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# **Living with haemodialysis close to death - patients' and close relatives' experiences**

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*To my late parents Arne and Gunilla Söderholm*



*"One can only hope  
that it will be a tolerable life  
until the day when*

*when something happens  
and it is over"*

Participant study I



# ABSTRACT

The overall aim of this thesis is to generate understanding and knowledge about the experiences of patients living with haemodialysis, and their close relatives, near the end of life. In studies I and II we conducted a series of 31 qualitative interviews over a period of 12 months with 8 severely ill patients (aged 66–87) treated with haemodialysis. For study I the text of the interviews was analysed using phenomenological hermeneutics to describe and to elucidate the meanings of being severely ill living with haemodialysis when nearing end of life. For study II the text was analysed using qualitative content analysis to describe inner thoughts and feelings relating to death and dying of these patients.

For studies III and IV, we conducted 14 retrospective qualitative interviews with close relatives of deceased patients treated with haemodialysis about their experiences during end of the patient's life. For paper III the interview text was analysed using phenomenological hermeneutics to describe and elucidate the meanings of being a close relative at the end of life of a severely ill family member treated with maintenance haemodialysis. For paper IV the text was analysed using qualitative content analysis to describe end of life for the patients from the perspective of their close relatives.

The findings of study I suggest that being severely ill and living with haemodialysis near the end of life means living with suffering from a deteriorating body, a high symptom burden, and dependence on advanced medical technology, simultaneously with reconciliation and well-being. The meanings of living with illness and dialysis are intertwined with the meanings of being old.

Study II shows that thoughts and feelings about death and dying are significant and complex for those living with haemodialysis as they approach the end of life. Patients experience a multifaceted presence of death. Their awareness of approaching death may include their repressing of thoughts of death, not as denial, but to allow them to focus on living as fully as possible the time they have left.

Study III shows that close relatives strive to maintain balance and well-being for themselves and for the patient, which we interpreted as their striving to regain balance, and inner equilibrium in their changed and challenged rhythm of life. Study IV shows that after gradual deterioration and increasing care needs, older patients in haemodialysis care with co-morbidities follow three different main paths at the end of life: uncertain anticipation of death; awaiting death after dialysis withdrawal; and sudden but not unexpected death. The ends of their lives are marked by complex symptoms and existential issues related to haemodialysis treatment and withdrawal, and their uncertainty of what to expect at the end of life suggests the need for increased continuity and coordination of whole person care. Both patients and their close relatives are often alone with their existential thoughts.

In their complex lifeworlds, intertwined meanings of living with illness and maintenance of life with haemodialysis treatment near the end of life show that patients live in a borderland of living-dying that is shared by the close relative. Patients and close relatives focus on living when death is close but uncertain, with severe illness and the maintenance of life through advanced technology.

Integrating the philosophy of palliative care (with a focus on symptom relief, team work, communication, relationships, and support of family members) into dialysis care, may support health care professionals in haemodialysis units and other renal contexts, to improve the care of severely ill patients, both earlier in their illness and as they approach the end of their lives.

**Keywords:** close relative, death, dying, end of life, end-stage renal disease, haemodialysis, palliative care, patient, phenomenological-hermeneutics, qualitative content analysis, retrospective interviews, serial interviews.

## LIST OF ORIGINAL PAPERS

- I. Axelsson, L., Randers, I., Jacobson, S. H., & Klang, B. (2012). Living with haemodialysis when nearing end of life. *Scandinavian Journal of Caring Sciences*, 26, 45-52.
- II. Axelsson, L., Randers, I., Lundh Hagelin, C., Jacobson, S. H., & Klang, B. (2012). Thoughts on death and dying when living with haemodialysis approaching end of life. *Journal of Clinical Nursing*, 21, 2149-2159.
- III. Axelsson, L., Klang, B., Lundh Hagelin, C., Jacobson, S. H., & Andreassen Gleissman, S. Meanings of being a close relative at the end of life of a family member treated with haemodialysis. (*submitted for publication*)
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## **LIST OF ABBREVIATIONS**

CKD	Chronic kidney disease
ESRD	End stage renal disease (CKD stage 5)
ACP	Advance care planning
AD	Advance directives

## INTRODUCTION

In my many years as a nurse in haemodialysis care I have met several patients who struggled with several chronic progressive and life-threatening illnesses. I have followed their gradual deterioration and declining health, with physical and existential struggle as they maintained life through advanced medical technology. This led to my interest in increasing understanding and knowledge of these patients' experiences in the haemodialysis unit and their needs for care when they are severely ill and approaching the end of life.

When I conducted interviews with patients for the first study I realized that I could not research these patients' end of life situations without including close relatives, as the fundamental significance and mutuality of the relationships of patients to their close relatives became apparent.

My interest in nursing care at the end of life evolved during my early years as a nurse on surgical care wards, where I met many patients dying of cancer. It was there I learned that when a patient was dying, the nurse was challenged on every aspect of knowledge of care.

In the haemodialysis unit, where the focus is on handling advanced medical technology and maintaining life, death may be regarded as a failure. However, death is not always a failure although not doing all that is possible for the life and well-being of the patient before death should be considered a failure.

When I was at a dialysis unit to inform a patient about the study and told him that I was interested in learning what it meant to live with haemodialysis, his immediate response was "I don't think one lives for long." His instant relation of his situation to death illuminates the vulnerable situation of these patients. Sometimes it is difficult to know when the end of life begins, but we do know in the haemodialysis unit that many patients we meet may be living their last year. My hope is that this thesis may contribute to increased understanding and better inter-professional and interdisciplinary care of these severely ill patients and their close relatives on their path towards the end of life.

## **BACKGROUND**

This thesis focuses on severely ill patients living with haemodialysis near the end of life and their close relatives. This chapter begins with a section describing end stage renal disease and haemodialysis treatment in order to provide a context for the experiences and situations of the patients and their relatives. The next sections focus on experiences of being a person or a close relative of a person living with haemodialysis, followed by the concepts of death and dying, and of palliative care.

### **END STAGE RENAL DISEASE AND HAEMODIALYSIS TREATMENT**

In chronic kidney disease (CKD) the kidney is permanently damaged and its function gradually deteriorates. The disease is classified into 5 stages of kidney function in which stage 5, also called end stage renal disease (ESRD), implies renal failure estimated as a glomerular filtration rate of less than 15 ml per minute [1]. Patients with ESRD (CKD stage 5) have several electrolyte, metabolic, and endocrine disorders that require renal transplantation or lifelong treatment with peritoneal- or haemodialysis.

The main causes for chronic kidney disease and renal replacement treatment are glomerulonephritis and diabetes nephropatia, followed by polycystic kidney disease and nephrosclerosis [2]. ESRD is increasing worldwide [3] and the number of patients on treatment with maintenance haemodialysis is growing in western societies [2, 4, 5]. In Sweden the prevalence of ESRD is more than 923 per million inhabitants, and the incidence of renal replacement treatment is 125 per million inhabitants. In 2011 approximately about 3030 people received haemodialysis in Sweden, two thirds of whom were men [2]. Patients undergoing haemodialysis are older and have several co-morbidities [2, 4, 5]. In Sweden the mean age for patients receiving haemodialysis is over 66 years [2]. Common co-morbidities are diabetes, cardiac disease, cerebrovascular disease, and peripheral vascular disease. Co-morbidities and complications increase hospitalisation rates for patients undergoing haemodialysis treatment [5]. Treatment intensity for patients 65 years and older has been reported as high, as 76% of patients were hospitalized and 49% were admitted to an intensive care unit during their last month [6].

Co-morbidities add to decreased life expectancy and high mortality rates, with cardiovascular disease as the main cause of death for patients in haemodialysis care [2]. Annual mortality rates in patients receiving haemodialysis treatment are about 20% [2]

to 28% [5]. Patients over 65 years have a life expectancy of less than 5 years after dialysis initiation [4, 5]. With co-morbidities and increasing age the efficacy of dialysis treatment has been questioned in relation to quality of life as studies show that for older patients with several co-morbidities survival on haemodialysis may be no longer than with conservative care (i.e. withholding haemodialysis) [7-9]. In chronic progressive disease the prognosis may be uncertain; however, for patients in haemodialysis care, clinical prognostic tools have been developed. Moss *et al.* [10] found that the clinical 'surprise' question (i.e., 'Would I be surprised if this patient died in the next year?') helped clinicians to identify patients in haemodialysis care at high risk of death. Cohen *et al.* [11] combined the 'surprise' question of death within six months with a co-morbidity index that was found valuable.

### **Haemodialysis treatment**

Haemodialysis treatment is a highly advanced technical treatment using semi-permeable membranes with a contra flow of blood and dialysis fluid in dialysis filters. Through diffusion and ultrafiltration toxic metabolites and surplus electrolytes and water are eliminated from the blood, hence haemodialysis requires well-functioning access to the blood stream [12]. This demands a surgical procedure to obtain an arteriovenous fistula or graft. More seldom a central venous catheter is used as a permanent access for dialysis. Maintaining a well-functioning access to the blood stream is still one of the main challenges in maintenance haemodialysis [13]. Dialysis regimens vary, but haemodialysis usually requires treatment for 4–5 hours three times per week. This is generally performed as an out-patient treatment at a dialysis unit in a hospital or at a smaller dialysis satellite. The journeys to and from the clinic add to time lost to dialysis. This life-long time-consuming treatment means spending much time in the haemodialysis unit, and relations with health care professionals may evolve over many years. The nurse–patient relation in the dialysis unit is described as therapeutic and involving long-term support [14], but nurses in this context may also be caught up in technology and getting patients' treatments processed [15].

### **Symptom burden in patients undergoing haemodialysis treatment**

Patients undergoing haemodialysis treatment suffer impaired quality of life because of both the disease and the consequences of the treatment ([16, 17]. Their symptom burden is high due to uremia, with its consequential disorders, and to the dialysis

treatment itself [18-20]. Some frequently experienced symptoms are lack of energy, decreased appetite, nausea, pain, pruritus, shortness of breath, sleep disturbances, anxiety, muscular cramp, and dizziness [21, 22]. Co-morbidities such as diabetes, cardiac disease, cerebrovascular disease, and peripheral vascular disease often add to the complexity and burden of their symptoms [23, 24]. Their symptom burden has been described as similar to that of patients with advanced cancer [18, 19]. The presence and severity of symptoms, however, have been found to be underestimated and symptoms undertreated in patients in renal care [25-27]. Different assessment instruments have been developed and validated to facilitate the assessment and treatment of symptom burden in patients with ESRD [22, 28, 29].

### **Withdrawal of haemodialysis treatment**

Reasons to withdraw haemodialysis treatment are chronic progressive deterioration, acute crisis, technical dialysis problems, or other problems [30, 31]. Patients' reasons to discontinue dialysis treatment include poor quality of life, pain, suffering, and the desire not to be a burden [32]. The significance of symptom burden and depression, along with pain, has also been suggested [33]. Withdrawal of dialysis precedes about 10% of deaths in patients treated with haemodialysis in the United States [34] and about 35% of deaths in these patients in Australia [35]. In Sweden the percentage of patients who die after withdrawal has been rather stable at about 16% [2]. Different mortality rates related to dialysis withdrawal may be due partly to unclear or different definitions in reports [36]. After dialysis withdrawal the average survival time is 8 days [31]. However, survival times ranging from 1 to 48 [30] and even up to 76 days [37] have been reported.

