001), China (Lee & Molassiotis 2002, Pang *et al.* 2001), Germany (Kugler *et al.* 2005), Italy (Porcu *et al.* 2007), Iran (Baraz *et al.* 2010), Japan (Sagawa *et al.* 2003), Malaysia (Barnett *et al.* 2008), Switzerland (Denhaerynck *et al.* 2007), Taiwan (Tsay 2003), The Netherlands (Mistiaen 2001), Turkey (Kara *et al.* 2007) and the USA (Molaison & Yadrick 2003, Pace 2007, Welch & Davis 2000, Welch *et al.* 2006) but also among researchers in the fields of psychology and nutrition (Ghaddar *et al.* 2009, Hailey & Moss 2000, Sharp *et al.* 2005b, Welch & Thomas-Hawkins 2005). By reducing fluid overload, renal nursing can have a positive impact on the detrimental effects of overhydration and decrease cardiac complications (Leggat *et al.* 1998, Raimann *et al.* 2008b).

Pragmatic and effective ways of helping patients with fluid management are lacking and the results of intervention studies in this area have in general been rather disappointing (Hailey & Moss 2000, Kutner 2001, Richard 2006, Sharp *et al.* 2005a, Welch & Thomas-Hawkins 2005). The relative effectiveness of various types of intervention programs to promote fluid adherence have been reported in several reviews (Richard 2006, Sharp *et al.* 2005a, Welch & Thomas-Hawkins 2005). As these reviews only include studies disseminated until 2005, a brief description of later studies is described in Table 3. The most common form of intervention is combinations of education and behaviour therapy (Richard 2006, Sharp *et al.* 2005a, Welch & Thomas-Hawkins 2005). Most studies appear to incorporate some form of behavioural technique but many fail to report the unique components of their intervention (Sharp *et al.* 2005a, Welch & Thomas-Hawkins 2005).

Table 3. *A brief description of intervention studies addressing fluid overload disseminated from 2005 and onwards.*

First Author (Year)	Theoretical framework	Design & intervention components	Outcome
Baraz (2010)	Not specified	Randomised clinical trial; educational intervention by video two times per week for two months: ESRD dietary management; identification of appropriate provisions; fluid restrictions; consequences of fluid overload.	Fluid overload reduced
Anson (2009)	Not specified	Single-case, cognitive behavioural strategies: awareness training; motivation; increase effort; competing events; thought stopping; break repetitive routines; elicit social support; and reinforcement.	Fluid overload reduced
Sevick (2008)	Social cognitive theory	Randomized clinical trial, dietary counselling and behavioural approaches, 16 weeks: twice weekly dietary counselling; electronic self-monitoring; stimulus control; elicit social support; verbal persuasion; mastery performance; problem solving; deal with lapses and relapses.	Fluid overload reduced
Fisher (2006)	Not specified	Single-case series; cognitive behavioural therapy and motivational interviewing addressing beliefs, behaviours and physical feelings.	Mixed results, fluid overload decreased in 3 and unchanged in 2 cases
Sevick (2005)	Social cognitive theory	Single-case series; behavioural approaches, 4 months; dietary self-monitoring; once/twice or biweekly dietary counselling; develop understanding of dietary adherence; establish stepped achievable goals; evaluate and reformulate goals; identify barriers; elicit social support.	Mixed results, fluid overload increased for 2 cases, was unchanged for 2 and decreased for 1 case
Sharp (2005b)	Not specified	Randomised clinical trial, cognitive behavioural therapy, 4 weeks: educational components; behavioural techniques; self-monitoring; environment control; goal setting; self-regulation.	Fluid overload unchanged post-treatment, reduced 10 week follow-up

Less elaborated regular reminders during ongoing dialysis regarding the importance and components of fluid and salt restrictions can result in significant and sustained improvements in IWG (Baraz *et al.* 2010, Barnett *et al.* 2008). Such a strategy included structured 10 min oral sessions each week for two months (Barnett *et al.* 2008) or a 30 min video two times per week for two months (Baraz *et al.* 2010). In contrast, common educational interventions do not decrease fluid overload (Casey *et al.* 2002, Molaison & Yadrick 2003, Richard 2006). Interactive programs addressing psychosocial and emotional needs (Christensen *et al.* 2002, Sagawa *et al.* 2003, Tsay 2003) and structured psychological approaches aimed at helping patients to change their beliefs, and thus develop healthy behaviours, have been used with some success to improve fluid management (Anson *et al.* 2009, Fisher *et al.* 2006, Hegel *et al.* 1992, Sevick *et al.* 2005, Sevick *et al.* 2008, Sharp *et al.* 2005b).

Although attentional cognitive styles have not been taken into account in any intervention study aimed at enhancing adherence to treatment, they have been recognized, for instance, in patient educational interventions (van Vliet *et al.* 2006, van Zuuren *et al.* 2006), a doctor-cancer patient communication intervention (Ong *et al.* 2000), and a cancer rehabilitation intervention (Petersson *et al.* 2002). Considering the importance of fluid control to the health of HD patients, further development is needed because few studies have revealed clinically important results. To circumvent some methodological weaknesses in previous research, it is important that theoretical models (Welch & Thomas-Hawkins 2005), patient-related factors (Richard 2006) and health system-related factors (Kammerer *et al.* 2007) guide further development of interventions studies addressing fluid overload.

Theoretical framework for this thesis

In order to understand psychological influences on how people stay healthy, why they become ill, and how they respond when they do become ill, it is of fundamental importance to define health and etiology. There is a biomedical component in health, but it exists in a setting that includes biological, personal, relational, social and political factors (Davies 2007). With such a perspective, the WHO definition “Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization 1948) is rather outdated. Davies (2007) proposes that “health is best seen as an ongoing outcome from the continuing process of living life well. Living life well would be defined in terms of wealth, relationships, coherence, fitness, and adaptability, with disease avoidance playing only a minor part” (p.450).

The biomedical model and the biopsychosocial model are commonly used to describe the interplay between health and illness. In the biomedical model all diseases are considered to be of physical origin that can be explained on the basis of aberrant physiological processes such as biochemical imbalances, neurophysiological abnormalities, and bacterial or viral infection. The biomedical model is, however, reductionistic in that it assumes that the disorder can be repaired or replaced and that illness is separate from psychological and social processes of the mind, all of which make the biomedical model disadvantageous to use in chronic diseases.

Biopsychosocial model

The biopsychosocial dimension of illness was introduced by Engel (1977) in the late 1970's and its core value is in guiding parsimonious application of medical knowledge to the needs of each patient. The philosophy of this model gives understanding of how suffering, disease and illness are affected by biological, psychological and social factors. Such influence dictates the patient to be an active mediator of change i.e. the behavioural dimension of illness. The model also gives a practical understanding of the patient's subjective experience of illness and the management of chronic medical problems. Hence, the biopsychosocial model considers psychological factors not only as possible consequences of illness, but also as contributing factors to its cause and maintenance. The biopsychosocial framework is included in several social-cognitive models of health behaviour e.g. the self-efficacy theory and the social learning theory (Bandura 2004) and its predictive value on patients' adherence to health-promoting or treatment behaviours have been supported by a large body of empirical findings summarized in reviews by Di Matteo *et al.* (2007) and AbuSabha & Achterberg (1997).

Self-efficacy theory

The conceptual system forming Bandura's (1977, 1982, 1991, 1997, 2004) self-efficacy theory (*Figure 3*) includes the characteristics of a person, the behaviour of the person and the outcomes of the behaviour. It also includes the person's efficacy expectations and outcome expectations. An outcome expectation is the person's estimate that a given behaviour will lead to a specific outcome and can take the form of physical, social or self-evaluative effects. An efficacy expectation concerns the confidence in one's capability to accomplish a specific behaviour and its magnitude and strength of this aspect will determine how much effort people will mobilize and their level of persistence (Bandura 1991). In other words, the essence in the self-efficacy theory is that the expectations of personal mastery and success determine whether an individual will engage in a particular behaviour. This means that self-efficacy is a temporary characteristic, capable of being influenced and related to situations and tasks. Moreover, the self-efficacy theory helps to explain the discrepancy between an individual's knowledge and behaviour, even though the person is fully aware of what should be done (Bandura 1982).

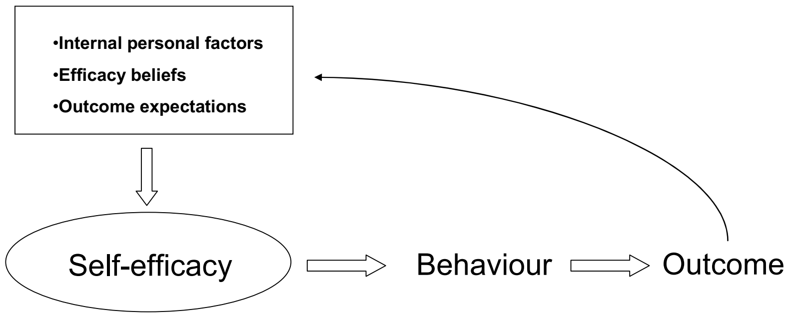

Figure 3. Adapted model from Bandura (1997, 2004) of the proposed causal relationship between self-efficacy and outcome

Self-efficacy and health behaviour/adherence

The underlying variables that constitute the concept of self-efficacy appear to predict change and maintenance of health-promoting behaviours (AbuSabha & Achterberg 1997, DiMatteo *et al.* 2007, Strecher *et al.* 1986). Self-efficacy is an important but task specific determinant of health behaviour because the posited sociocognitive causal model described by Bandura (2004) includes paths wherein self-efficacy affects health behaviour both directly and through its impact on other determinants. Self-efficacy is, however, often confused with closely related constructs that often describe more generalized personality traits such as self-esteem and self-confidence. AbuSabha & Achterberg (1997) emphasize that it is the specificity attribute of self-efficacy that distinguishes it from most other constructs. Thus self-efficacy aids in the adoption and maintenance of health promoting behaviours as well as in the control of risky health habits. Individuals with high self-efficacy overcome obstacles by improvement of self-management skills and stay the course in the face of difficulties. Whereas those of low sense of efficacy do not try to adopt healthy practices and if they do try, they quickly abandon their efforts if success is not immediately achieved (Bandura 2004).

Measurement of self-efficacy

Self-efficacy is estimated by obtaining ratings of its three dimensions, namely magnitude, strength and generality (Bandura 1997). The magnitude dimension refers to the judgement a person has on performing a specific behaviour and tasks are ordered according to their level of difficulty; strength refers to the confidence level a person has in performing the specific behaviour; and generality refers to the degree self-efficacy varies across type of activity and domains of functioning in which people judge themselves as efficacious. To measure these dimensions, individuals are presented with a list of specific behaviours or tasks reflecting various levels of difficulty and are asked to rate the strength of their belief in their ability to accomplish each task. Bandura (2006a) states that scales measuring self-efficacy must be tailored to the particular object of interest because the concept is not a global trait. People differ in how they think, feel, motivate themselves and how they act in various activities. Therefore, a measurement of perceived self-efficacy in an all-purposive global scale usually has limited explanatory and predictive value. Although a general focus on mastery is applied in some studies focusing on adherence to ESRD treatment (Oka & Chaboyer 2001, Takaki *et al.* 2003, Tanner *et al.* 1998). Other studies (Brady *et al.* 1997, Zrinyi *et al.* 2003) have adapted a more or less domain specific measure. The questionnaire used by Brady *et al* (1997) is described as a proper and theoretically consistent fluid adherence self-efficacy measure. The original was, however, unpublished. Consequently, a scale to measure situation specific self-efficacy for constructive fluid intake behaviour in HD settings was lacking.

A behavioural medicine approach

In order to treat health problems properly, health care providers need to understand the social and psychological factors that contribute to an illness and the promotion of healthy habits. Active self-management is the key to successful control of a chronic disease. The patient's belief that s/he is able to control a particular behaviour (i.e. self-efficacy) is an important determinant for the practice of health behaviours. Human behaviour, however, is complex. By applying a biopsychosocial perspective the behaviour is understood from physiological, psychological, behavioural and contextual aspects. Behaviour is viewed as dynamic and in constant interaction between the individual and the environment. The functional interdependence between internal personal factors (i.e. cognitive, emotional and physiological events), the external environment, and the human behaviour is conceptualized in the notion of "the triadic reciprocal causation" (Bandura 1997). Behavioural medicine is defined as "the interdisciplinary field concerned with the development and integration of behavioural, psychosocial, and biomedical science knowledge and techniques relevant to the understanding of health and illness, and the application of this knowledge and these techniques to prevention, diagnosis, treatment and rehabilitation" (Society of Behavioral Medicine 2010).

A more full understanding of HD patients' fluid intake could be gained by applying a bio-psychosocial and behavioural medicine perspective. In particular, the influence of self-efficacy and other psychological factors is highlighted in the HD treatment context. Such a basis for understanding also involves the interplay between professionals and patients, especially during development of clinically applicable methods to promote the individuals ability to exercise self-management of distress and annoyance related to the limited fluid allowance. Until now, few studies have applied these perspectives in renal nursing and therefore this thesis focus on prevalence of non-adherence to fluid allotments and modifiable individual characteristics related to self-regulation of fluid intake.

Aims

The overall aim of this thesis was to study aspects of excessive fluid overload and haemodialysis patients' self-regulation of fluid allotments from a bio-psychosocial and behavioural medicine perspective.

Specific aims for the studies in this thesis were;

Study I
The aim of **Study I** was to describe the extent of non-adherence behaviour to fluid restrictions among haemodialysis patients, and to describe the extent to which inadequate ultrafiltration rates were set by renal nurses during dialysis.

Study II
The aim of **Study II** was to develop and evaluate the psychometric properties of a self-administered scale intended to measure situation-specific self-efficacy to low fluid intake for use in haemodialysis settings.

Study III
The aim of **Study III** was to determine whether distinct subgroups exist within a sample of haemodialysis patients with regard to self-efficacy, attentional style and depressive symptomatology and to validate clinical relevance of the subgroup-structure.

Study IV
The aim of **Study IV** was to introduce, evaluate and discuss acceptability, feasibility and efficacy of a social-cognitive intervention programme designed to reduce haemodialysis patients' fluid intake.

Methods

Design

The PhD-project was initiated in 2004 and concerned haemodialysis patients' confidence in being able to manage fluid intake between haemodialysis treatments, and whether the fluid intake was influenced by certain modifiable personality characteristics. Four empirical studies (**I-IV**) are included in this thesis. **Study I** deals with estimation of prevalence regarding excessive fluid overload and a repeated cross-sectional observational design was used. In **Study II and III** a cross-sectional multi-centre survey was used for methodological (**II**) and explorative (**III**) purposes. **Study IV** comprised a single case series in an AABA format with distinct phases (Kazdin 1982, 2010). The initial A-phases consisted of baseline and recruitment; B was the intervention phase; and the third A-phase was an untreated post-intervention follow-up were subjects are supposed to perform learned skills on their own. The first three studies comprise four independent samples. An additional four individual participants with excessive fluid overload were included in **Study IV**. An unobtrusive research method (Kazdin 2010) was used in **Study I**, i.e. data was not directly elicited from respondents. All subjects in the studies **II-IV** were recruited when attending for scheduled treatment at Swedish haemodialysis unit. An overview of the studies is presented in Table 4.

Table 4. *Overview of study design sample and data sources used in the studies.*

Study	Design	Sample	Data source
I	Repeated cross-sectional observational	9,633 treatment observations of 4,498 haemodialysis patients	Annual national registry data
II	Cross-sectional, multi-centre survey	144 haemodialysis patients	Questionnaires and medical record
III	Explorative cross-sectional multi-centre survey	133 haemodialysis patients	Questionnaires, proxy assessment and medical record
IV	AABA single-case quasi-experimental	4 haemodialysis patients	Questionnaires and medical record

Subjects and procedures

Study I included 4,498 subjects registered in The Swedish Registry of Active Treatment of Uremia (SRAU) and registered at least once in the Swedish Dialysis DataBase (SDDB) in the years 2002-2006. In brief, SRAU consists of epidemiological data for renal morbidity and co-morbidity, and SDDB consists of cross-sectional data of dialysis treatment. According to a validation procedure in 2006, the SDDB covered about 95 % of the Swedish HD population. Data regarding gender, age, primary renal disease, diuretic use, years on dialysis program, duration of dialysis session, height, body weight before dialysis and dry body weight were extracted from the registries for all subjects aged 18 and above and on regular treatment with HD 3 times per week. A selection of variables describing the participants is presented in Table 5.

Table 5. *Participant characteristics in study I-III*

	Study I, n=4498	Study II, n=144	Study III, n=133
Gender, male/female %	63/37	61/39	62/38
Age, mean (SD) years	64.8 (14.4)	65.4 (13.8)	64.8 (14.0)
Dialysis vintage mean (SD) years	4.7 (5.4)	5.4 (6.6)	5.7 (6.7)
Renal disease history, mean (SD) years	Not recorded	13.3 (13.4)	13.2 (13.4)
Dry weight, mean (SD)Kg	72.1 (16.1)	73.9 (16.1)	74.1 (16.5)
IWG%, mean (SD)	2.8 (1.7)	3.1 (1.2)	3.1 (1.2)

In **Study II**, covering the development and evaluation of a questionnaire, three independent samples were used of which two were used in the development process and the third in the evaluation phase. All subjects were recruited consecutively among persons treated with HD at a total of 14 Swedish dialysis centres. In the two samples used during the development, 15 subjects from one centre agreed to participate in the interpretability test, i.e. to eliminate ambiguous or incomprehensive items (Streiner & Norman 2008), and 37 subjects from two centres agreed to participate to examine the face validity of proposed questions. The evaluation phase included estimation of construct validity and psychometrics such as criterion-related validity and internal consistency. Informed consent was obtained from 144 subjects (Table 5), and this corresponded to a response rate of 65% at 11 dialysis centres. To be included, the patient had to be at least 18 years old, have sufficient knowledge of Swedish, and had to be able to answer the questions by themselves. In addition, in order to achieve a homogenous group with stable dialysis treatment and similar interdialytic weight gains, the patients had to have had HD treatment 3-4 times per week for at least six months. Data were collected using two self-report questionnaires in combination with extraction from the medical record regarding weight measurements before and after each dialysis session during one month.

Study III comprised the same sample (Table 5) as the one in the evaluation phase of Study II. The 133 subjects who provided data on all self-report measurements were included (63 % response rate). Data were collected by three self-report questionnaires. A brief self-report form comprising demographics and data on interdialytic weight gain from medical records was also used.

Study IV included four HD patients with excessive fluid overload. Patients were regarded by nursing staff or physicians as having persistent problems with fluid management. Inclusion was restricted to outpatients >18 years of age; undergoing HD treatment for at least three months before entry; IWG >3.5% of the current dry weight; and to patients clinically stable during ongoing HD treatment. The subjects were fully aware that fluid restriction is essential in the treatment of ESRD and they expressed a constant struggle limiting fluid intake as well as disappointment about their limited success in reducing fluid intake between dialysis sessions. Their respective ages were 62, 63, 66 and 80. There were three men and one woman. Diabetes mellitus or glomerulonephritis was their primary kidney disease; three had haemodiafiltration treatment and one had HD treatment; and dialysis vintage ranged between 18 and 69 months. Further characteristics of the subjects are presented in Table 6. Data collection methods were extraction of weight registrations in medical record and self-report questionnaires.