## **LIVING WITH CHRONIC ILLNESS AND HAEMODIALYSIS TREATMENT**

The experience of chronic illness is multifaceted with various meanings in different phases and life contexts [38]. In chronic illness the familiar world is disrupted, which means living with uncertainty, loss of control, and loss of future goals [39]. There are various transitions following the diagnosis of the chronic illness ESRD [40], and beginning life on maintenance haemodialysis treatment is described as a new way of being in the world [41]. Life is restricted because of dependence on dialysis technology, healthcare professionals, and significant others [41-43]. Life with

haemodialysis involves losses due both to illness and to the time-consuming treatment [41-44] and the repetitive persistent treatment also involves strain on family and social life [41, 42, 45]. Patients also experience an uncertain future [41, 45]; life on haemodialysis involves an existential struggle, with little space for living [46] and the redefinition of the self [41, 45]. Patients awaiting transplantation maintain hope of regaining their lives in the future [43, 45, 47], but hope for life on haemodialysis may also involve a focus on living in the present [48]. Deteriorating health raises questions about the meaning of life and how much life is left [41], and dependence on haemodialysis as a lifeline is a continuous reminder of how short the remaining time may be [42]. Patients on haemodialysis struggle for personal preservation while recognizing their shorter life expectancy [48].

### **BEING A CLOSE RELATIVE OF A SEVERELY ILL PERSON**

In health care research there are various terms used to describe people with a close relationship to an ill person. Next of kin usually means the close family, but may include a significant person who is unrelated [49]. Spouse, family member, family carer, family caregiver, and close relative are some other terms often used. In studies III and IV the term ‘close relative’ was used because it is congruent with the next of kin identified in the patients’ medical records; for that reason, close relative is also the term used throughout this thesis.

Chronic illness also affects the lives of the patients’ close relatives and causes them losses. It has been described as an “intruder” in life [50] and the experience as living in the “shadow” of the illness [51], with an altered relationship to the patient, changing roles, struggles with changes in everyday life, and an uncertain future on several dimensions [50-52]. Close relatives of the seriously ill express both satisfaction, when they are able to help the ill family member, and guilt, when their ability is lacking [53, 54]. Being needed entails feelings of both comfort and strain [55], and close relatives who support ill people are themselves in need of support [56-58] and acknowledgement [56, 59]. A review of end-of-life care showed that health care professionals were significant in the relatives’ involvement, stress, and satisfaction with their own care of a family member in a situation that could change from day to day [60]. A review of existential concerns found that close relatives living with the awareness of death wished for support in the forms of information and dialogue [59]. The meaning of having

support in in-home palliative care has also been interpreted as sensing togetherness in the caring situation [61].

### **Being a close relative of a person treated with haemodialysis**

The chronic illness ESRD (CKD 5), together with lifelong haemodialysis treatment, changes the lives of close relatives through alterations in roles and relations, it reduces freedom, and it leads to feelings of social isolation [62, 63]. The illness and haemodialysis may dominate daily life of close relatives [63, 64], who may feel they are caring for the ill person at the expense of their own health [62, 65]. Close relatives of patients' on haemodialysis report an impaired quality of life [66, 67, 68] influenced by both fatigue [69] and emotion [68]. They live with the constant worry of their family member's declining health and the uncertain prognosis, and they fear the family member's death knowing the disease is life-threatening [64].

## **DEATH AND DYING**

### **Death, dying, end of life, and trajectories**

Death and dying are a part and the end of all lives and have always been topics for philosophical thought [70]. Dying is defined as the phase when the individuals' critical life functions fail and symptoms show that death is near [49] but when subjective experiences are described the concept of dying often encompass a longer end-of-life phase. End of life is described as the period when death is inevitable within the foreseeable future [71], but recognizing when the end of life and the process of dying begin may be difficult, especially in progressive chronic illness. End of life may also be unpredictable; in chronic heart failure this has been described as a "roller coaster ride" with irregular "ups and downs" of improvement and deterioration [72]. A vacillating pattern of uncertainty is also described in patients with severe chronic obstructive pulmonary disease [73].

The sociologists Glaser and Strauss [74] described the significance of certainty or uncertainty of death to interactions during the dying process, and they identified four kinds of death expectations related to time and certainty: certain death at a known time; certain death at an unknown time; uncertain death but a known time when the question will be resolved; and uncertain death and unknown time when the question will be



resolved. These different, and sometimes changing, expectations have an impact on both patients and those around them [74]. Glaser and Strauss [75] stressed the importance of knowing and understanding the prognosis and the dying trajectory to understanding caring at the end of life. They described the process of dying as following perceived trajectories that vary in duration and shape [75]. Different trajectories of death were later described: sudden death with little warning; terminal illness with rapid decline; organ failure with episodes of acute deterioration followed by improvement but with a downward tendency; and for very old and persons with dementia, a gradual decline and frailty [76]. It is complicated to identify and predict a general pattern of death trajectories for patients with ESRD as their co-morbidities vary and interact, and thus the reasons for their physical decline and death differ. However, the importance of recognizing the individual trajectory in patients with ESRD has been acknowledged [77, 78]. Haemodialysis treatment increases the complexity of the trajectory towards death, which may also involve the decision to withdraw haemodialysis [79]. Dying may be a long process for patients in haemodialysis care, and sometimes the question is raised of whether dialysis is prolonging life or prolonging dying [80].

### **Experiences of dying**

Kubler-Ross [81] interviewed very ill people about their experiences of dying and identified five stages of psychological response: denial, anger, bargaining, depression, and acceptance. Her theory has had great influence, although the experience of dying as a move through specific psychological stages has been questioned because the experience of dying is very complex. Feigenberg [70] described dying as a multifaceted individual psychosocial process intertwined with a biological process, with feelings and reactions oscillating between, for example, acceptance and denial, hope and resignation, or dignity and humiliation. Qvarnström [82] also identified dimensions of opposite reactions to dying and sorted them into broader domains summarized as fear of loss of personal identity, fear of dependency, fear of loss of body parts, fear of loss of self-control, and fear of loss of relations [82]. Copp [83] however criticized theories of dying based on the emotional reactions of individuals as ignoring the bodily dimensions of dying, and suggested the need to separate the body from the self to better understand a person's readiness to die.

## **Awareness of dying**

Information and open awareness of dying is a cultural question and attitudes vary through countries, but in contexts where it is established people are seen to strive to maintain control and self-identity [84]. Glaser and Strauss [74] early described different contexts of “awareness of dying” that are still clinically relevant to possible improvements in care [85]. The type of awareness in the interplay between patients, family, and professionals illuminates the consequences of behaviours and communications on the experience of dying, and involves complexities of morals, ethics, and values [74]. In the context of “closed awareness”, the staff knows about the impending death, but strive to not reveal this to the patient, with the result that the patient and family do not have time for shared preparedness. In the context of “suspicion awareness,” patients suspect they are dying and try to have their suspicion confirmed or refuted, but staff avoids responding to their efforts. In “mutual pretence” all parties know about the impending death but pretend otherwise, and thus still do not communicate about dying. Only with “open awareness” do both patient and staff acknowledge dying, and this openness makes it possible for them to talk honestly and to act upon the knowledge that the patient is dying. However, even with open awareness, complexities arise as ambiguities remain. The different contexts of awareness can change into others, and the various awareness contexts can also be either full or partial (i.e. in open awareness some aspects of dying may be discussed, while others remain closed) [74]. Field and Copp [86] later proposed the addition context of “conditional” openness, in which health care professionals strive to recognize the changeable wish of the patient of what to know, rather than to communicate with active open full awareness at all times. The challenge of conditional openness is to avoid allowing any desire for professional control or one’s own discomfort to decide how and what to communicate to the patient. Seale *et al.* [84] found that people dying from other diseases were less likely to die in the context of open awareness of their prognosis and death than were patients with cancer.

## **PALLIATIVE CARE**

Palliative care aims to relieve suffering and promote well-being for patients living with life-threatening illness and to support life until death. It is described as active care for the whole person, focusing on quality of life and symptom management,

including physical, psychosocial, emotional, and existential needs. Palliative care confirms life and regards dying as a normal process. Palliative care also emphasizes support of the ill person's family, both during the illness and after the death [87]. Modern palliative care developed from early hospice philosophy that originated in the United Kingdom in an effort to improve care of the dying [88]. The most important practice components of palliative care philosophy are relief of symptoms, team work, communication, and relation, along with support of the next of kin [89]. As defined by the World Health Organization (WHO), palliative care may also be used early in the illness in combination with treatment aimed to prolong life [87]. Palliative care therefore includes both a long early phase and a late phase lasting from days to months. Although palliative care is usually associated with the late phase and end of life, the importance of integrating the palliative care philosophy in the early phase, which may last for years, has been emphasized [89]. A randomized controlled intervention trial of early palliative care integrated with oncologic care [90] found that patients with integrated palliative care reported higher quality of life, lower rates of depression, fewer emergency department visits and hospitalizations, and longer survival times.

The need for palliative care in severe chronic progressive illness other than cancer has been stressed by WHO [87]. That palliative care should include all patients in end of life regardless of their diagnoses is also put forward in Sweden [89].

## **PALLIATIVE CARE FOR PATIENTS WITH ESRD**

Despite the particularly difficult situation of severely ill patients with ESRD, palliative care has been a neglected field in renal care [91, 92]. The limited access of patients with ESRD to palliative care has been explained as misunderstandings of the reasons for, and the practice of, palliative care philosophy. Some misconceptions are that palliative care equals hospice care, and that chronic disease does not require palliative care; survival and mortality rates are also often misread [93]. The lifesaving culture of nephrology, which includes denial of death, has also been identified as a barrier to palliative care for patients with ESRD [94]. It is reported that few people undergoing haemodialysis die with access to palliative care, and also that palliative care services for patients with ESRD vary, both within and among countries [91, 94, 95]. However,

collaborative initiatives between nephrology and palliative care professionals to develop renal palliative care are growing internationally [96-98].

In the field of nephrology, the term “renal supportive care” is also used for the care of patients with ESRD [99] based on the principles similar to palliative care philosophy. This use of two terms for two similar, but not identical, concepts can be confusing and the terms are often used together. Although Noble *et al.* [99] clarified that supportive care is not limited to the end of life, according to the WHO [87] definition, neither is palliative care. In this thesis I refer to the concept of palliative care as defined by WHO [87].

Research into, and practice of, renal palliative care have focused mainly on withholding dialysis [37] or withdrawing from dialysis [30, 100]. However, several authors have pointed to the need for earlier integration of the philosophy of palliative care [101-103] and for its use along with haemodialysis care [104, 105]. Part of palliative or supportive care, is advance care planning (ACP), a process of communication between patients, families, and health care professionals on end-of-life care. The process, involving sharing information and reflecting on the prognosis, the treatment options, and end-of-life values and issues, has been attributed with increasing hope in patients with ESRD as more knowledge and earlier information helps them to plan for the future [106]. Patients with ESRD have found ACP to alleviate fear and uncertainty, facilitate preparation for the end of life and for death, and strengthen relationships with families and professionals [107]. A focus group study including patients, close relatives, and health care professionals recommended that more family education, support, and communication is required, but adjusted to individual needs [108]. Advance directives (AD) is in some countries, although not in Sweden, a legal document stipulating the patients’ end-of-life wishes regarding treatment options, or a suggested substitute for decisions, should they not be able to communicate themselves. Still, the use of AD is rare [107, 109] and patients’ attitudes towards completing AD vary [48, 108, 109]. Palliative care in the renal care context is still largely overlooked in Sweden, and the term is often used in nephrology as equivalent to conservative management (i.e., the treatment of uremia when a decision of no initiation of dialysis treatment is taken). A recently published national care programme for palliative care [71], generated in collaboration with several disciplines and different care professions, emphasizes the need for palliative care irrespective of medical diagnosis. However, the particular perspective of end of life with end stage renal disease was not stressed and renal care associations were not represented.

## RATIONALE

In the dialysis unit many patients have several chronic progressive and life-threatening illnesses and they suffer from a high symptom burden. These severely ill patients' lives are sustained by medical technology, which also raises existential issues in a changed life situation. The complexity of their declining health and the maintenance of life with advanced technology also changes the lives of, and challenges, the patients' close relatives. Being a close relative of a person diagnosed with ESRD and treated with haemodialysis means watching the ill family member's health deteriorate over time. In haemodialysis units where the focus is on maintaining life with advanced technology, whole-person and end-of-life care may be overlooked. In a chronic progressive disease complicated by co-morbidities, it may be difficult to know when end of life begins, and this also contributes to insufficient end-of-life care. Still, about one fourth of patients in haemodialysis care are in their last year of life, which suggests the presence of death and dying in the haemodialysis unit and the need for end-of-life care.

Because many patients in haemodialysis care are older and have several chronic progressive and life-threatening illnesses, they have a need for end-of-life and palliative care. However, research into the lived experiences of severely ill patients treated with haemodialysis – and their close relatives – is still scarce. More research is needed to understand the need for, and to develop, care for progressively declining patients in the haemodialysis unit and their close relatives. The perspectives and experiences of severely ill patients' as they approach the end of their lives, and those of their close relatives, should be further investigated.

## THEORETICAL FOUNDATION

The epistemological standpoint of this thesis is the theory of the lifeworld (Lebenswelt), introduced by the philosopher Edmund Husserl as the world of people's individual subjective experiences, their lived experiences, in their human everyday world. The lifeworld is the world known before all theoretical explanations, and although we cannot leave our lifeworld, we can share it [110]. In the lifeworld our consciousness is intentional; it is directed towards something that has meaning to us, so what we experience, we experience with meaning. Thus our lived being is intentional and this lived meaning is a lived truth [111].

Merleau-Ponty [112] further developed the concept of the lifeworld, saying that as human beings we are our body and experience the lived world through our subjective and lived body. It is through our subjective body that we have access to the world by "being to the world" ("être au monde"), we are connected to the world by our body, and the body is always present. We live and have a world as long as we have – as long as we are – our lived subjective body [112]. To research lived experience is an approach in the caring sciences to increase our understanding of human existence through regarding the human being as a living whole [111]. The lifeworld is complex and multifaceted, and this complexity of intertwined dimensions is illustrated by the words of Merleau-Ponty, who wrote "The perceptual something is always in the middle of something else, it always forms part of a field" [112 page 4]. To ask openly for patients' or their close relatives' experiences of living with illness and treatment is to focus on their lived experience and their lifeworlds' with health and illness. With increased or new understanding of their lifeworlds, our behaviour may also change as our new understanding reveals new possible ways of acting [113].

## **AIMS OF THE THESIS**

The overall aim of this thesis is to generate understanding and knowledge about the experiences of patients living with haemodialysis, and their close relatives, near the end of life. The specific aims were:

- I. to describe and to elucidate the meanings of being severely ill living with haemodialysis when nearing end of life
- II. to describe inner thoughts and feelings relating to death and dying when living with haemodialysis approaching end of life
- III. to describe and elucidate the meanings of being a close relative at the end of life of a severely ill family member treated with maintenance haemodialysis
- IV. to describe end of life for patients treated with maintenance haemodialysis from the perspective of their close relatives

# METHODS

## DESIGN

To increase understanding of what it is to live with haemodialysis near the end of life a qualitative design was chosen for all four studies. Studies I and III have an interpretative design [113] and studies II and IV have a descriptive design [114].

Studies I and II are based on findings of serial [115] qualitative interviews [116] with patients over a period of 12 months. Data for studies III and IV were collected through retrospective interviews performed with close relatives of patients who had died.

Together the four studies provide different perspectives on and meanings of end of life with haemodialysis treatment.

Study II was decided upon after data collection as the interviews with patients in study I revealed rich data on their thoughts of death and dying. Study III (meanings of being a close relative of a patient treated with dialysis) was inspired by the findings of studies I and II. Study IV was conducted to add to our knowledge and understanding of the end of life until death.

*Table 1. Overview of studies*

	Study I	Study II	Study III	Study IV
Aim	To describe and to elucidate the meanings of being severely ill living with haemodialysis when nearing end of life	To describe inner thoughts and feelings relating to death and dying when living with haemodialysis approaching end of life	To describe and elucidate the meanings of being a close relative at the end of life of a severely ill family member treated with maintenance haemodialysis	To describe end of life for patients treated with maintenance haemodialysis from the perspective of their close relatives
Participants	8 patients treated with haemodialysis		14 close relatives of deceased patients	
Data collection	31 interviews over 12 months		14 retrospective interviews	
Data analysis	Phenomenological hermeneutics	Qualitative content analysis	Phenomenological hermeneutics	Qualitative content analysis



## **PARTICIPANTS AND PROCEDURES**

### **Participants: studies I and II**

Eight severely ill patients participated. They were recruited from four different dialysis clinics, two in university hospitals and two smaller satellite centres, all in an urban area of Sweden. For these studies (I and II) patients were clinically assessed as severely ill, and therefore possibly in their last year of life, by the nephrology physician and the registered nurse responsible for their dialysis treatments. For the studies, we defined this state of illness as approaching death. The assessment was based on the presence of symptoms, co-morbidities, malnutrition, and other complications according to a protocol developed specifically for this study. Inclusion criteria also required patients to have been treated with haemodialysis for at least three months, not to be listed for kidney transplantation, and to be able to read, write, and speak Swedish. Besides kidney disease, the participants had a variety of co-morbidities, including cardiac disease, previous stroke, peripheral vascular disease, diabetes, and cancer. Most participants had several co-morbidities. At the time of inclusion, all participants lived in their own homes and received haemodialysis as outpatients. Five participants lived with a spouse, and three lived alone. Their ages ranged from 66 to 87 years with a mean of 78 years. They had been undergoing haemodialysis between 15 months and just over 7 years.

### **Procedures: studies I and II**

Registered nurses in cooperation with nephrology physicians at the four dialysis clinics assessed severely ill patients according to the study-specific protocol for clinical judgement and inclusion and forwarded inclusion data and assessment according to the study protocol for 26 patients. I then selected eight of the identified patients (as previously decided) with various co-morbidities and family situations. Purposeful selection [117] was important in this study to gain rich narratives of the lived experience of the phenomenon under study. The contact nurse (for this study) at each dialysis clinic was then informed which two of their selected patients we would like them to contact first concerning the study. Selected patients received an information letter concerning the study from their dialysis nurse, including an offer to meet the researcher (and would-be interviewer) to obtain further information; this first letter did

not ask them to decide whether or not to participate. Before consenting to participation, the participants received additional written and verbal information from the researcher concerning the aim of the study, the voluntary nature of participation, their right to withdraw at any time, and the confidential treatment of data. Two selected patients declined further information after the first letter because of fatigue, and one selected patient declined participation while being given verbal information, citing pain and fatigue as reasons for non-participation. This was the first patient who had been given verbal information, and I realised then that it was important during the verbal information session to repeat their right to withdraw at any time and to emphasize that they could decide on each interview individually. I decided to contact only a few patients at a time about the study because I did not want to inform more people about the study than could be included. My plan was to inform and include patients step by step, rather than informing more patients than would be required. Because the study was prospective, it was uncertain how many interviews would be performed with each participant. However, because the first eight participants were followed over 12 months, resulting in 31 interviews and rich data, we decided not to include more participants.

### **Participants: studies III and IV**

Participants in studies III and IV, close relatives of deceased patients, were recruited through three different dialysis clinics situated in an urban area of Sweden. Two clinics were in university hospitals and the third was a smaller dialysis satellite. Inclusion criteria were being reported as a close relative in the medical record of a deceased person who had been assessed as severely ill and treated with haemodialysis (and whose death was therefore not surprising) and being able to speak and understand Swedish. Fourteen close relatives (2 daughters, 1 son, 1 sister, 9 wives, and 1 husband) participated. Participants' ages ranged from 48 to 86 years. Spouses had been married from 45 to 60 years.

Besides ESRD, the participants' deceased family members had had a multiplicity of co-morbidities including cardiac disease, previous stroke, peripheral vascular disease, diabetes, and cancer. Most had had several co-morbidities and none were listed for kidney transplantation. At 4 months prior to death 11 of the deceased patients had lived

at home, 2 were in full-time institutional care, and 1 in part-time care. In the end only 1 person died at home. Age at death ranged from 71 to 87 years (mean 80). Duration of their haemodialysis treatment ranged between some weeks and 12 years.

### **Procedures: studies III and IV**

With the assistance of a nurse, all participants but one were identified through a search of the medical records of the most recently deceased patients at the dialysis clinics. The other participant was a close relative of a deceased participant of study I and II, and also listed in the patient's medical record. The procedure for the identification of participants was approved by the head of the department and the ethical review board. An information letter outlining the aim of the study, the voluntary nature of participation, the participant's right to withdraw at any time, our wish to audiotape the interview and to use quotations, and the confidential treatment of data was sent to selected close relatives. A few days later I telephoned potential participants and offered additional information and asked if they wished to participate (except one who telephoned me first). Six people declined participation, either citing emotional stress or giving no reason; 14 agreed to participate and were then asked to suggest a suitable time and place for the interview. The 14 narrative interviews yielded rich text and were thus considered satisfactory, and no more relatives were contacted.

## **DATA COLLECTION**

### **Qualitative interviews**

From a phenomenological perspective, the aim of a qualitative interview is to access the participants' lifeworld and lived experience to research a particular phenomenon (e.g., being severely ill and living with haemodialysis nearing the end of life). The interview is meant to elicit knowledge from experiences narrated and expressed in everyday language, and the openness of the qualitative interview makes nuanced descriptions of people's lives and worlds possible [116]. The interviewer seeks the respondent's free narrative, but because the dialogues in the interviews are influenced by the interviewer, the interviewer is always a co-creator of the text [113] despite the most earnest efforts not to influence answers [111]. Interviews conducted in lifeworld

research encourage the participant to narrate as freely as possible [113] but guide the participant towards the research topic with open and follow-up questions. The interaction between the informant and the interviewer has also been described as human interplay [116].

### **Serial qualitative interviews (studies I and II)**

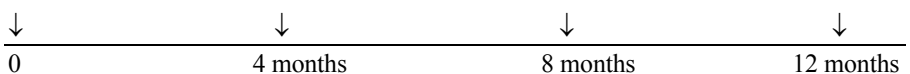
To increase the potential of gaining in-depth understanding of the participants' lived experiences while living with haemodialysis and approaching the end of their lives, I conducted serial [115, 118] qualitative interviews [116] with participants of studies I and II. Six of the participants were followed, according to plan, with four qualitative interviews each over 12 months (about every four months) from 2007 to 2008 (figure 1). One participant was interviewed five times, because one interview was interrupted, and one participant was interviewed only twice, due to family matters. Altogether I conducted 31 interviews, all in a private room.

According to participants' requests, most interviews took place in their homes; however, five interviews were conducted at a nursing home or hospital ward because, although the participants were hospitalized, they still wanted to be interviewed. All interviews took place on a day free from dialysis treatment, which I consider important for the result of rich narratives. On a dialysis day the patient is usually under stress or tired, and may be inclined to focus solely on the treatment. My offer to interview them at home was likely important to their decision to participate, as otherwise the interview would have meant an additional day of travel away from home (i.e., at least 4 days that week). Conducting the interviews in the participants' homes likely facilitated patients' free narration of living with haemodialysis, since they probably felt more comfortable and relaxed, and may have seen me as a humble guest as well as a researcher. The researcher being a nurse experienced in hemodialysis care and knowing the context is also likely to have contributed to the ease of patients' narrations.