Table 6. *Participant characteristics at baseline in study IV*

	Participant A	Participant B	Participant C	Participant D
Dry weight, Kg	99.5	87.0	112.5	114.5
Marital status	Married	Widowed	Married	Cohabiting
Occupational status	Retirement pension	Retirement pension	Sickness pension	Part-time work
Urine output, dl/day	7	3-5	<3	0
Diuretic use, defined daily dose ddd/day	25	25	0	0
HbA1c%	4.9	4.6	N/A	N/A
Plasma sodium, mmol/l	136	140	138	139
Sodium dialysate mmol/l	140	140	142	140
Dietary sodium intake, index/week	50.5	45.5	40.5	32.5
Drug sodium intake, mmol/day	74	102	2	25

The intervention in study IV

A social-cognitive framework that addressed beliefs, behaviours and emotional and physical feelings was used to elicit and assess the relative contribution of self-reported factors influencing thirst and drinking. Each patient was given up to eight treatment sessions and an additional booster session. Standard dietetic advice regarding sodium intake was reinforced during the intervention period. The advice for reducing dietary sodium intake emanates from the DASH-diet tips (Lindley 2009) and may include using fresh food rather than canned, smoked or processed products; strategies to avoid instant or flavoured products; or encouragement and reminders to check nutrition labels to find products with lower sodium content. Standard advice for thirst management was also reinforced and included established strategies such as limiting salt intake, using ice chips, measuring daily allotment, performing mouth care, eating raw or frozen fruits and vegetables, sucking on acid drops and chewing gum (Bots *et al.* 2005, Jacob & Locking-Cusolito 2004). Thus, promoted self-regulation strategies included pre-planning, substitution, dietary modification, situational control, distraction, and record keeping in order reducing fluid intake (Welch & Davis 2000). During the intervention period interdialytic weight gains were recorded for patients as feedback. All gains below the individualized criterion for that time were highlighted and graphs indicating the dry weight gain threshold were used.

The programme comprises five phases: individualized analysis, basic skill acquisition, applied skills acquisition, generalization, and maintenance. The phases could overlap in time, but their respective component is distinct. Patients were seen on an outpatient basis during ongoing HD treatment, usually once a week. Sessions included instruction and monitoring of homework assignments and skill application as well as discussion and monitoring of problem-solving skills. The number of sessions was adjusted according to the participant's requirements. The following areas made up the treatment programme.

1. *Individualized analysis* based on self-report data, the nurse's assessment of the nature and extent of problems presented by the patient, as well as formulation of specific and measurable treatment goals. This area included components such as the history of fluid intake behaviour, reports of physiological symptoms, gathering of self-report data on self-efficacy (**Study II**), attentional style (van Zuuren *et al.* 1996), depressive symptomatology (Andresen *et al.* 1994), examination of dietetic knowledge, investigation of sodium and fluid consumption, analysis of cognitions and its relation to fluid intake, and experienced symptomatology. The individualized analysis was used to understand the problems of individual patients in order to derive a treatment based upon the individual circumstances and motivations of problems aroused. This made it possible to identify reinforcers and cues linked to fluid intake behaviour, i.e. to provide a profile of situation specific fluid intake behaviour and personal triggering circumstances for fluid intake in order to elicit relevant dietetic and psychosocial factors. Specific and measurable goals were stated in concordance between the patient and the investigator. Complete data processing could require a couple of weeks.

2. *Basic skill acquisition*.
This area refers to acquisition of skills considered necessary for goal attainment. Skills were in all cases related to the behavioural goal of fluid limitation. The recognition of negative interpretations and cognitions was

practiced. Self-efficacy related to fluid intake behaviour in specified locations, activities or situations was reinforced. The purpose of each homework assignment was clarified and basic education in renal function and fluid balance was given as needed. A situation diary was introduced as soon as basic skills exercises were started. The diary served two important functions: it was an indicator of adherence to skill training and it served as a tool for the nurse to check, shape, and reinforce the patient's efforts and progress.

3. *Applied skills acquisition*
In this phase, basic skills are applied in more complex situations that were conceived to represent the challenges the patient may encounter in daily life. The choice was based on patient's self-recordings of situations connected with fluid intake.

4. *Generalization of skills to daily life*
This phase included systematic and programmed interventions to make sure that learned skills were applied in situations reported to be connected to fluid intake. A list of these situations was constructed and the patient was asked to rank them according to difficulty. Practice of learned skills then started in the activity ranked as the least difficult. Practice in real life was noted in a diary. When the patient felt confident about using skills in a situation, practice started in the next situation on the list, using the same procedure until the patient mastered all situations. Exactly how and when the generalization component was administered was tailored to each individual patient.

5. *Maintenance including relapse prevention*
This phase included determination of what type of regular self-management regime would suit the patient, the identification of possible high-risk situations for relapse, and planning of how the latter should be dealt with. These actions resulted in a personal maintenance programme, in writing, to which the patient could henceforth refer to.

Measures

Study I:

Necessary data was obtained from the national population-based renal registry (SDDB). IWG was calculated as percent of dry body weight (see Table 1). Ultrafiltration rate during the dialysis session was calculated as ml/h/kg dry body weight (see Table 2).

Study II:

The instrument "Self-efficacy for Managing Chronic Disease" was developed for the Chronic Disease Self-management Study (Lorig *et al.* 2001) and is considered as reliable and valid (Lorig *et al.* 2001, Lorig *et al.* 1996). Bandura (2006b) recommends this instrument for assessment of chronic disease self-efficacy. The instrument is a six-item scale covering symptom control, role function, emotional function, and communicating with physicians. In this study, it was employed as a general self-efficacy measure and used in validation procedures.

The Fluid Intake Appraisal Inventory (FIAI) was developed and evaluated in this study as a situation-specific self-efficacy measure. The FIAI consists of 33 items allocated to four factors (physiological, affective, social, and environmental). This a priori allocation was based on theoretical considerations in order to capture the generality dimension of self-efficacy to low fluid intake. The FIAI measures situation-specific self-efficacy to low fluid intake in HD patients. IWG% was used in validation procedures.

Study III:

The following instruments were used in combination with demographical data and data from medical records.

The Threatening Medical Situation Inventory (TMSI) (van Zuuren *et al.* 1996) was used to measure cognitive confrontation/avoidance coping style to medical threats. This instrument consists of four descriptions of medically threatening situations (stressors) and each scenario includes three monitoring and three blunting alternatives in random order to be answered on a five point scale. Total scores are obtained by summing the monitoring and blunting alternatives separately, i.e. a sum ranging 12-60 is calculated for a monitoring and a blunting subscale. The scale is found to be theoretically sound; it has a stable factor structure and it is shown to be internally consistent in different samples. The subscales Cronbach's alpha coefficient is ranging between 0.78 and 0.86 in various samples (van Zuuren *et al.* 1996).

The Centre of Epidemiological Studies – Depression scale (CES-D) (Radloff 1977) was used to measure symptoms of depression. The validated short ten item version (Andresen *et al.* 1994, Hyre *et al.* 2008) assesses frequency of depressive symptoms over the past week. Points for response options are coded on a scale ranging from zero (none of the time) to three (all of the time), with two items reversed in scoring. Overall scores are obtained through summation of the items, ranging from 0 to 30. Higher CES-D scores represent greater occurrence of depressive symptoms. A sum >10 is considered to indicate possible depression (Hyre *et al.* 2008, Lopes *et al.* 2004). Internal consistency (alpha 0.72) and confirmatory factor analysis indicates adequate reliability and validity respectively (Lee & Chokkanathan 2008).

The Fluid Intake Appraisal Inventory (FIAI) was developed and evaluated in **Study II** and measures situation-specific self-efficacy. The response format is a numerical rating scale where 0= not at all confident and 10=totally confident. Internal consistency is desirable high (Cronbach's alpha 0.96), and the criterion-related validity and known-group validity is supported in Swedish (**Study II**) and Portuguese (Lindberg & Agostinho 2010) HD contexts.

Demographic data included gender, year of birth, year of first dialysis session (to calculate dialysis vintage), self-reported daily urine-volume (coded into a ordinal scale from "less than three decilitre" to "more than one litre"), and a question aimed to check for any advice regarding fluid intake received during the past six months (yes vs. no). Data were obtained regarding weights before and after dialysis the previous month from the medical record.

Study IV

Study IV used repeated measurements of fluid intake behaviour during four phases: baseline (phase A_1, lasting five weeks), recruitment (phase A_2, two weeks), intervention (phase B, six to eight weeks) and post-intervention (phase A_3, eight weeks). One booster session was given four weeks after termination of the intervention and was included in the post-intervention phase.

The primary outcome measure used was IWG% per day (see Table 1). Weights are recorded at each dialysis session as a part of the routine treatment and consequently data were available in the participant's medical record.

Data management and statistical procedures

In **Study I**, descriptive statistics were reported regarding registry data from five annual cross-sectional cohorts. Prevalence of non-adherence was estimated and the chi-square test was used to test differences in proportions between the cohorts. Depending on the kind of data used, repeated measures ANOVAs or one way ANOVAs were used to evaluate the pattern over time, and significant differences were further analyzed with Bonferroni post hoc test (Brace *et al.* 2006, Howell 2010).

In **Study II** the aim was to evaluate psychometric properties of the developed measure of situation specific self-efficacy. Face validity is crucial in a self-efficacy scale (Bandura 2006a); hence the evaluation procedure included insurance of item sufficiency. Cronbach's alpha coefficient was calculated to determine internal consistency reliability. Criterion-related validity (Streiner & Norman 2008) tested how the scale related to other variables as hypothesized by the self-efficacy theory. The Spearman's Rho was used to test concurrent validity, i.e. the correlation between situation specific scoring of self-efficacy and general self-efficacy scores. Moreover, subgroups of adherent and non-adherent patients were constituted to evaluate the known-group validity (Polit & Beck 2008) with the independent t-test. Furthermore, structural validity was tested through first-order confirmatory factor analysis (Byrne 2005).

In **Study III**, occasional missing items were imputed to obtain complete data sets. The means of individual values observed on each scale or subscale substituted missing data in 31 % of the subjects and 1.4 % of all items. A two-step cluster analysis (Norusis 2004) was conducted to delineate natural groupings within data (Aldenderfer & Blashfield 1984). Self-efficacy (FIAI), attentional style (TMSI) and depressive symptoms (CES-D) were used as clustering variables. Cluster analysis assumes independent variables, and bivariate correlations by Pearson's correlation coefficient were therefore computed. The correlation coefficients ranged from $r=-0.015$ to $r=0.188$, which indicate satisfactory independence among the clustering variables.

In two-step cluster analysis, the data records are automatically standardized and then scanned one by one to decide if the current record could be merged with the previously formed pre-clusters, or if a new record, based on the log-likelihood distance criterion, should be started. The log-likelihood measure is a probability based distance measure and cases are assigned to the pre-cluster that leads to the largest log-likelihood. Subsequently, an agglomerative hierarchical clustering method is used to form clusters by treating the pre-clusters as a single entity. The optimal number of clusters is automatically selected by an algorithm based on the Schwartz Bayesian Criterion (BIC). The clustering algorithm gives the best result if all variables are independent and if the continuous variables are normally distributed. However, the algorithm is fairly robust even if these assumptions are violated (Norusis 2004).

Cluster analytic methods will always produce clusters and therefore it is essential to validate the clinical meaningfulness of the results in its context

(Aldenderfer & Blashfield 1984, Beckstead 2002, Hair & Black 2000). Validation by demographics and a criterion related validation were conducted as one way ANOVA were used for comparing clusters on ratio data, and Pearson's chi-square tests were used for nominal data. Significant mean differences (ANOVA) were further analysed by pair-wise, multiple comparisons using the Tukey's honestly significance difference test (Howell 2010).

In **Study IV**, descriptions of the participants' acceptability of the content, intensity, duration and the timing of the intervention were summarized descriptively. The feasibility analysis searched for barriers in the procedures of intervention delivery, in the environment around the delivery and in inclusion procedures (Craig *et al.* 2008, Resnick *et al.* 2005). The findings were summarized descriptively.

To analyse efficacy, the initial individualized analysis and scores on outcome measures (IWG and self-efficacy) were presented descriptively. Data of the outcome (IWG) were plotted graphically and visual inspection of changes in level, trend, and latency of change across the phases was applied to judge any intervention effect (Kazdin 1982, 2010). The criteria for graphical data evaluation in single-case designs are presented in (Table 7). The Microsoft Office Excel 2007 for Windows was used for plotting purpose (Dixon *et al.* 2009).

Table 7. *Criteria for graphical data evaluation in single-case designs (Kazdin 2010)*

Characteristics related to magnitude of change and rate	Definition
Changes in means	The mean rate of the behaviour shows a change from phase to phase in the expected direction.
Change in level	When one phase changes to another, a level refers to the change in behaviour from the last data point of one phase and the first data point of the next phase. An abrupt shift facilitates data interpretation.
Change in trend	The direction of the trend changes from phase to phase.
Latency of change	The speed with which change occurs once the condition are changed.

Results

A summary of the findings in studies (**I-IV**) is provided below, respectively.

Study I

The results indicate that non-adherence to fluid management was common in the Swedish HD population. The prevalence of non-adherence to fluid restriction was estimated to be about 30 %, meaning that three out of ten HD patients have a weight gain exceeding 3.5 % of dry body weight between dialysis sessions. The prevalence of non-adherence to fluid restrictions differs (χ^2=28.68(df4), p<.001) between the five cross-sectional measurements and there is a tendency for lower frequency in more recent years. Estimated prevalence per annual measurement is presented in *Figure 4*.

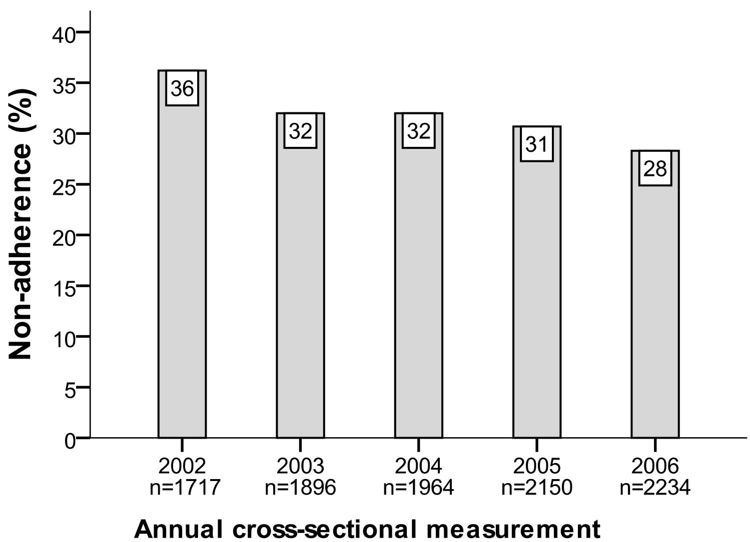

Figure 4. Estimated prevalence of haemodialysis patients' non-adherence to fluid restrictions (IWG >3.5% dry body weight)

Inadequate ultrafiltration rate was common as one of five HD patients with weight gain between the dialysis sessions was at risk for intradialytic hypotension and mortality during treatment monitored by nurses. That is, 15-20 % of the patients were constantly exposed to an ultrafiltration rate exceeding the cut off point usually associated with mortality risk (10 ml/h/Kg). There was no difference in proportion (χ^2 6.721 (df4), p=0.151) over the years. The patients had either consumed more fluid than could be removed at lower rates during the treatment, or the treatment time was too short for the needed removal of fluids. Estimated prevalence per annual measurement is presented in *Figure 5*.

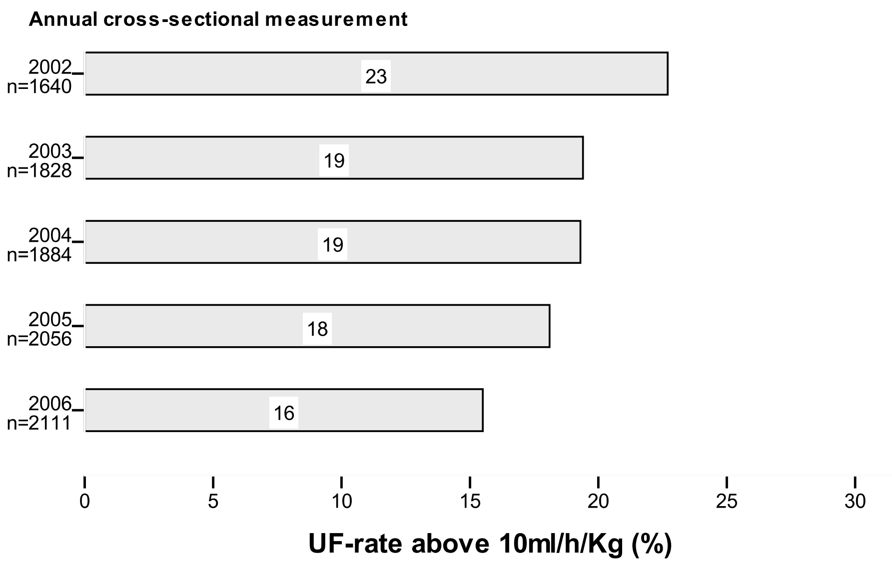

Figure 5. Estimated prevalence of nurse performed ultrafiltration (UF) rate above 10 ml/h/Kg on patients with excess fluid by annual cohort

Study II

A situation specific measure for HD patients' self-efficacy to low fluid intake was developed. **Study II** was conducted to estimate the reliability and validity of the Fluid Intake Appraisal Inventory (FIAI). Examined psychometric properties had satisfactory results. The final scale comprised 33 items that were theoretically divided into four subscales (factors). Cronbach's alpha coefficients were calculated for each subscale (α=0.85-0.92) and for the total scale (α=0.96), which indicates that the FIAI have high internal consistency. That is, items proposed to measure the same general construct produce similar scores. The scales mean inter-item correlation was r=0.46 (range 0.13-0.96) and the corrected item total correlation ranged from 0.46 to 0.75.

The theoretical assumptions for criterion-related validity were supported in that 1) the situation specific self-efficacy (FIAI) was significantly correlated (rs=0.315 p<0.001) to a general self-efficacy measure; 2) the FIAI was significantly correlated (rs=-0.246 p=0.003) to IWG%; while 3) the general self-efficacy measure was nearly un-correlated (rs=-0.005 p=0.950) to IWG%. A significant difference in FIAI-ratings (p=0.001) was found between adherent and non-adherent patients. More specifically, individuals with higher self-efficacy were more disposed to be adherent to fluid intake allotments, as hypothesized. The structural validity of the FIAI was, however, not confirmed because the postulated relation among variables was only partly supported (CMIN=2087, df=489, p<0.001; CMIN/df=4.27; CFI=0.605; RMSEA=0.151; RMSEA 90% CI ranged between 0.144-0.157) indicating that the hypothesized four-factor model was inadequate. Although not compatible with the a priori theoretical structure, the FIAI can nevertheless be used in research and in clinical settings to measure HD patients' self-efficacy to low fluid intake.

Study III

HD patients' profiles regarding self-efficacy, attentional style and depressive symptoms were explored and clusters were defined. The clusters were confirmed to relate to HD patients fluid control and thus clinical relevant to account for. Three distinct subgroups (*Figure 6*) were found and subsequently labelled: 1) low self-efficacy, 2) distraction and depressive symptoms, and 3) high self-efficacy. The subgroups differed in fluid intake but not in age, dialysis vintage, gender, residual urine output, or whether they had received any fluid intake advice or not from the renal care team during the last six months. Cluster 1 (41% of the sample, n=55) was characterized by low self-efficacy, no dominant attentional style and a low level of depressive symptoms. Since the most distinguishing feature in this cluster was the low ratings for situation specific self-efficacy, the cluster was labelled "low self-efficacy (1)". Cluster 2 (33% of the sample, n=44) was characterized by high self-efficacy, a dominance of a distracting ("blunting") attentional style and possible depressive symptomatology. This cluster was therefore labelled "distraction and depressive symptoms (2)". The third cluster (26% of the sample, n=34) was characterized by high self-efficacy, no dominant attentional style and low level of depressive symptoms. This cluster was labelled "high self-efficacy (3)". As the labelling implies, the most typical characteristic in this cluster was high ratings of situation specific self-efficacy.