During the interviews the participants were encouraged to talk freely about their experiences of being ill and living with haemodialysis. The interviews began with an open-ended question, "Please tell me your experiences of living with illness and haemodialysis." The follow-up interviews started with a similar question, "Please tell me about your experiences at present of living with illness and haemodialysis?" although the participants sometimes began their narrations without being asked. During interviews both open and clarifying questions were asked to help participants talk of

different dimensions (as physical, emotional, existential, and social) of their lives with illness and haemodialysis. Follow-up questions included “What did you feel?” “What did you think?” “What do you mean?” “Can you tell me more?” “Can you describe a situation?” and similar probes for detail. I found that repeating the last words the participant spoke tended to facilitate and encourage further narration without my having to direct it. Because open questions invited participants to talk about different dimensions of their experience, their thoughts and feelings about death and dying were also expressed. A question about their thoughts for the future often encouraged participants to talk of death and existential issues. Participants also related different experiences to existential issues. Dahlberg [111, page 184] quoted Gadamer on facilitating narration as being able to “be with” the participant. The importance of being near and open to the participants’ experiences was also evident in the interviews. It was also important to let participants know that silence is normal and sometimes needed in an interview, as some participants felt the need to apologise for not being conversational, and it was vital to create a permissive and comfortable atmosphere for them [113]. After the interviews (and sometimes during the interviews, according to participants’ wishes), we often had coffee and were sometimes joined by their spouses. This was a good way to finish the session and an important way to confirm and listen to the spouse, who, if at home, had been in another room during the interview. After each interview participants were asked if they were willing to be contacted again, in a few months and asked if they would like to continue to participate, or to answer any questions I may have had from the last interview. All agreed. They also had my telephone number in case they wanted to contact me. The interviews were audiotaped (33 hours) and were later transcribed verbatim. Altogether the text contained 228 930 words.

*Figure 1. Serial qualitative interviews (↓) studies I and II*



### **Retrospective interviews (studies III and IV)**

For studies III and IV I conducted qualitative interviews [116] with close relatives of deceased patients to retrospectively research [cf. 119, 120] their experiences at the end of life. The first interview was performed in 2009, the rest from December 2011 to

March 2012. The interviews were conducted about 3 to 13 months after the death of the family member.

All interviews took place where the participants wished: five in the participant's home and nine either at the participant's workplace or mine. All interviews were conducted in a private and quiet room. The participants were encouraged to narrate freely about their experiences and the interviews began with the open-ended question, "Please tell me about your spouse's (parent's, sibling's) end of life?" This question was chosen to give the participants the opportunity to decide for themselves whether to begin their narration with their own experience of being a close relative or to start with their experiences of the deceased family member's situation. This choice was considered interesting and important to the two aims of the studies (III and IV). It was also important to give participants the opportunity to decide when in their experience with their ill relative they wanted to start their narrative. The participants were encouraged to narrate freely, but were also guided, with broad questions, towards talking of different dimensions of their experiences as close relatives. During the interviews it was apparent that the close relatives had a story that they wanted to tell, with a beginning, a middle, and an end.

Some interviews lasted more than two hours, and the shortest one hour; altogether the 14 audiotaped interviews yielded 23 hours of recorded data. Interviews were transcribed verbatim and the text consisted of 216 328 words.

### **Transcription of interviews**

All interviews used in this thesis were audiotaped and transcribed verbatim. Nonverbal data such as laughter, crying, silence, pauses, and interruptions were also noted in the transcriptions to facilitate understanding and interpretation during the analyses [113, 114, 116]. I transcribed the first eight interviews myself, and an assistant reliably and accurately transcribed the remaining interviews after having received thorough instructions. Nevertheless, I read all transcriptions thoroughly while listening to the interviews. Hence the text and recordings were compared, and when appropriate, they were corrected or completed with comments on the interview in the margin of the transcribed text. Having performed all of the interviews myself and thus being close to the narration, listening once again while reading the transcripts was sufficient for me to be able to enter deeply into the interview texts.

## **DATA ANALYSIS**

### **Phenomenological hermeneutics**

To elucidate the meanings of participant's lived experiences in studies I and III, we chose a phenomenological hermeneutical method in three phases developed for health care research [113]. This method, inspired by the interpretation theory of the French philosopher Paul Ricoeur [121], combines the lifeworld philosophy of phenomenology and the hermeneutic tradition of text interpretation to understand and illuminate meanings of lived experience. Phenomenology is the study of phenomena (i.e. "things" that show themselves to human consciousness), and the lifeworld is how the world reveals itself to our conscious. Phenomenology, founded by Edmund Husserl, is the mutual philosophical underpinning for approaches that hold the lifeworld and the lived experience paramount [111]. This inspired various fields of human science research, including the science of caring. In phenomenological hermeneutics [113] experiences narrated from the lifeworld are interpreted as an autonomous text. The interpretation of this text should search for the meaning lying in front of the text, in which the utterer's meaning lies within the meaning of the utterance [121]. The lived human experience is individual, but its meaning may be interpreted in its narration in recorded interviews, transcribed as autonomous text, thus understood, and explained as a phenomenon and knowledge of human experience [113]. This method of interpretation and understanding aims to open up the possibilities in front of the text, to the world [113, cf.121]. Ricoeur [122] held that transcribed speech is not a text. The phenomenological hermeneutic method according to Lindseth & Norberg [113] is therefore not strictly in accordance with Ricoeur's ideas, since their method was developed specifically for interviews transcribed as text. However, the lived experience may be researched and interpreted through transcribed interviews, and Ricoeur's interpretation theory [121, 122] has inspired a method [113] to elucidate the meanings of lived experience, and thus to identify new opportunities for care.

### **Data analysis: studies I and III**

With the aim to describe and to elucidate the meanings of lived experience the three phases of the phenomenological hermeneutical method [113] was used to analyse the interview texts in studies I and III. In the first phase of the analysis, naive reading, the text was read as a whole several times. During the first phase (naive reading) I strived for the openness and closeness typical of the phenomenological attitude. The naive

reading resulted in a first naive and overall understanding of the meaning of the lived experiences of these patients and their close relatives.

There after the structural analysis, the methodical explanation phase, was performed. All text was divided into meaning units i.e. a part of a sentence, a sentence or a paragraph containing a meaning. Meaning units were then condensed, abstracted and assembled into themes. Themes revealed by the structural analysis were compared to and validated the naive understanding.

During the phases of analysis of data in study I the text of interviews was analysed as a whole but I also compared the text of serial interviews of each participant to identify changes or differences over time. This procedure, in both the naive reading and the structural analysis, was intended to allow a deeper understanding of the phenomenon. In the final phase, comprehensive interpretation (or understanding), the naive understanding together with findings of the structural analysis were summarized and interpreted in the light of other relevant literature and the authors' reflections and different pre-understandings. We consulted several sources in the relevant literature to illuminate aspects of the phenomenon under study [cf.113]. The method is described in three phases between which there was a dialectic movement back and forth, between understanding the whole and explaining the parts, and between closeness to and distance from the text [113] ; cf. [121].

I read all interviews several times. In study I, two other authors read the first interviews of all participants and shared between them reading some of the rest of the interviews. In study III the last author also read all of the interviews, and two other authors read some of them.

### **Preunderstanding**

The concept of pre-understanding is important in phenomenological hermeneutics. In the phenomenological hermeneutical method [113] researchers need to reserve judgement during the first phases of analysis to be open to new experiences and meanings, but then need to engage their pre-understandings in the comprehensive interpretation. However, the researcher needs to reflect upon their pre-understandings and be open to the unexpected in all three phases. Graneheim and Lundman [114] argue that in qualitative content analysis it is also important that the researcher's personal history be considered as it will influence the interpretation.

The research group engaged in the studies reported in this thesis had various different professional, clinical, and theoretical experiences and bases of knowledge, and thus



their pre-understandings also differed. The areas of experience represented included palliative care, ethics and older people, living with cancer, nephrology, and quality of life and patient education in patients with ESRD. My pre-understandings mainly originate from many years of experience as a nurse in haemodialysis care and earlier years in surgical care wards where I often nursed dying people.

### **Qualitative content analysis**

For studies II and IV qualitative content analysis was chosen [114] to analyse the data. Content analysis was originally a quantitative research method used in media research, which was later adapted for, and became important in, the social sciences [123]. Methods using qualitative content analysis have been further developed [114, 117, 124] and are increasingly used in nursing research [125]. The ontology and epistemology of qualitative content analysis is not clear but may be associated with communication theory [114]. The method is systematic and allows various depths of interpretation based on the identification of differences and similarities in the text, which are sorted into categories or themes [114]. Different methods use different concepts in qualitative content analysis [114, 117, 124]. The approach can be either inductive or (when based on earlier works for pre-existing theories) deductive. This depends on the aim of the study [117, 125]. During analysis both manifest (more obvious) content and latent content, of underlying meaning may be identified and interpreted [114, 117, 124]. For studies II and IV we chose the research procedure and concepts described by Graneheim and Lundman [114] as they take a clear standpoint about the steps and choices of concepts to be used in the methodology of qualitative content analysis.

### **Data analysis study II**

Qualitative content analysis was applied to analysing the data for study II [114], and the data from 31 interviews were then analysed with the aim of describing the patients' inner thoughts and feelings relating to death and dying. This aim was decided on because of the rich data in interviews collected in study I on this topic, hence its importance came forth.

The interview texts were read several times again to grasp the overall content in relation to the new study aim. "Meaning units" (i.e. parts of sentences, sentences, or paragraphs each containing a meaning) corresponding to the aim of study II were identified and extracted. The text of the meaning units relating to death and dying was

thereafter condensed and coded. To gain a deeper understanding during the analysis, meaning units of all interviews of each participant both over time and as a whole were compared and analysed. The coded units were re-read, compared, interpreted, and re-combined when appropriate. Thereafter the coded units were further abstracted into sub-themes and themes of underlying meaning. The abstraction into sub-themes and themes was reflected on in discussions with other authors, which resulted in an agreement of findings. The analysis procedure is described as linear but involved going back and forth between the described steps of the analysis [114]. In the process of coding, the software Open Code [126] was used to more easily gain an overview of, and sort, the data of the coded units.

I read all of the interviews several times. Two other authors read the first interviews of all participants and shared between them some of the later interviews.

#### **Data analysis study IV**

We used qualitative content analysis on the data collected in study IV [114]. The text of the 14 interviews was the same as for study III, but in this study the text was analysed with the aim of describing the end of life for severely ill patients on maintenance haemodialysis from the perspective of their close relatives. The procedure followed the steps of content analysis described above for study II, but differed in its main focus on manifest, rather than latent, content. This decision, to focus mainly on manifest content, was taken as the topic/content area was the dying person's end of life narrated from the perspective of someone else, although a close relative. This was a second analysis of the interview text (after the analysis for study III), using a different analytic method, and with a different study aim (IV) in mind. Sometimes meaning units consisted of the same words as in study III, but they were condensed or coded differently in accordance with the different aim of study IV.

I and the last author read all interviews; two other authors read some of the interviews.

## ETHICAL CONSIDERATIONS

Research involving patients close to death raises ethical considerations that must be addressed during the whole course of the research. Therefore, the principles of research ethics such as informed consent, autonomy and integrity, confidentiality, and avoidance of causing harm [127] were considered and discussed throughout this research project.

To obtain informed consent, all selected participants were provided with a letter informing them of the aim of the study, the voluntary nature of their participation, their right to withdraw at any time, our wish to audio-tape the interviews, and the confidential treatment of data. For studies III and IV, our wish to use quotations from the interviews was added to the information letter; participants for studies I and II were informed about this when given verbal information. The serial interviews with patients demanded clear and repeated information about their right to discontinue participation at any time (i.e., obtaining informed consent from patients was an ongoing process).

An ethical dilemma in studies I and II might have arisen from the clinical assessment of patients as severely ill and therefore possibly in their last year of life. This assessment was conducted to identify and describe the severity of patients' illness for the purposes of the studies, and the assessment was not conveyed to participants. They were told that they were identified through purposive sampling because of their severe illness.

In our effort to minimize potential harm we decided not to contact close relatives until at least two months after the death of their family member. The introductory letter informed them why they were contacted and how I had received their contact information. At the time of the interviews, one participant asked why she had received the letter without having first been contacted by a known nurse, who could have asked for her permission to be contacted by a researcher. I listened openly and said it was good to learn her perspective on this always difficult question. I also told her that the research group had reflected on the most ethical way to contact presumptive participants and had concluded that if close relatives were first contacted by a nurse they knew from the dialysis clinic, it might make them feel more obliged to accept participation.