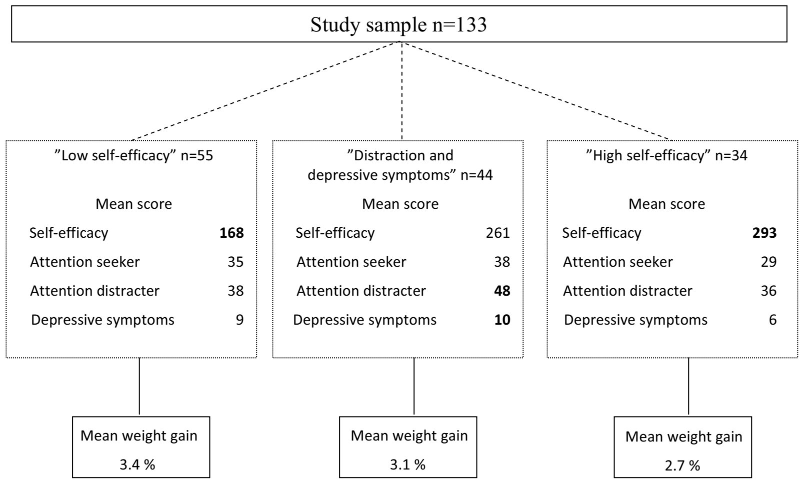

Figure 6. Description of the three clusters. Mean scores in bold type represent variable(s) characterizing each cluster.

For external validation of the clusters, a comparison of the clusters was undertaken and revealed an overall statistical difference in fluid intake, i.e. IWG; ($F[2, 132]=3.473$, $p=0.034$). The subsequent multiple comparisons with the Tukey's HSD post hoc test identified the difference ($p=0.025$) to be between the "low self-efficacy (1)" and the "high self-efficacy (3)" clusters. This reflects a 30 per cent difference in fluid intake between these clusters.

Study IV

Acceptability

All participants declared that they were pleased to carry out the intervention programme during ongoing HD treatment. Some disadvantages were identified regarding duration of the intervention and that the programme should have been introduced earlier in the course of the participants' dialysis vintage. Altogether, adequacy of the intervention was confirmed and some improvements of the content, intensity, duration and the timing of the intervention were suggested by the participants.

Feasibility

The intervention programme was found to be clinically feasible, i.e. ready to be implemented in regular practice and "real life setting". Regarding practicability of the programme, however, some important barriers to treatment fidelity were identified. Certain circumstances made adherence to the intervention protocol difficult because both planned an unplanned events interfered with the intervention scheduling. Thus, the participants were not always available at the agreed upon times at the dialysis unit.

The tools used for the homework assignments (food frequency questionnaire and diaries) as part of the intervention were also used as treatment fidelity check. An important conclusion was to prepare alternative tools to account for each participant's preference and cognitive skills.

Efficacy

An overview of the findings from the initial individualized analysis is presented in Table 8. The most pronounced triggering circumstance related to fluid intake for participant A (PA) was the physiological drive of thirst, probably due to osmometric reasons. Participant B (PB) had dry mouth as the most frequent trigger and this demanding problem caused uncontrolled fluid intake. Frequent and difficult situations for PB were social situations involving a meal or coffee. For participant C (PC), the physiological drive of thirst following a sodium rich meal and the resulting urge to moisten a dry mouth was most common. This was contradictory, however, to self-efficacy ratings, which involved social activities as the most problematic situations e.g. participation in a party, visiting a pub, or having a coffee. Participant D (PD) was unable to identify specific situations related to the common fluid intake trigger of dry mouth. Social activities emerged as highly problematic situations for reduced fluid intake e.g. exercising, taking a sauna, participation in a party, visiting a pub, or having a coffee with intimates.

All four participants had a clear reduction in their fluid overload severity but the intervention programme did not lead to reduction of excessive fluid overload to the desired extent, i.e. a mean daily IWG% less than 1.75% (*Figure 7*). A distinct change in level existed between the baseline measure and the recruitment phase, i.e. before the actual intervention was introduced. This effect could therefore not be attributed to the intervention, because manipulation of the independent variable was not in operation. Two trends were distinguished; PA and PC had an S-shaped pattern while PB and PD had a V-shaped pattern in their interdialytic weight gains. The latter could indicate a less successful application of the step-wise goal adjustment, which could have undermined these participants' efficacy expectations and thus self-efficacy. The S-shaped pattern could on the other hand indicate that the intervention had a reinforcing effect on these participants' fluid intake behaviour.

Table 8. *Overview of findings in the individualized analysis at baseline (Study IV)*

Variable	Participant A	Participant B	Participant C	Participant D
History of fluid intake, litres per day	1.7-2.0	1.7-2.0	2.9-3.2	3.0-3.2
Physiological symptoms	Pronounced thirst, especially in the afternoons.	Frequent occurrence of ankle oedema, and shortness of breath the night before dialysis. Dry mouth troubled every day.	Shortness of breath occurred frequently the night before dialysis and occasionally also on dialysis-free day. Dry mouth every day.	Shortness of breath occurred occasionally the night before dialysis.
Self-efficacy, (FIAI) sum score	230	195	140	233
Interpretation of self-efficacy ratings	Marked lowering in physiological and environmental situations.	Marked lowering in physiological and social situations.	Marked lowering in all situations; ratings were lowest in physiological situations.	Lowering in physiological situations.
Attentional style	No dominant	No dominant	No dominant	No dominant
Depressive symptoms, (CES-D) sum score and interpretation	5 i.e. no depressive symptomatology	12 i.e. borderline case for depressive symptomatology	4 i.e. no depressive symptomatology	6 i.e. no depressive symptomatology
Dietetic knowledge sodium and fluid	Insufficient	Sufficient accompanied by a lack of understanding	Excellent	Excellent
Sodium/fluid intake	Unaware about present high intake	Unaware about present high intake	Awareness of present dietary intake	Awareness of present dietary intake
Medication related sodium intake	High sodium supply from pharmaceuticals	Very high sodium supply from pharmaceutical	Almost no sodium supply from pharmaceutical	Low sodium supply from pharmaceutical
Cognitions	Catastrophic thoughts connected to feelings of guilt. Do not set physical symptoms in relation to fluid intake.	Do not set physical symptoms in relation to fluid overload nor fluid intake behaviour.	Adequate understanding about the relationship between salt-intake and fluid balance.	High understanding about the relationship between salt-intake and fluid balance.

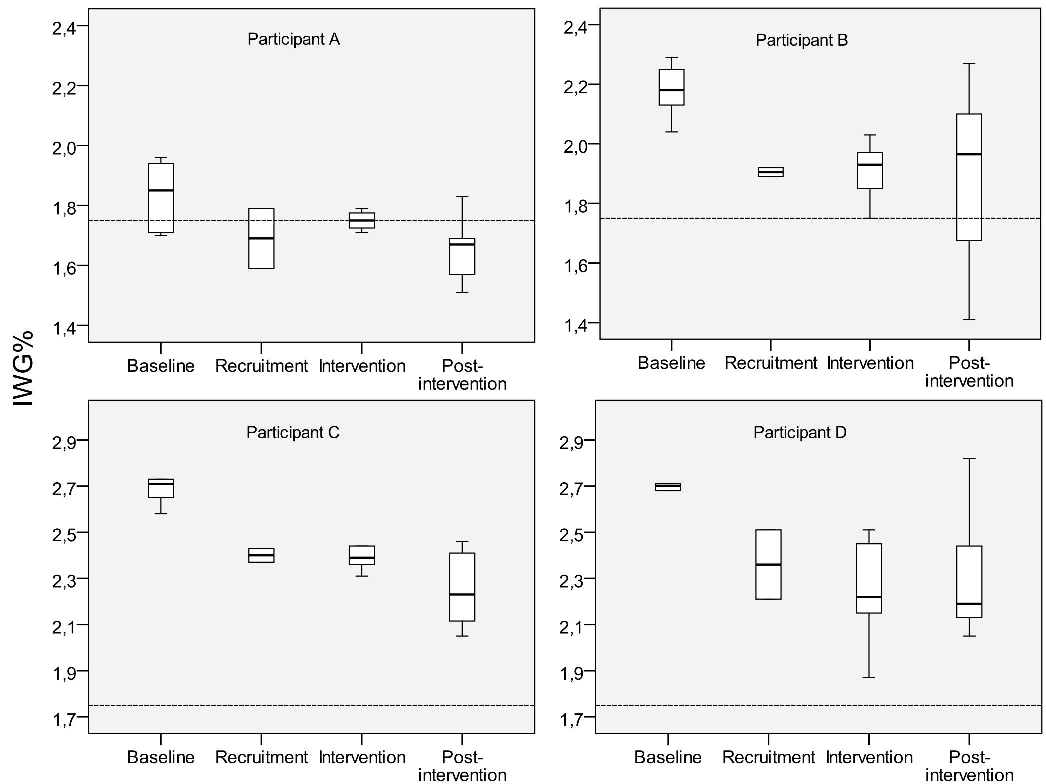

Figure 7. Participant A-D, variability in daily IWG%. The box-plots show ranges, medians, and inter-quartile ranges for weekly mean weight gains during the baseline, recruitment, intervention and post-intervention phases of the design. The dashed reference line represents the daily fluid allowance cut-off.

Discussion

Summary of results

In the years 2002-2006, three out of ten HD patients in Sweden (**Study I**) were at risk for medical consequences of fluid overload because they had higher IWG than 3.5% dry body weight. Simultaneously, one out of five HD patients (**Study I**) was at risk for intradialytic complications during treatment monitored by renal nurses due to a too high ultrafiltration rate.