These severely ill or bereaved participants narrated their lived experiences, their thoughts, and their feelings, which required the researcher to be thoughtful and

attentive during interviews. Because of the distress the interviews might invoke, and the possibility that participants would need support, a contact at the dialysis clinic was available. Participants were also invited to contact the interviewer (the telephone number was in the information letter) if they wished to talk after the interview. Two participants called shortly after the interview, one to clarify some data, the other to express her appreciation of having had the opportunity to talk. This further confirms that interviews may be positive experiences for people in vulnerable situations, as shown both in after-death interviews [128-130] and in interviews with patients [131, 132].

Patients from the dialysis clinic in which I then worked were not included, as it could have been difficult for both me and the participants to consider the interviews and findings strictly as research. It was also vitally important that staff in partaking dialysis clinics had no part in deciding who, of the assessed and identified patients, to invite to participate. This, as personal relationships with the patients could have influenced their choices and skewed the sample.

The ethics of conducting research in a group as vulnerable as severely ill patients with progressive illness must be considered very carefully. However, excluding severely ill people from participation solely because of the severity of their illness would mean depriving them of their autonomy in a phase of life when they are already experiencing several types of human loss. To exclude a patient group because of their illness may also be questionable according to the principle of justice [cf.127].

All four studies were granted ethical approval by the Ethical Review Board, Stockholm, Sweden with Dnr 2006/1199-31/2, 2009/407-31 and 2011/1189-32.

# MAIN FINDINGS

## STUDY I

### **Living with haemodialysis when nearing end of life**

Being severely ill and living with haemodialysis when approaching the end of life means living with suffering simultaneously with reconciliation and well-being. Participants' narratives revealed meanings of being severely ill and living with haemodialysis as intertwined with being old. The structural analysis disclosed meanings of living with haemodialysis when approaching the end of life as 11 subthemes gathered into the 3 themes presented below in bold text, with the 11 subthemes introduced in italic text.

**Being subordinate to the deteriorating body** involved *feeling that fatigue is taking over life*, thus feeling excluded from important parts of life. Fatigue also raised questions of how much longer they would manage living with haemodialysis. They were *interpreting their deteriorating body*; observing, comparing, and recognising different conditions with different meanings. Feelings of not being allowed to grow old in peace were expressed, when patients were examined or treated for conditions they considered normal for old age. Progressive illness and dialysis entailed *being increasingly dependent* on family and professional caregivers. This involved fears of being a burden on close family members and increased feelings of vulnerability, also in the haemodialysis unit. As their illness progressed, hours of freedom faded away and participants experienced *feeling trapped* in time and place by their dialysis schedules, other medical appointments, and frequent hospitalizations. Dialysis was acknowledged as adding time to life, but also taking time from the life left. Patients experienced *having a changing social life*, with growing impediments but also a narrowing focus. Social interactions at the dialysis clinic helped many to endure the lifelong treatment. For some a social role as a cheerful patient was helpful, but that role could also be limiting.

**Changing outlook on life** involved *living with the sorrow of having to give up plans* and hopes for old age as they were lost to illness and haemodialysis. Participants expressed *having to accept a changed life* and its associated losses. This seemed an ongoing and sometimes difficult process with a progressing illness that constantly required adjustments in living. When approaching the end of life, earlier worries about incapacities could also change into attitude of being happy for present achievements.

Participants were *hovering between living in the present and worrying about the future*. Focusing on the present was one way to cope with lifelong treatment and knowing that their “future” was already behind them. Facing the future now meant facing worries and dying. Participants expressed hopes, however, of enjoying life in the present and in their remaining time. Patients had ambivalent feelings towards haemodialysis and reported *reflecting on the meaning of a life with haemodialysis* when they were in pain or suffering from such imminent threats as amputation. This was not, however, to be understood as a wish for dialysis withdrawal; these patients still wished to live. Participants described **striving for upheld dignity** as they were *losing control in life with illness*. When losing control over the deteriorating body, lack of participation in decisions added to feelings of losing control. The complexity of having several co-morbidities increased feelings of insecurity, as participants perceived that they were solely responsible for coordinating their medical care as they were the only one living with, and taking interest in, the whole. Narratives also revealed tension between the desire to trust the professionals and the fear of being deprived of participation. When *striving to maintain sense of self*, feeling appreciated and respected in life was important, hence encounters with health care professionals who lacked, or had lost, interest in their situation negatively affected their sense of self. It was vital that health care professionals listened to and acknowledged their suffering apart from the effects of dialysis. Complexities arose when patients and health care professionals were out of step in their understandings and expectations.

## STUDY II

### **Thoughts on death and dying when living with haemodialysis approaching end of life**

The presence of death was multifaceted and significant for patients living with haemodialysis and approaching the end of life. Patients’ thoughts and feelings about death and dying were complex, and they fluctuated both during and between interviews, revealing that existential issues and needs are interwoven with experiences in the physical, social, and psychological dimensions. The findings of study II were formulated as 10 sub-themes (*italics*) within three themes (**bold text**).

**Being aware that death may be near** involved *being reminded of death and dying by the deteriorating body*, and some pains involved an especial threat of impending death. Old age in itself was also a reminder of death. Patients were *reminded also by the worsening conditions or deaths of fellow patients*, which caused internal questions of

their own about dying and who might be next. Closeness to death was also expressed as *knowing haemodialysis as a border to death*, which was sometimes apparent in the body between treatments. Death had for some become a threat as soon as haemodialysis had become necessary.

**Adapting to approaching death** involved *looking upon death as natural* when ill and old, and as an inevitable part of everyone's life. Feelings of having lived a prolonged life were expressed, along with wishes to live longer. *Preparing to face death* involved reflecting on possible causes of death considering all co-morbidities, and reflections on whether and how to prepare oneself and others. *Hopes for a quick death* were expressed and appeared to be connected to uncertainty about the end of life and dying, but the possibility of a quick death was also a threat. *Repressing thoughts of death and dying* were a way to distance death, not to deny its approach, but to allow a focus on living.

**Being alone with existential thoughts** involved a *wish to avoid burdening family* additionally with thoughts on death and dying, although some felt that their concerns were pushed away. Participants also expressed *lack of open communication with healthcare professionals* on existential issues, and the importance of trust and of professionals showing an interest was raised as important. However, patients' needs to talk varied. When a fellow patient died, the ambience in the haemodialysis unit was one of silence.

Being alone also involved reflections on *haemodialysis withdrawal*, which emerged as a *hypothetical option*. Some wanted to know more, but feared that their questions might be interpreted as a wish to discontinue haemodialysis. It was also considered a delicate topic that could be provocative if raised by personnel. When discussing their worries about dying a prolonged death, none of the participants mentioned haemodialysis withdrawal as a reassuring alternative. The hypothetical criteria for, and their views on, withdrawal, however, did sometimes change over time and in various directions as their conditions worsened. Regardless of the question of withdrawal, some participants reflected on the value of prolonging life versus maintaining well-being.

### STUDY III

#### **Meanings of being a close relative at the end of life of a family member treated with haemodialysis**

Narratives reveal that close relatives were *striving for balance and well-being following the ill family member on the path towards end-of-life* including balance for the the ill family member and for oneself. This struggle for balance was further interpreted as their maintaining health through maintaining inner equilibrium in the changed and challenged rhythm of their lives. The structural analysis yielded meanings of being a close relative at the end of life of a severely ill family member treated with haemodialysis formulated as six themes presented below in bold text.

Being a close relative means **striving to be supportive and helpful without doing harm to the ill person's self**. This demands attentiveness and flexibility in the face of challenges from the fluctuating illness and deterioration. Being supportive involved protecting the ill person, and trying to be encouraging, which involved uncertainty about whether or how to talk about death, which in turn could lead to ignoring or dismissing the ill person's hints or questions about death or dialysis withdrawal. Supporting the ill person's self until death was vital, and it was important that health care professionals recognized the dying family member as a person, thus a confirming contact with a known person at the haemodialysis unit was important even after the death. When **balancing the will to help with one's strengths and capacities**, strength was seen in sharing, meaning was found in caring, and reliance on inner strength was vital. In this balance the support of health care professionals through information and collaboration was increasingly important, and lack of such support left relatives feeling alone and abandoned. The narratives showed that it might be difficult for relatives to show their need of support in their most vulnerable times.

**Balancing the will to help with one's own ongoing life** was important as the illness and treatment influenced the whole family, and for some took over their lives. For some participants the increasing demands of their family member's illness became more and more problematic, and the will to help changed to a feeling of being burdened. With deterioration of the ill person's health, the complexity of the illness, the dialysis, and the co-morbidities **increasing responsibility involving dilemmas** arose.

Responsibilities could change incrementally with the deterioration of health, but could also increase quickly, and could change with fluctuating health. Relatives could also feel obliged to become an agent for coordinating professional care. Increasing responsibility also involved difficult moral dilemmas. Deterioration could raise



questions about resuscitation or haemodialysis withdrawal, and some relatives were involved in those decisions. Participants expressed the importance of being invited to talk about their family member's illness, situation, and treatment, and expressed that the responsibility and the attendant moral dilemmas could provoke feelings of guilt. Being a close relative during the end of life of an ill family member also means **striving for a good life together in the present**. Achieving tolerance towards life and its restrictions helped them to see the good in a situation that could not be altered. Living as normally as possible appeared to support their balance in life, and taking one day at the time was a way to cope with challenges and to enjoy life towards the end.

**Living with awareness of death** means knowing that the old and severely ill family member may not live very long with haemodialysis. Some had appreciated being informed about the prognosis earlier; others who had not been informed earlier expressed their wish to have had the opportunity to ask their own questions. However, they did not talk with the ill family member about the prognosis because they were unsure that the family member had understood or wanted to recognize it. Some close relatives described becoming accustomed to a fluctuating illness with critical episodes, and feeling that the ill person would survive each crisis as they had the last. Even though death was unpredictable, the ill person's weakening body was a sign that the end of the path towards death and the end of their lives together was drawing near. Narratives revealed that awareness of death might still involve feelings unpreparedness; it was difficult for participants to grasp the closeness of death, since awareness is not the same as understanding.

#### **STUDY IV**

##### **End of life of patients treated with haemodialysis as narrated by their close relatives**

The end of life patterns of older patients with co-morbidities treated with haemodialysis, as narrated by close relatives, are presented as five categories in bold text and seven sub-categories in italics and in figure 2.

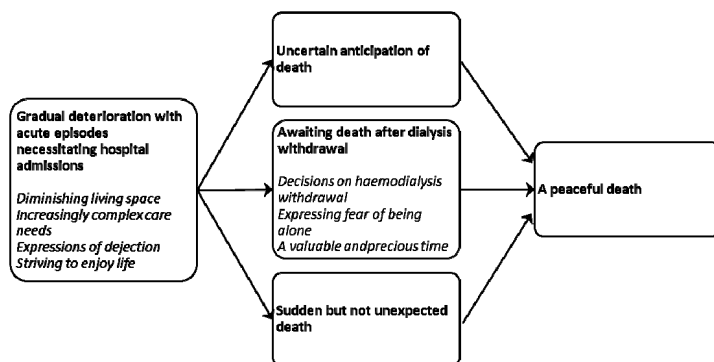


Figure 2. Gradual deterioration passed in the last weeks into three different end-of-life paths.

Close relatives described patients' **gradual deterioration with acute episodes necessitating hospital admissions**. This involved *diminishing living space*, as patients' bodies gradually deteriorated and their dependence on others increased. Patients had various co-morbidities and thus various symptoms, with fatigue and pain the most recurrent, and these symptoms were not always well managed. As patients' health deteriorated, their close relatives experienced *increasingly complex care needs* and they described the difficulties of managing several co-morbidities and complications with different specialists and care givers. In the last months, some patients went back and forth between emergency ward, home, nursing home, and dialysis clinics. Four months prior to their deaths, 11 patients still lived at home; institutional care was often unthinkable to them, but only one died at home.