Self-efficacy, a mediator between knowledge and action, is an essential component in health-promoting nursing interventions. A situation-specific self-efficacy measure for constructive fluid intake behaviour in HD patients was lacking and consequently the Fluid Intake Appraisal Inventory (FIAI) was developed and evaluated. The psychometric properties were satisfactory in the HD context (**Study II**).

Based on psychological factors, meaningful subgroups among HD patients were found. Three distinct subgroups were thereby labelled and characterized by their most prominent feature: group 1 "low self-efficacy", group 2 "distraction and depressive symptoms", and group 3 "high self-efficacy" (**Study III**). The validation procedure showed that it is clinically relevant to take account of profile characteristics of a respective subgroup as the groups differed in fluid intake. Moreover, the profile patterns suggest that theoretically-based differential general nursing strategies may be relevant for each subgroup. That is, the "low self-efficacy" subgroup had a low level of self-efficacy to restrict fluid intake and theoretically-based nursing strategies should therefore be based on an approach that will enhance self-efficacy beliefs regarding low fluid intake behaviour.

Addressing individual beliefs, behaviours, emotions and physical feelings during ongoing HD treatment is acceptable and clinically feasible. Although such intervention might be ineffective in obtaining adherence to fluid allotment, it may reduce excessive fluid overload in HD patients (**Study IV**).

Excessive fluid overload

It was surprising that the problem of excessive fluid overload still occurs frequently (**Study I**) considering the long withstanding and somewhat broad attention in clinical renal research. Clinical problems of fluid overload in ESRD patients have always existed, and dietary control has been and is the cornerstone of its treatment (Gillespie 1915, Hoffart 2009). Promotion of sodium and fluid restrictions are thus essential (Hoffart 2009), even though the importance of concurrent sodium restriction (Lindley 2009, Thomas *et al.* 2001) might have been forgotten or even neglected in the enthusiasm of new technical solutions for fluid management and dialysis treatment. The lack of attention to sodium could also reflect ignorance of current trends in the industrialized food processing, and thus changed dietary habits, as it has become more and more difficult to buy low-salt food. According to recent debates, however, sodium limitation seems to have regained its position in fluid management (Ok 2010, Ok & Mees 2010, Shaldon *et al.* 2008).

Fluid overload is the normal condition in most patients treated with thrice-weekly HD (Abuelo 1998, Charra 2007, Newmann & Litchfield 2005) while excessive fluid overload, which is associated with non-adherence to treatment regimen, is undesired (Johnstone & Halshaw 2003, Newmann & Litchfield 2005, Oka & Chaboyer 2001, Pace 2007, Sharp *et al.* 2005a). Considering that ESRD is characterized by an extreme loss of personal control; an array of acute and chronic stressors; emotional distress; the challenge of lifelong behavioural change (Christensen & Ehlers 2002); and illness and treatment-related endeavours that greatly impact on the patient's well-being and independence, it is understandable that non-adherence to treatment regimens exists. The problem of excessive fluid overload is even more comprehensible when the many aspects of fluid intake behaviour are considered (Abuelo 1998, Lindberg & Lindberg 2008, Lindley 2009, McKinley *et al.* 2004, Mistiaen 2001). Adherence to fluid allotments was among the top five content areas of study in renal nursing research disseminated between 1979 and 1989 (Molzahn 1993). To be judged by the presence of more recent literature e.g. (Baraz *et al.* 2010, Barnett *et al.* 2008, Denhaerynck *et al.* 2007, Kara *et al.* 2007, Kugler *et al.* 2005, Lee & Molassiotis 2002, Mistiaen 2001, Molaison & Yadrick 2003, Pace 2007, Pang *et al.* 2001, Porcu *et al.* 2007, Sagawa *et al.* 2003, Tsay 2003, Welch *et al.* 2006, Vlaminck *et al.* 2001), the marked interest in this research topic seems to be unaffected by time. The continuously high occurrence of excessive fluid overload (**Study I**) could reflect that the research endeavours have not reached clinical renal practice and/or that current practice is based on ineffective interventions due to lack of theoretical guidance. Further developments of HD patients' capability to self-manage their fluid allotment and implementation of evidence-based renal nursing measures that could assist the patients are therefore desired.

As estimated in the national sample, three out of ten Swedish HD patients had excessive fluid overload (**Study I**). This corresponded to average adherence rates in previous studies (Leggat *et al.* 1998, Manley & Sweeney 1986, Sharp *et al.* 2005a) and the tendency of lower frequency of excessive fluid overload in more recent years indicate that some improvements have been made. It is a well known fact that many HD patients have difficulty following fluid recommendations (Johnstone & Halshaw 2003, Mallick & Gokal 1999, Newmann & Litchfield 2005, Pace 2007, Sagawa *et al.* 2003, Sharp *et al.* 2005a, Sharp *et al.* 2005b) and the negative effects of excessive fluid overload on clinical outcomes and survival in HD patients is well documented (Banerjee *et al.* 2007, Holmberg & Stegmayr 2009, Kalantar-Zadeh *et al.* 2009, Kimmel *et al.* 1998, Leggat *et al.* 1998, Lopez-Gomez *et al.* 2005, Movilli *et al.* 2007, Ozkahya *et al.* 2006, Saran *et al.* 2003, Stegmayr *et al.* 2006).

Fluid overload is influenced by several clinical factors. The residual renal function is very important as are sodium levels, and dialysis technique including the occurrence of treatment related complications. Another important issue is whether the dry weight is reached or not at the end of each dialysis session (Ballantine & Barcellos 2004, Murphy 2006). Urinary output ceases in most HD patients within the first 18 months of dialysis vintage (Rottembourg 1993). It might therefore be appropriate to give patients recently initiated on HD more attention regarding preventative strategies to fluid overload (Welch *et al.* 2006). Interestingly, an early introduction of behavioural nursing strategies is also requested by the participants in **Study IV** as an effort to mitigate some suffering related to the limited fluid allotment. Other patient characteristics associated with excessive fluid overload are younger age, lower body mass index, longer experience of dialysis treatment and high blood-pressure (Leggat *et al.* 1998). These relationships were confirmed in **Study I** and, although they are difficult to modify with nursing strategies, they are important to pay attention to as risk factors.

IWG is recommended to be within the range of 2.5% to 3.5% of dry body weight (Holmberg & Stegmayr 2009) to reduce the risk for cardiovascular events and at the same time maintain a good nutritional status. Using percentage weight gain corrects for imbalance between absolute values (kg) and relative numbers (% of dry weight) because the latter do take into account patient size (Holmberg & Stegmayr 2009, Welch *et al.* 2006). Besides fluid intake, patients accumulate a certain amount of fluid daily in combination with good nutritional habits (Lopez-Gomez *et al.* 2005) although it is highly unlikely that weight gain between two consecutive HD sessions would be due to reasons other than retention of the fluid (Kalantar-Zadeh *et al.* 2009). Accordingly, IWG% is a reliable measure of fluid overload in anuric HD patients.

The so called dry body weight (**Study I-IV**) is a theoretical normovolemic clinical state used as a target weight for the dialysis treatment (Charra 2007, Leggat *et al.* 1998, Manley & Sweeney 1986, Raimann *et al.* 2008a, Wystrychowski & Levin 2007). The clinical method to assess the dry weight implies four categories of information: case history, clinical signs, X-ray, and lab data (Charra 2007). Unfortunately estimating, achieving, and periodically confirming or re-estimating dry weight remains a clinical problem (Wystrychowski & Levin 2007), and requires knowledgeable staff members and a sensible patient. Over time, a staff member who is very familiar with the patient's condition may be the best one to estimate the dry weight that will be comfortable for the patient and effective in achieving adequate dialysis. Renal nurses play an integral role in the renal team's effort (Carver *et al.* 2008, Ilumin 2003, Murphy 2006, Rastogi *et al.* 2008) and thus have a significant impact on improving the estimation of the dry weight. One possible development would therefore be to establish new expert nurse positions with a responsibility to assist primary care nurses with dry weight assessment and fluid management.

Registry-based data sets are often used in research because it offers larger sample sizes and improved ability to generalize compared with obtrusively collected data. In addition, registry data can be acquired relatively easy and are free from reactive error (Brewer & Hunter 1989, Kazdin 2010). There are, however, some advantages and some problems that must be considered in the analysis and interpretation of studies based on unobtrusively collected observational data from registries. Since the data are naturally occurring and not collected with research objectives in mind (Brewer & Hunter 1989), their appropriateness for specific research questions needs to be considered on a case-by-case basis. In addition, the data sets might be lacking in variables of relevance for a specific objective. For instance, the SDDB do not include parameters like the predialysis sodium and the dialysate sodium for each patient, which would have been appropriate to include in **Study I** because it has been demonstrated that reduced sodium dialysate effectively decreases interdialytic weight gain, reduces blood pressure in hypertensive patients, decreases the severity of treatment related symptoms and reduces cardiac volume loading (Flanigan 2008).

Cognitive factors and depressive symptomatology in relation to fluid overload

HD is a life-sustaining treatment for individuals with ESRD that does not simply require a short-term adjustment but rather requires a long term concomitant of coping with chronic illness and its treatment (Quinan 2007, Ran & Hyde 1999). Diet and fluid are self-managed through daily self-care activities by the patient, while the actual dialysis treatment may be beyond his/her control. The key to effective self-management and improved patient outcomes is the partnership between the patient and the renal team (Polaschek 2003b, Quinan 2007, Yokoyama *et al.* 2009). Breiterman-White (2004) go in to detail and suggest that incorporation of patient-centred care, continuous education, removal of barriers to adherence (scheduling of treatment, friction with staff, transportation), and use of cognitive behaviour strategies might be beneficial for adherence outcomes. Furthermore, the literature on control and adherence suggests that nursing strategies are most effective when patient characteristics, or preferred style of coping with illness-related stress, are consistent with the contextual features or demands of the particular type of medical intervention the patient is undergoing (Christensen & Ehlers 2002, Quinan 2007). Consequently, congruence between a patient's coping style and self-care demands is an important determinant of adherence (Brady *et al.* 1997, Christensen & Ehlers 2002). This should be taken into consideration while planning nursing care directed to improve adherence to fluid allotment (**Study III**).

Successful limitation of fluid intake is most likely facilitated by a motivation to be adherent and a confidence in self-regulation skills. This conceptualization is consistent with the self-efficacy theory (Bandura 1977, 1997) and available data supports that self-efficacy has an important influence on adherence to restricted fluid-intake (Brady *et al.* 1997, Ghaddar *et al.* 2009, Oka & Chaboyer 2001, Takaki *et al.* 2003, Tanner *et al.* 1998, Tsay 2003, Zrinyi *et al.* 2003). A scale measuring situation specific self-efficacy to low fluid-intake among HD patients was lacking and such a scale was consequently developed and psychometrically evaluated in **Study II**.

The development of the FIAI (**Study II**) was made in accordance with recommended sequences for scale construction (Bandura 2006a, Streiner & Norman 2008). This included exposure to critique on the format, vocabulary, readability and comprehension of instructions and statements by an interpretability group. Self-efficacy scales should have face validity (Bandura 2006a) and a group of HD patients were therefore engaged to ensure item sufficiency. The methodological limitations of the empirical part may have affected the interpretation of the results because there could be a selection bias due to convenience sampling procedure and the response rate of 65%. However, a comparison of demographical data with the Swedish Registry for Active Treatment of Uremia (SRAU) (Schön *et al.* 2004) gave no indication of such a bias. Another limitation is that the scale was developed and tested in Sweden. The FIAI has been translated into Portuguese and culturally validated in Portugal (Lindberg & Agostinho 2010) although further research is needed to assess socio-cultural validity and stability.

Subgroups with different profiles regarding situation specific self-efficacy, attentional style and depressive symptoms among patients treated with HD were explored in **Study III**. Three homogeneous clusters were identified in the sample: the "low self-efficacy (1)" group; the "distraction and depressive symptoms (2)" group; and the "high self-efficacy (3)" group. The "low self-efficacy (1)" subgroup did consume significantly more fluid than did the "high self-efficacy (3)" subgroup. This is in accordance with theoretical assumptions regarding the function of self-efficacy as a mediator of health protective behaviours (Bandura 1997, 2004). It is also in accordance with previous empirical findings in the dialyzed population e.g. (Brady *et al.* 1997, Tsay 2003, Zrinyi *et al.* 2003). Although the seemingly small difference in interdialytic weight gain (0.7 %, see *Figure 6*) could be considered as a matter of secondary importance or even unessential, it is quite the opposite. More specifically, an interdialytic weight gain of 0.7 % is equivalent with the recommended total daily fluid allotment (Ash *et al.* 2006) for an anuric individual of approximately 70 kg body weight.

The diverse subgroup profiles based on self-efficacy, attentional style and depressive symptoms imply that differential nursing strategies should be used to help HD patients reduce excessive fluid intake. The profile of the "low self-efficacy (1)" subgroup indicates that members in this cluster had a low level of self-efficacy in regards to restricting their fluid intake, low "attention seeking" and low "attention distracting" scores, and low ratings on depressive symptoms. Nursing strategies targeted to the characteristics of the "low self-efficacy (1)" group should therefore be based on an approach that will enhance self-efficacy beliefs regarding low fluid intake behaviour. This can be done by focusing on the four principle sources that influence self-efficacy beliefs: performance accomplishments (that the person himself feels he has mastered the task); vicarious experience (observation of others and seeing how they perform successfully); verbal persuasion (convincing the persons that s/he can succeed); and the self-evaluation of physiological information and emotional states (Bandura 1997). In this way self-efficacy may be enhanced and a sense of being in control of the fluid restrictions may be brought about.

The combination of high “attention distracting” scores and an occurrence of depressive symptoms and high self-efficacy in the “distraction and depressive symptoms (2)” subgroup suggest an approach targeting the depressive symptoms. According to Johnson & Dwyer (2008), about 70 % of untreated depressed HD patients show attitudes or perceptions that inhibit diagnosis and treatment. Theoretically, it is reasonable to assume that patients with low attentiveness to physiological, psychological or psychiatric symptoms, e.g. “attention distracters” (Miller 1989, Miller *et al.* 1988), do not seek care for their depressive symptoms. Depression is, however, highly correlated to unfavourable adherence outcomes (Christensen & Moran 1998, Kaveh & Kimmel 2001, Pang *et al.* 2001, Taskapan *et al.* 2005). If the patients do not consult health care for their psychosocial needs, the demands on the nursing staff to provide appropriate treatment will, from an ethical point of view, increase. The primary dialysis nurse is therefore in a key position to identify patients with depressive symptoms (Wilson *et al.* 2006).

The profile of the “high-self-efficacy (3)” subgroup shows that these subjects had a high level of self-efficacy to restricted fluid intake, low seeking/distracting scores and low levels of depressive symptoms. Nursing strategies targeting this subgroup may be based on educational approaches and a general supporting approach as patients may be expected to self-manage to a great extent.

A genuine tailoring of an intervention requires that individual problems are identified and that individualized intervention material or strategies are created (Kreuter & Skinner 2000). By enhancing individuals’ belief that the fluid limitation could be performed and their belief that a restrained fluid intake will be beneficial (Bandura 1977, 1997, 2004, Bandura *et al.* 1977), healthful behaviours are likely to develop among HD patients with fluid overload (Brady *et al.* 1997, Sharp *et al.* 2005a, Sharp *et al.* 2005b, Welch & Thomas-Hawkins 2005). In addition, the eventual presence of pronounced attentional style needs to be taken into account when designing interventions to facilitate long-term adherence. This would assist “attention seekers” who look for and amplify threat-related cues, as well as “attention distracters” who do not respond to such cues, to overcome cognitive, emotional and practical barriers that undermine long-term health protective regimens such as self-management of fluid restriction behaviours (Miller *et al.* 1996a, Miller *et al.* 1996b).

Cluster analytic methods are used in exploratory phases of research and will always produce clusters. As there is not any a priori hypothesis, it is essential to validate the clinical relevancy of the results (Aldenderfer & Blashfield 1984, Beckstead 2002, Hair & Black 2000). Validation by demographics is considered a weak procedure (Aldenderfer & Blashfield 1984), while validation of the cluster solution by significance tests on external variables is a more powerful approach. A criterion related validation (Aldenderfer & Blashfield 1984) implies that the variable used to assess validity provides a strong theoretical or practical support and that it differs across the clusters (Aldenderfer & Blashfield 1984, Hair & Black 2000). Thus, the significant difference between the "low self-efficacy (1)" and the "high self-efficacy (3)" clusters in **Study III** suggests that there were clinically meaningful subgroups. Replication of the clusters in another independent sample is needed before it can be assumed that the defined subgroups are stable and thereby meaningful in a clinical and empirical sense. In order to establish the generality of the cluster solution in **Study III**, a replication of the findings in different subjects, settings and times (Aldenderfer & Blashfield 1984, Hair & Black 2000) will be the topic of forthcoming research. In contrast to statistical inference techniques, cluster analysis is an objective methodology for quantifying the structural characteristics of a set of observations. Consequently, the requirements of normality, linearity and homoscedasticity, which are important in inference techniques, have little bearing in cluster analysis. There are no rules-of-thumb about the sample size required for cluster analysis, although the obtained sample must be representative of the population. A non-representative sample would introduce a bias in the statistical estimation of the structure (Beckstead 2002, Hair & Black 2000). A representative sample was, however, obtained because a multi-centre approach was used and the fact that the available demographical data corresponded with national population data (Schön *et al.* 2004). Another critical issue in cluster analysis is multicollinearity, which could act as a weighting process and distort the cluster solution (Beckstead 2002, Hair & Black 2000). This issue was, however, not relevant in **Study III** as the inter-correlations among variables used in the clustering process were low.

Clinical nursing practice

Renal nurses need to increase their emphasis and reliance on their professional competence in providing care as well as to continuously evaluate the quality of provided care. But this requires them to identify core elements of renal nursing and to define indicators of renal nursing quality. Dialysis adequacy is often framed in terms of the percentage of patients receiving a Kt/V of greater than 1.2 (Kt/V stands for quantification of urea clearance during dialysis (K) multiplied with dialysis treatment time (t) and divided by urea distribution volume (V)) (Daugirdas 2008, Hecking *et al.* 2004). Defining quality nursing care as the waste clearing of urea molecule is, however, very narrow and conflicts with the caring and nursing ethics (Keen 2009). Furthermore, it places a high value on an indicator that ignores variables modifiable by nursing interventions and defines quality of cure rather than quality of care (Couchoud *et al.* 2009). The introduction of ultrafiltration rate as a quality indicator (**Study I**) could, however, be a possible direction for measurement of renal nursing care quality. Furthermore, evidence-based ultrafiltration rate (Movilli *et al.* 2007, Saran *et al.* 2006) is also a complementary indicator of dialysis adequacy because Kt/V in isolation provides little benefit for the patient (Twardowski 2007). Kt/V creates an illusion about quality dialysis but conceals the reality why patients could feel so unwell, before, during and after dialysis. Excellence in renal nursing is evidenced by enabling patients to promote well-being in order to achieve a higher quality of life while shouldering the burden of ESRD. To be affected by too high ultrafiltration rates and the associated complications, as was demonstrated in **Study I,** was something the HD patients really did not deserve. A possible explanation might be that the highly technological setting of the dialysis unit often conflicts with the caring and supportive environment, which is necessary for the care of those who are critically and long-term ill. It should be noticed, however, that reliance on technological aspects of nursing may lead to a dehumanised and depersonalized type of nursing care (Polaschek 2003a, Ran & Hyde 1999, Rittman *et al.* 1993) and because of this additional nursing quality indicators are needed.