Close relatives described patients' *expressions of dejection* and described that although some reflected on haemodialysis withdrawal, the relatives felt at the time that their ill family member did not really wish to end treatment, as they continued to find reasons to live longer and seemed saddened by questions from the dialysis clinic about withdrawing from treatment. The relatives also described seeing that the patients were *striving to enjoy life* and moments of well-being.

Gradual deterioration passed in the last weeks into three different end-of-life paths (figure 2 above). For some, the last weeks involved a gradual physical decline that led to an **uncertain anticipation of death** as life faded away. These patients expressed the feeling that they were dying, and some also sought closure with the haemodialysis personnel. **Awaiting death after dialysis withdrawal** was a path marked by

deterioration, suffering, and complications resulting in *decisions of dialysis withdrawal*. These were most often reported as independent decisions by the patient, but prompted by a question from the physician. Withdrawal was also described as a way for the ill person to regain control and self-determination in their vulnerable state, and some surprised their close relatives by deciding to terminate treatment. Some close relatives felt there was not enough time for reflection and that they were faced with an ultimatum when asked about withdrawal by the physician. Awaiting death, some patients had expressed a *fear of being alone*, and had asked their close relative to stay at the hospital. However, some relatives had been uncertain about how to respond to this request because they were unsure about how much time remained to the patient and how the staffs would react towards them staying. The time between haemodialysis withdrawal and death varied from 4 to 21 days, and experiences during these days varied and sometimes fluctuated. It was described as a *valuable and precious time* for the dying person with family and sometimes friends gathering and reminiscing, but some patients in their last days were also described as to have suffered, mainly from itching, and wished in agony for their lives to end.

For other patients **death was sudden but not unexpected** after recent intensive care, as they had expressed the feeling that death was approaching. Afterwards one spouse wondered whether home would have been a better place for the end of life than the intensive care unit had it not been for the haemodialysis treatments.

Close relatives tended to think that the patients avoided talking about death, also after a decision to withdraw dialysis, either because it was too painful or because they did not want to burden their relatives. Some patients had touched upon the subject of death but had not talked about it any further.

Although different and individual, all end-of-life paths were described as ending in a **peaceful death**. Death by cardiac arrest in the haemodialysis unit was also described as peaceful when the decision not to resuscitate had been taken beforehand. Most patients' deaths were described as if they had fallen into a deeper and deeper sleep, but some were suddenly alert and awake the day before their deaths, and these deaths seemed more cruel to their relatives.

# DISCUSSION

## REFLECTIONS ON FINDINGS

The findings of two prospective (I and II) and two retrospective interview studies (III and IV) illuminate the experiences of patients' living with haemodialysis when approaching end of life and those of their close relatives' as death approaches. Findings show intertwined meanings of their complex lifeworlds near the end of life. Their lived experience informs us about being human in the world at the end of life, and thus gives us the opportunity to learn how to enhance care in the haemodialysis unit.

### Living close to death in a borderland of living-dying

Taken together the findings show that being severely ill and living with haemodialysis means living close to death on several dimensions, as if in a borderland of living-dying. Patients know their life path is approaching death; they feel their future is already behind them, that their life is vulnerable, and that they are close to death since their existence depends upon haemodialysis treatment. Death is also threateningly close because of frequent acute episodes of co-morbidities and complications. Thus though they continue to live, patients live with a multifaceted and imminent presence of death in a borderland between life and death. Findings suggest a shared borderland between living and dying where patients and close relatives focus on living. In this borderland the beginning of the end of life and what will be the cause of death are uncertain in their lifeworlds of illness and maintenance of life through advanced technology. Life in this uncertain borderland may complicate and challenge communications and interactions for all parties: the patient, the close relative, and the health care professional, and hence the approach of end of life may not be openly acknowledged and planned for. The findings of study IV show that patients' gradual deterioration, complicated by co-morbidities and increasing acute episodes (marked by complex symptoms and existential issues) towards the end, may follow three main patterns in the last weeks, when some face the boundary situation of deciding whether to withdraw from haemodialysis and when the uncertainty of death becomes a certainty.

### In a borderland of living-dying with suffering, reconciliation, and well-being

Patients' lived experiences revealed the meanings of being severely ill and living with hemodialysis when approaching end of life as living with suffering simultaneously

with reconciliation and well-being (I). Their suffering from increasing impediments and the consequences of their deteriorating bodies (e.g. progressive losses, threats, and uncertainty facing the end of life) showed not only physical suffering, but also psychosocial, emotional, and existential pain, as these dimensions are intertwined (I, II, IV). Suffering, defined as the experience of threat to some crucial aspect of one's self, being, or existence [133], is evident in all four studies. This was related to illness, treatment and/or interaction with others, as health care professionals. A deteriorating body and increasing symptoms evoked meanings of suffering and existential loss and threat (I, II, IV) such as social abandonment, loss of dignity, loss of identity, and imminent death, showing that as human beings we experience in terms of meanings [cf.111]. This emphasizes the significance of the symptom burden these patients experience. The meanings ascribed to being subordinate to the deteriorating body may be enlightened by Merleau-Ponty's assertion that as human beings we *are* our body, and experience the lived world through our always present body as we are connected to the world through our lived subjective body [112]. Thus the deteriorating body changes our lifeworld and access to the world. These patients' bodies are also connected to the world by their dependence on dialysis treatment, which further points to their changed of access to the world, and thus to their changed existence. Suffering is experienced through the lived body, as illuminated in the findings of this thesis, as the old and ill deteriorating body limits living space and existence (I, IV) and involves questions about the meaning of life with haemodialysis (I, II, IV).

Meanings of the lived body further the complexity of the symptom burden these patients experience. The complications of the several co-morbidities and symptoms reported in the findings also suggest that these patients' symptoms may be overlooked (I, IV). This may increase their suffering not only through lack of treatment for the condition, but also through their possible feelings of being neglected by the personnel. Symptoms have been found to be underestimated in renal care [25-27] and to contribute to reflections on haemodialysis withdrawal [33]. The extent of patients' suffering from symptoms and the meanings of their symptoms are highlighted in this thesis as they enhanced their close relatives' understanding of patients' decision to withdraw from dialysis (IV).

The body and physical contact were found to be important also in alleviating suffering. For some patients the care from the nurse in the dialysis unit was as important for human bodily contact and well-being as for medical treatment.

The focus on living in the borderland between living and dying was evoked by findings showing that patients (I, II) and close relatives (III) focused on living in the present and strived to enjoy life, despite the difficult circumstances. In a previous interview study [48] regarding end-of-life decisions it was also found that patients on haemodialysis preferred to focus on living while enduring the burden of illness and treatment. In study I patients expressed reconciliation with their present and burdened life and thus found well-being (I). Close relatives reported achieving tolerance of their changed life as part of finding joy in life in their search for balance and well-being (III). Our interpretation of reconciliation with life and hence experiencing suffering simultaneously with well-being is in line with Dahlberg *et al.* [134], who interpret Heidegger to mean that as human beings we have the potential to reconcile ourselves to life with limits; in spite of losses and suffering we can find well-being. Well-being has been described as a vitality that includes the opportunities of movement (engagement and connectedness with others, other spaces, times, and mood), and peace (coming to terms with the present, i.e. the changed life) [134]. Reconciliation with the changed life may also be regarded as the ability to find meaning in life. The existential philosopher Frankl [135] posited that as human beings we have the ability to find meaning in situations we *cannot* change by choosing our attitude, which he called attitudinal values. In our findings, coming to terms with the constraints of the disease and its treatment appeared to be an on-going process accompanying deterioration and complications, new losses and challenges, and thus new situations for both patients and relatives. Hence, acceptance of, and reconciliation with, their present and changing lives were continually challenged (I, II, III, IV). This may be regarded as a challenge met by a change of attitudinal values (i.e. changing the stand we take in an unchangeable situation) [cf.135], which the older participants related to being old. They described having to accept living with infirmities and limitations as part of nearing the end of life (I).

The evident pattern of close relatives striving for balance and well-being in their lives with an ill person may be related to their exposed and vulnerable situation in the shared borderland of living-dying. When close relatives (III) follow their ill family member towards the end of life, their life rhythms are changed and challenged, which

may be illuminated by the philosopher Gadamer's [136] description of health as inner equilibrium and his idea that in the rhythm of life we strive always to regain balance. This may also be consistent with patients' expressions of reconciliation to limitations in their changing lives, which may express a struggle for balance as an important component of well-being (I, II). Their reconciliation with their changed lives and their focus on living may also be an expression of the importance of the meaning of life when living close to death, and as life closes down life values may be reappraised. This is especially interesting in relation to patients' reflections on prolonging life versus maintaining well-being at the end of life; prolonging life (postponing death) was not always regarded as a crucial value.

Feeling connected to close family or other relations appears to be increasingly vital to the patients' meaning of life towards the end (I), while worries about being a burden to those who make life worth living also increase (I, II). These taken together may greatly contribute to these patients' vulnerability. Feeling important to loved ones, in spite of illness and dependence, was very significant to the patients (I) and also to their close relatives, who wished for confirmation of their significance to the patient (III). Patients' connections to their families (I) may also be understood as their means of gaining strength in life; close relatives also expressed caring in terms of meaning as strength, and strength is a facet of sharing the illness (III). This may be understood as an expression of being with each other, of giving and receiving, as the two other values and sources of meaning in life (in addition to attitudinal) described by Frankl [135] – creative values and experiential values. Creative values are all we give to others and the world; experiential values are those we receive, such as love.

Feelings of connectedness have also been shown to be important in alleviating suffering [137]. This thesis shows the significance to the patient of being seen and valued as a person and confirmed in their lifeworld with its existential struggle and suffering (I, II) which is in line with findings by Haggren *et al.*[42]. With increasing demands, close relatives also need professional support that offers them acknowledgement for their own sakes, along with collaboration and information (III) which is also described in previous studies of their situation at end-of-life [59, 60]. This strengthened relatives in their complex situation and vulnerable state as they faced increasing responsibility which involved moral dilemmas (III).

## In the borderland of living-dying – with complexities of awareness and uncertainty of dying

Life in the borderland of living-dying, with death approaching but uncertain, illuminates the complexities associated with awareness of dying. Findings show patients' and close relatives' awareness of death to entail a long period of uncertainty, with the threat of death present since the initiation of dialysis (II, III) also seen in previous studies [42, 63]. Living with the presence of death, patients' existential thoughts and feelings related to their bodies, their co-patients, their dependence on treatment, and their various co-morbidities fluctuated and changed (I, II). These fluctuating feelings are consistent with earlier findings in the dying [70, 82]. However, our findings show that these patients lived with a complex awareness of their long existential struggle in the borderland of living and dying (I, II). Being aware of and adapting to the nearness of death may be consistent with repressing thoughts about death (II, III), which may in turn be related to maintaining a subtle balance between recognizing approaching death and recognizing remaining life [138].

Being repeatedly confronted with death complicates people's awareness and can be interpreted as living on a roller coaster [55]. Severely ill patients and relatives may then also feel distress to repeatedly say their last farewells [131]. In the findings of study III close relatives revealed that the patient's fluctuating illness and sometimes critical periods could be alarming, but their repeated (if limited) recovery could also leave relatives feeling at the next episode that their loved one would recover again as before. Awareness of death may therefore still involve difficulty comprehending the actual closeness of death. These findings suggest that despite a long period of awareness, when death is uncertain close relatives may still not feel prepared when it occurs. This further confirms that awareness of death and dying is a complex concept on several different levels. This complexity may be arduous seeing that in a questionnaire study [139] of awareness time of a husband's impending death of cancer a tendency was found that a longer awareness time (more than a year) implied an increased risk of morbidity of the widow.

Findings from all four studies show that expectations about death sometimes changed or fluctuated with co-morbidities and complications, although in study IV close relatives' experiences showed three main patterns in the last weeks of the patient's



life. After the patient's gradual deterioration with an increase of acute episodes relatives experienced; uncertain anticipation of death as life fades away; awaiting death after dialysis withdrawal; or, sudden but not unexpected death after recent intensive care. Findings show that awaiting death with certainty, after dialysis withdrawal, may be a valuable and precious time, but may also involve the fears of death and of being alone.

#### Challenged communication and interaction in a borderland of living-dying

The uncertainty inherent in living close to death in the living-dying borderland involved significant complexities and challenges in communications and interactions. Findings suggest that both patients and close relatives repressed thoughts of death or worries about the future not only to focus on living, but also out of consideration for each other as they did not want to increase the other's burden (I, II, III). This may also be related to the subtle balance between living and dying that both parties try to maintain. However, the desire to protect their family member entailed facing existential loneliness for both patients and close relatives (I, II, III). In a small questionnaire study in patients receiving haemodialysis 78 % of participants responded that they were comfortable talking about death, but only 50% of participants were comfortable talking about death to family and friends [140] which also shows a hesitation to talk to each other about death. In study III some relatives wished they had talked more about existential issues before their loved one's death (III). This finding may support health care professionals in their guidance of families about communicating about death. In a nationwide study [141] of parents who had lost a child to malignant disease, it was found that no parent who had talked of death with their child regretted this, but nearly a third who had not talked of death regretted not doing so. Despite the different context, this may further support health care professionals in the issue of communication. Findings show that existential loneliness may partly be due to one's inability to share death, but may also arise from the uncertainty of how to share existential issues, and with whom.

Patients described feeling hesitant and uncertain about talking to health care professionals about death and dying and found it difficult to bring up existential topics (II). Their awareness of approaching death also seemed to be based on signs and inferences, rather than on open communication with health care professionals (II). The importance of trust in communication was mentioned by both patients (II)

and close relatives (III). One barrier to communication on difficult issues may be that some patients feel they have a social role to fulfil in the haemodialysis unit and withhold their thoughts in order to be liked (I). This suggests that nurses in haemodialysis care must reflect upon the power difference in their long term relations and social interactions with patients. Withholding existential concerns from health care professionals may also add to feelings of existential loneliness (II). Our findings coincide with reports of obstacles to existential support such as stress, fear, and lack of knowledge on the part of health care professionals [142]. This may be related to nurses being enmeshed in technology in the dialysis unit as earlier described [15]. However, attending to technology may also be a way for nurses in the dialysis unit to avoid challenging communication situations that demand additional knowledge.

In this thesis we learned about the existential and ethical complexities of communicating about patient's dependence on advanced technology to sustain life. When patients worried about the end of life, the possibility of dialysis withdrawal was mentioned as a hypothetical option, rather than as a reassuring alternative (II). However, the patient's struggles to find or maintain meaning in life were sometimes expressed through reflections on the meaning of haemodialysis (II, IV). Over time and with deterioration in health, attitudes towards dialysis withdrawal could shift to both a more negative and a more positive approach (II, IV). During the last weeks of life some patients faced the existential question of dialysis withdrawal, which also meant deciding to allow their own lives to end (III, IV). This decision might be understood as reaching the point when their suffering outweighed any meaning they could find in a life situation that could not be changed. This attitudinal value [135] weighing the meaning of life against suffering may offer the patient taking the decision to withdraw from haemodialysis an opportunity to fulfil another meaningful value: dignity at end of life. In study IV, the patient's decision was understood by close relatives as a way to regain control and self-determination after a period of pain, loss of control, and suffering (IV). This may be the point at which a patient feels that dialysis prolongs suffering rather than life and meaning.

Physicians face ethical dilemmas and feelings of authority over the patient in relation to decisions on haemodialysis withdrawal [143]. We found that the decision on haemodialysis withdrawal was most often reported as an independent decision by the ill person, although it tended to occur after a probe by the physician (IV). Some close relatives felt that the question of withdrawal was put forward as an ultimatum rather

than an option and without enough time for reflection (III, IV), which raises the challenge of communications between physicians, other health care professionals, patients, and patients' families. That patients expressed a fear that the physician would misunderstand them as wishing to cease dialysis reflects the authority of physicians (II). When the question of haemodialysis withdrawal is raised by health care professionals in the dialysis unit, it may also be provocative (II) and cause sadness and feelings in the patients of having their worth as human beings questioned (IV) at an already vulnerable time when feelings of value greatly influence suffering or comfort (I). This points to the challenge of showing that life is allowed to end, and that dialysis may be withdrawn, without professionals lessening the patients' feeling of worth and the meaning of their life. This is important, as we found (in agreement with Öhlén [137]) that feelings of worth are vital to the alleviation of suffering close to death. The respect for the routine of the haemodialysis treatment itself may also be reflected on, as some close relatives said that the patient could have died at home had it not been for the demands of journeys to the dialysis treatment.

We found that patients may need closure after their long relationships with the health care professionals in the haemodialysis unit (IV). Closure or maintaining contact should be considered when patients have to change or leave a dialysis unit at the end of life, because a broken relationship may evoke feelings of unimportance that increase suffering at end of life. Showing respect for the patients and their value was significant also after their deaths, as after a long period of haemodialysis treatment and contact close relatives tended to need confirmation and closure (III).

The difficulty of knowing when the end of life begins, since death is often unpredictable and uncertain in haemodialysis care, may be a barrier to communicating about the end of life, as shown in a study of care of severely ill patients with heart failure [144]. However, our findings show the importance of inviting the patient and the family in the borderland of living-dying to talk about the situation and their thoughts for the future. However, patients and close relatives may not always want to talk at the same time, and patients may not want to talk during dialysis treatment [108]. Patients express worries about their future and the end of life, but report that renal care professionals seldom talk to them about these matters (II), which is consistent with earlier findings [145]. Discussions of the prognosis and the end of life may enhance patients' hope, because this helps them to plan for their future [106]. Study I also shows that patients hope for a good life in their time

remaining, thus communication earlier in the illness and the haemodialysis treatment is important, as an early relationship of openness may also facilitate support when death is imminent but unpredictable. Listening to and sharing the patients' uncertainty may also help to alleviate their suffering instead of allowing the uncertainty to increase their existential loneliness. An uncommunicated uncertain awareness of death should not reduce the quality of care at the end of a patient's life. Findings showing the complexities that arise when patients and professional caregivers are out of step in their understandings and expectations underline the importance of talking openly to patients and to their close relatives and listening to their own understandings of the illnesses, treatments, and situations they are dealing with.

## **METHODOLOGICAL CONSIDERATIONS**

To reach trustworthy findings and conclusions choices must be made carefully and reflected upon throughout the entire research project. Thus the interrelated concepts of credibility, dependability, and transferability were reflected on at different stages of this research [114, 117].

### *Design*

The choice of qualitative design is a strength of this thesis as it increases opportunities to expand our understanding of the lifeworlds of patients approaching the end of life and of their close relatives. This is paramount to developing and improving care for these people [cf.111]. Our aims further directed decisions on the designs and methods of the four studies, which further strengthen the credibility and trustworthiness of our findings [114].

### *Inclusion and participants*

In qualitative studies the purposive selection of participants is vital to collect rich, in-depth data that reflects variations of the phenomenon under study [117]. The clinical assessment of patients to identify potential participants with severe illness for studies I and II based on their symptoms, co-morbidities, malnutrition, and other complications may be considered a weakness. However, the research group, in collaboration with clinical experts, considered this the best way to identify severely ill patients approaching end of life. Potential participants in the study group were identified by

experienced physicians and nurses in dialysis care according to a study-specific protocol. I then purposively selected identified candidates for the study from the four different dialysis clinics, of both genders and various family situations and co-morbidities, thus with various experiences, which also adds to the credibility of the research [114, 117]. The purposive selection was important partly to make sure, for example, that not all participants by chance had cancer, which might then have led to narratives dominated by the experience of cancer illness. It was also vitally important that the clinic staff did not decide who to invite to participate because a patient's personality or personal relations could have influenced decisions about inclusion. Participants' narratives show that they also thought that their lives were ending and death was approaching, which adds to the credibility of the inclusion protocol. The decision to limit the sample size to 8 participants was taken when 31 interviews with these people had resulted in rich, varied, and in-depth data. Because the data collection was prospective with severely ill patients, the number of interviews per participant could not be predicted beforehand.

In studies III and IV, 14 close relatives (2 daughters, 1 son, 1 sister, 9 wives, and 1 husband) were included. The numbers of various relations to patients were determined by their positions in the medical records of the most recently deceased patients described in the inclusion criteria. Participants were identified as the close relatives mentioned in the medical records of the most recently deceased patients who had been treated with haemodialysis and assessed as severely ill, and whose deaths were therefore not unexpected. This strategy was intended to identify close relatives of deceased patients corresponding to the study group of patients in studies I and II, i.e. severely ill with co-morbidities. A majority of the participants in studies III and IV were spouses and women, which should be considered in reflecting on the transferability of the findings; however, this also mirrors the reality that ESRD is more prevalent among men. Nevertheless, close relatives of both sexes and various relations and ages participated, which contributed to variation in the data and hence to increased credibility of the studies [114, 117].

The inclusion criteria for all four studies that required participants to be able to speak Swedish excluded speakers of other languages, and thus diminished the variation of the phenomenon in the collected data. Although this must be considered when judging the transferability of the findings, we considered it important not to be hindered by language problems or to risk miscommunication via a translator, either of which could

have compromised compliance and flexibility during the interviews intended to gain rich and nuanced narratives.

#### *Data collection with interviews*

The decision to collect data through serial interviews (studies I and II) was taken to increase our understandings of living with haemodialysis as the end of life approaches. This approach was significant in yielding an in-depth understanding, as the participants were severely ill with various progressive chronic diseases. The longitudinal approach increased the possibility of identifying changes and variations in their experiences [115, 118] and thus increased the richness of the data and our understandings. Repeated encounters in interviews over time are likely also to have facilitated conversations on existential issues, as trust built in earlier interviews may be vital to participants' willingness to talk about such subjects. That all interviews were conducted on a day free from dialysis is a strength of these studies, contributing to rich narratives of living with haemodialysis, since on a day with dialysis the patient is likely to be stressed, tired, and prone to focus on the treatment itself, rather than life as a whole. Most interviews were conducted at the patient's home, which is likely to have put interviewees at their ease; however, rich data were also obtained from interviews conducted in hospital or at a nursing home. The wish to be interviewed, even when hospitalized, may have been more fundamental than the place of the interview.

The decision to conduct retrospective interviews for studies III and IV was taken to increase understandings of being a close relative of a patient at the end of life, but also to increase understanding of end of life for patients, through the perspective of their close relatives. This was thus also a way to augment the findings of the earlier patient studies, as those participants were not followed until their deaths. The retrospective interviews therefore also contributed to the main aim of this thesis through the inclusion of more patients' stories, even though they were narrated from the perspectives of close relatives. It is also a strength of study IV that this research question was decided on before the data collection in studies III and IV, allowing the narration and follow-up questions to be asked with both studies in mind.

Sometimes, especially in these retrospective interviews with two aims, it could be difficult to decide on follow-up questions during interviews; however, there was always time to come back to topics or crossroads in the interview. Participants were told

beforehand that during interviews I might write down words (i.e., memos of what to remember to ask more about later in the interview). In this way I could avoid disturbing their narration, but still remember to ask follow-up questions.

Retrospective interviewing is a well-known method for researching the end of life [120] but its limitations must be acknowledged since narratives based on memory may be reconstructions or participants' memories may fail. There is no consensus on the best timing for interviews after the death of a loved one. One strength of these studies may therefore be the variation in the interval, from 3 to 13 months, between the death of the family member and the interview. Close relatives had rich narratives to tell and their lived situations were easily recalled. What was important to them seemed to be well remembered, and what is important to participants is fundamentally important to this thesis, since close relatives can provide important insights [120, 146].