The fact that one of five HD patients was treated with inadequate ultrafiltration rate (**Study I**) suggests that there is a need for continued improvements of the patient care and that follow up studies are important in order to monitor the development. Preferably such studies could also focus on renal nurses' clinical decision making and ethical reasoning regarding use of too rapid ultrafiltration rate during treatment, the impact of dialysis unit culture and dialysis prescription routines on applied ultrafiltration rates as well as the impact of nursing competence on applied ultrafiltration rates. These aspects were impossible to include in **Study I** because the data source used did not record such data.

Renal nurses who monitor HD treatments might increase treatment time in order to ultrafiltrate excessive fluids at acceptable rates. However, this strategy might have been insufficiently used (**Study I**) in Sweden during 2002-2006. The average ultrafiltration rate was, however, lower in **Study I** than the rate reported from the DOPPS I and DOPPS II studies (Saran *et al.* 2006). This indicates that Swedish HD patients receive evidence-based fluid removal to a larger extent than others in an international perspective. Fluid overloaded patients would thus benefit from a more individualized duration of each dialysis session. Further benefit would arise if all HD patients had the opportunity to receive HD on a daily basis with tailored scheduling. This would mean that it might even be possible to eliminate the problem of non-adherence to fluid restrictions.

It is recognised that patients having higher IWG than 3.5% dry body weight have more cardiovascular illness than others (Holmberg & Stegmayr 2009) and cardiovascular disease is the leading cause to high mortality rates in HD patients. A powerful act to manage the problem with fluid overload in these patients would be more frequent dialysis e.g. nocturnal or daily dialysis to all patients, although it might not be possible with available resources. The renal care team therefore needs more knowledge about alternative tools, besides medical and pharmacological strategies, to support the individual patient in behavioural adjustments to treatment requirements i.e. low fluid intake. Such strategies may contribute to preservation of less fluid and thereby decreased ultrafiltration rate without expanding treatment time or the number of sessions.

Because HD involves a complex behavioural regimen (Newmann & Litchfield 2005), an integration of psychological factors in the renal care (**Study III-IV**) would make it easier for the patient to become an active mediator of change. Chamney *et al*. (2009) concludes that patients with ESRD should be encouraged to become involved in the management of their care along with their families and carers. She further points out that the education provided should be individualized and tailored to the needs of each patient but she does not indicate how to do this in clinical practice. Adherence to fluid intake restrictions is improved in studies using psychological interventions (Anson *et al.* 2009, Fisher *et al.* 2006, Sevick *et al.* 2005, Sevick *et al.* 2008). It is, however, noticeable that the literature review by Sharp (2005a) emphasizes the use of diverse methods in the intervention described as educational, behavioural, cognitive or holistic approaches.

Study IV represents a first introductory step toward the design and implementation of an intervention intended to reduce HD patients' fluid intake. The programme addressed beliefs, behaviours emotions and physical feelings related to fluid restrictions, and the rationale for such tailoring was to mobilize the inherent force of self-management, i.e. self-efficacy (Lindberg & Agostinho 2010, Tsay 2003, Zrinyi *et al.* 2003). The participants demonstrated a distinct reduction in fluid intake very early in the programme i.e. during the recruitment and individualized analysis (see *Figure 7*). This effect was in contrast to Sharp (2005b) where no improvements in fluid intake were seen until after a 10-week treatment follow-up. Possible differences between the interventions that gave a more immediate reduction of fluid intake in **Study IV** could be ascribed to the combination of cognitive, emotional and behavioural components in an individual rather than group format. The reduction in fluid intake could also have been biased by the participants' expectations and their knowledge of being included in the study. In particular this could happen if a motivational hope was aroused by the inquiry to participate in such a study.

The essential goal of the programme is to teach patients cognitive and behavioural strategies appropriate to initiate and maintain desired fluid intake behaviour. The individual analysis including history of fluid intake behaviour, experience of physical symptoms related to excessive fluid overload, dietetic knowledge and self-efficacy was the base for tailoring the treatment to each patient's problem, capacity, goal and specific fluid intake circumstances. Formulating strategies in writing is an essential process to link the goal desired with behaviour. The goals were individually set and cognitive, environmental and social circumstances that could affect the patient's behaviour were discussed. Another central feature of the programme is the homework assignments -monitoring fluid intake behaviour and identification of risk situations for uncontrolled fluid consumption. By filling in a diary between sessions, it was possible for the patients to assess their own management in relation to intermediate goals set in stepwise achievements. By such means the patients were given positive or negative feed back on their efforts and the possibility to reformulate the intermediate goal. This procedure is one of the main strengths of the intervention as the patients took an active part in the process for their own self-management of the limited fluid allotment.

Based on the results (**Study IV**) it is possible to conclude that the length of intervention may be insufficient. Moreover, the participants felt that the intervention should contain further sessions focusing on performance mastery. A programme integrated in ordinary practice does generally not need to consider time limits since HD is a lifelong treatment.

Renal nurses are in a good position to influence HD patient's self-efficacy to low fluid intake and thus encourage them to adopt effective self-management strategies (Tsay 2003). By applying self-efficacy measures (**Study II-III**) (Lindberg & Agostinho 2010) for tailored support, renal nurses can assist patients to set realistic daily performance goals, provide anticipatory guidance, clarify symptom management, and assess progress (Tsay 2003). Adjusting the teaching to each patient's prerequisites is a fundamental factor when the task is to enhance the patient's skills for preplanning, substitution, dietary modification, situational control and distraction. Such measures and tactics can thereby provide a comprehensible foundation for behavioural nursing strategies to enhance HD patients' self-management of fluid intake.

Study III has illustrated the heterogeneity of patients treated with HD, and the importance of distinguishing subgroups of patients with different cognitive profiles in relation to treatment of excessive fluid overload. The effect of an approach tailored for the type and information to meet individual coping needs (van Zuuren *et al.* 1996, van Zuuren *et al.* 2006) could though not be tested in **Study IV** as none of the participants had any pronounced attentional style. Following Millers model, the type of information provided for attention seekers should be detailed and specific about risk while effective information to attention distracters should be short and basic (Miller 1995). **Study IV** does illustrate, however, that a theoretically and empirically based behavioural medicine approach is feasible and can result in an important reduction of excessive fluid overload. But it is important to be aware that results of experimental single-case studies do not prove efficacy (Kazdin 2010) and only gives preliminary suggestions of the effect. The results further indicate that renal nurses can by means of cognitive-behavioural techniques improve HD patients' self-regulation of fluid intake. Since renal nurses have regular and frequent interactions with the patient during the treatment, it is feasible to study the efficacy of such a strategy in regular practice. A controlled trial is in a preparatory stage, although a randomized control group design does not appear possible due to the highly integrated nature of the typical HD unit, the frequent and prolonged interaction between patients (Christensen *et al.* 2002) and the treatment fidelity barriers reported in **Study IV**. In particular, scheduling of intervention sessions have to account for the patients' need for flexible timing of their dialysis session, the regular working hours of the delivering nurse, as well as allocation of resources and the organisation of the dialysis unit. Altogether, the logistics including flexibility have to be carefully considered before a larger group study is launched.

Conclusions and clinical implications

- Three out of ten Swedish HD patients had excessive fluid overload (**Study I**).
- One out of five Swedish HD patients was at risk for treatment related complications due to too rapid ultrafiltration rate during haemodialysis monitored by renal nurses (**Study I**).
- The variables IWG and ultrafiltration rate should be used as quality indicators of adequate renal nursing care and as outcomes in the continuing improvement of haemodialysis care (**Study I**).
- The Fluid Intake Appraisal Inventory (FIAI) is a reliable and valid situation specific self-efficacy scale in haemodialysis settings (**Study II**).
- HD patients with excessive fluid overload are a heterogeneous group in regards to their cognitive profile based on self-efficacy, attentional style and depressive symptomatology (**Study III**).
- The individual profile of self-efficacy, attentional style and depressive symptoms is associated with fluid overload and has to taken into account when tailoring interventions designed to reduce haemodialysis patients fluid intake (**Study III**).
- The acceptability of carrying out a social-cognitive intervention designed to reduce haemodialysis patients fluid intake was confirmed (**Study IV**).
- The social-cognitive intervention programme addressing beliefs, behaviours, emotions and physical feelings related to fluid intake was found to be clinically feasible (**Study IV**).
- All four participants had a reduction in their excessive fluid overload. But the intervention programme did not improve adherence to fluid allotment (**Study IV**).

Effective management of excessive fluid overload in haemodialysis patients is dependent on the recognition that the patient is the main manager. Frequent and repeated contacts with renal nurses can help these patients develop problem-solving skills, set goals, and understand their progress in managing multiple aspects of their disease. Nursing support is critical to help patients develop proficiency in performing certain skills and tasks. Individualization of the common educational approach by incorporating the patient's beliefs, behaviours, and emotional and physical feelings as well as culture, economic situation, ability and knowledge of the disease and its treatment supports self-management. Other strategies include encouraging the patient and his/her social network to ask questions, informing patients of their progress, taking time to listen, and helping to develop a plan of action with short and long-term frames. Furthermore, as a renal nurse it is important to stay up to date with the results of current studies in order to help patients navigate the multiple aspects of managing ESRD and haemodialysis treatment. Utilizing other members of the multidisciplinary team can help patients overcome barriers and develop strategies for managing their own care.

This thesis indicates that there are potentials for improvements in the fluid management care of haemodialysis patients. Patients having excess fluid would benefit from an adjusted dialysis prescription including longer HD duration or increased frequency of treatment, and/or support to reduce fluid intake. In the end, a reduced fluid overload due to less fluid consumption is probably the most beneficial way to solve the problem. The prevalence of excessive fluid overload implies that joint efforts to reduce HD patients' fluid intake is needed within the renal care team. Interventions that aim to assist HD patients to achieve fluid control should be applied more extensively. Cognitive profiles of the patients should be taken into account when nursing intervention aiming to encourage and maintain the patient's fluid control is introduced.

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