The possible significance in the 45 interviews of my experience as a nurse in dialysis care should also be reflected on. Knowing the context may have facilitated the dialogue and interplay in the interviews. When the interviewer is an experienced nurse, patients and close relatives may feel a level of trust that allows them to narrate freely. On the other hand, being so familiar with the context may also mean I risked making hasty interpretations of some answers without asking for further elaboration. I did, however, strive to be open and to ask follow-up questions, aware that interviewees are also co-creators of interview narratives through the effect of their questions, behaviours, and abilities to listen. I also strived to be compliant and considerate to encourage free narratives, which also supports the credibility of the studies [113, 114]. I discussed the interviews with my co-authors, and at the beginning of my doctoral studies the interviews as conducted were examined and discussed thoroughly regarding follow-up questions.

### *Data analysis*

For studies I and III phenomenological hermeneutical method [113] was chosen to analyse the text of the interviews, since the aims were to elucidate the meanings of the lived experience. The three-phase method was chosen to increase the chances of expanding the possible meanings, and thus to contribute to a probable interpretation. This method also awakens an increased awareness of pre-understandings, which strengthens the trustworthiness of the studies.

For study II qualitative content analysis was chosen as the study was intended to identify and describe seriously ill patients' thoughts on death and dying through interviews. For study IV content analysis was chosen as the study was intended to describe patients' end of life from the perspective of their close relatives.

Phenomenological hermeneutics was not considered an appropriate method as the close relatives could only report their experiences and interpretations of the patients' end of life situation.

Ricoeur [121, 122] describes validation as an argumentative discipline, demanding reflection and argumentation throughout the research process in order to reach a probable interpretation. Therefore, I discussed the analyses and findings of all studies several times with my co-authors. The authors' different pre-understandings of the phenomenon under study contributed to critical reflections and open and argumentative discussions of the analyses, which adds to the credibility and thus to the trustworthiness of the findings [113] as also in descriptive methods there is always some degree of interpretation that should be considered [114]. There are several possible interpretations of any text [121] but after argumentative discussions we agreed upon the most probable interpretations of data in studies.

### *Use of quotations*

To illustrate the research findings, representative quotations were presented in the findings of all four papers, which added to their trustworthiness [114]. Some quotations required grammatical revision when translated into English, as spoken language may be difficult to read and understand, idioms tend not to translate directly, and direct translations may offend the quoted participant. Therefore unrevised translations may be considered unethical [116].

In study II the quotations were presented as poems, to allow the reader to appreciate the participants' quotations more slowly and therefore more deeply. In this technique the words were still transcribed and presented verbatim, but the text was divided into lines based on the participant's speech rhythms, i.e. when speaking of existential issues, participants often spoke thoughtfully with pauses, and their pauses and hesitations defined the line breaks. This presentation was chosen as most useful for the findings of study II because it was more sensitive to the participants and their narratives, since how a story is told contributes along with the content to our understanding of its underlying



meanings. The presentation of quotations as poetry in nursing research has been described as a fruitful method for helping to convey – and to touch the reader with – the experiences of the interviewees and the deep meanings of their stories [cf.147-149].

### *Transferability*

Qualitative findings are not intended to be generalized, but to increase understanding and knowledge. The findings of this thesis may be transferable to similar contexts if they are recontextualized [cf. 113] and may be of value in the care of other groups of patients than those treated with haemodialysis. The rich presentations of the findings together with descriptions of the participants and their contexts should facilitate the reader's judgement about their transferability to any other context.

# CONCLUSIONS AND CLINICAL IMPLICATIONS

## CONCLUSIONS

The overall aim of this thesis was to generate understanding and knowledge about the experiences of patients living with haemodialysis, and of their close relatives', when near the end of life. In their complex lifeworlds, the findings show intertwined meanings of living with illness and maintenance of life with haemodialysis treatment towards end of life.

The findings show a shared borderland of living-dying in which patients and their close relatives focus on living when death is close but uncertain, and a life fraught with illness is maintained with technology.

Being severely ill living with haemodialysis near the end of life means living simultaneously with suffering and with reconciliation and well-being. The meanings of living with illness and dialysis are intertwined with being old. The findings illuminate meanings of close relatives striving for balance and well-being in their exposed and vulnerable situation in the shared borderland of living-dying.

Thoughts and feelings relating to death and dying are significant and complex for people living with haemodialysis approaching the end of their lives. Patients live in a multifaceted presence of death, but their awareness of approaching death may include repressing thoughts of death, not to deny death, but to focus on living in the time left.

Living with a deteriorating body, a high symptom burden, and dependence on advanced medical technology as haemodialysis treatment was found to involve complex existential issues and suffering, and both the patients and their close relatives were often alone with their existential thoughts. The complexities of existential issues and lack of communication may increase existential loneliness for patients in haemodialysis care and their close relatives, and open communication and acknowledgement may alleviate their suffering.

The unpredictable and uncertain approach of death may complicate and challenge communication and interaction for all parties: the patient, the close relative, and the health care professional, and therefore the approach of end of life may not be acknowledged.

After a decision to withdraw from dialysis, the last weeks, from the perspective of close relatives, may become a valuable and dignified end of life that they can share, when the life and uniqueness of the dying person is more evident than the death.

Findings suggest that after a gradual deterioration in health and increasing care needs, older patients with co-morbidities in haemodialysis care follow three different main paths at end of life: uncertain anticipation of death; awaiting death after dialysis withdrawal; and sudden but not unexpected death. The end of their lives are marked by complex symptoms and existential issues related to haemodialysis treatment and withdrawal, and the uncertainty of what to expect at the end of life suggests the need for increased continuity and coordination of whole person care.

## **CLINICAL IMPLICATIONS**

Both earlier in illness and towards end of life, healthcare professionals in haemodialysis settings should:

- combine technical and medical abilities with open communication skills; listen to patients' and close relatives' lived experiences and understandings of their situation and lifeworld, and follow up with ongoing communication to avoid being out of step with the patient and family;
- conduct systematic overall assessment of symptoms;
- invite the patient and close relatives to talk about their lives and thoughts for the future, thus opening the path to talk about the prognosis and the uncertainty, about what may be expected at the end of life, and about the different care possibilities towards the end, with or without haemodialysis, and thus give them an opportunity to plan and prepare;
- address patient's and families' existential thoughts and feelings and offer opportunities to talk about death and dying, with sensitivity to individual and fluctuating needs in the unpredictable and uncertain course of dying, and support families in communicating about death;

- identify close relatives' own needs for open talk, support, and interaction with health care professionals towards the end of their family member's life, and contact the spouse or closest relative after the death even if they have other bereavement support;
- work to improve and identify the coordination and organization of care to facilitate patients' and close relatives' negotiation of the health care system in their specific situations of co-morbidities and haemodialysis treatment towards the end of life.

Altogether, the findings of these studies suggest that integrating the philosophy of palliative care [87] in the dialysis unit may support health care professionals in haemodialysis units and other renal contexts to improve care for severely ill patients on haemodialysis, both earlier in their illness and as they approach the end of their lives.

## FUTURE RESEARCH

Findings of this thesis show a need for future research into:

- the complexities of interaction, relationship, and communication in existential and ethical issues in haemodialysis care;
- existential issues and the multifaceted presence of death and dying in the haemodialysis unit from the perspectives of patients, close relatives, and health care professionals;
- patients who have decided to withdraw from haemodialysis, their decision making, and their care needs;
- the symptom burdens of severely ill patients and how much their symptom burden influences their thoughts and feeling about existential issues;
- the integration of early palliative care in the haemodialysis unit (using a randomized controlled study).

## SVENSK SAMMANFATTNING

Många patienter i hemodialysbehandling har ett flertal progressiva och livshotande sjukdomar och lider av en hög symtombörda. Dessa svårt sjuka och ofta äldre patienter är samtidigt beroende av avancerad livsuppehållande dialysbehandling vilket väcker existentiella frågor. Trots den tekniska utvecklingen är dödligheten fortfarande hög och mortalitetsstatistik visar att många patienter på dialysavdelningen lever sitt sista år. Mer forskning behövs om patienters och närståendes erfarenheter i denna situation.

Det **övergripande syftet** med denna avhandling är att öka förståelsen för och kunskap om att leva med hemodialys nära livets slut utifrån patienters och närståendes erfarenheter. Avhandlingen omfattar fyra delarbeten:

**Delarbete I** hade till syfte att beskriva och belysa innebörder av att vara svårt sjuk och leva med hemodialys vid närmandet av livets slut. Åtta svårt sjuka patienter i åldrarna 66-87 år, från fyra olika dialysavdelningar, ingick i studien. Förutom njursjukdom så hade deltagarna även andra sjukdomar såsom hjärtsjukdom, tidigare stroke, perifer kärlsjukdom, diabetes och en deltagare hade cancer. Vid tiden för rekrytering bodde alla hemma. Deltagarna följdes över ett års tid med intervjuer där de uppmuntrades att fritt berätta om sina erfarenheter av att vara svårt sjuk och leva med hemodialys. Totalt genomfördes 31 intervjuer och intervjutexten tolkades med fenomenologisk-hermeneutisk metod. Analysen resulterade i 11 subteman som sorterades i tre teman.

*Att vara underordnad den försämrande kroppen* innefattar att känna en trötthet som tar över livet, att tolka den försämrande kroppen, att vara beroende av andra, att känna sig fångad och förändring av det sociala livet.

*Att ändra inställning till livet* inkluderar att leva med sorg över att vara tvungen att ge upp planer, att vara tvungen att acceptera ett förändrat liv, att reflektera över meningen med ett liv med hemodialys samt att pendla mellan att leva i nuet och att oro sig för framtiden. *Att sträva efter bibehållen värdighet* omfattar strävan efter att bibehålla känslan för jaget och att förlora kontroll i livet med sjukdom. Osäkerheten tilltar av att ha flera sjukdomar och själv känna ansvar för att koordinera behandling. Resultaten visar komplexiteten i dessa patienters livsvärld med sammanflätade

innebörder av att leva med lidande, av den försämrande kroppen med en hög symtombörda och beroende av behandling, samtidigt med försoning och välbefinnande i livet.

**Delarbete II** hade till syfte att beskriva tankar och känslor relaterade till död och döende hos patienter som lever med hemodialys vid närmandet av livets slut.

Insamlade data från 31 intervjuer med åtta patienter (se studie I) analyserades med kvalitativ innehållsanalys. Av resultaten framgår att dödens närvaro är mångfasetterad för dessa patienter och deras tankar relaterade till döden växlade både under och mellan intervjuer. Analysen resulterade i tio subteman som sorterades i tre teman.

*Att vara medveten om att döden kan vara nära* omfattar att vara påmind om död och döende av den försämrande kroppen, av medpatienters försämrade tillstånd och död, samt av dialysbehandlingen såsom en gräns mot döden.

*Att anpassa sig till att nalkas döden* innefattar att se döden som naturlig, att förbereda sig för att möta döden, att hoppas på en snabb död, vilket samtidigt är ett hot, men också att borttränga tankar om döden. Detta framstod inte såsom förnekande av döden utan som ett sätt att fokusera på att leva.

*Att vara ensam med existentiella tankar* omfattar en önskan om att undvika att belasta familjen, bristande kommunikation med vårdpersonal samt reflektioner om avslutande av dialysbehandling. Det framkom att patienter kunde önska mer kunskap om konsekvenserna av upphörande av dialysbehandling men samtidigt befara att frågor kunde misstolkas av personalen såsom en önskan att avsluta dialysbehandlingen. Frågan om upphörande av dialysbehandling ansågs också kunna vara provokativ om ställd av personalen. Dialysavslut framkom ej såsom en reell men såsom en hypotetisk möjlighet, där attityder till avslutsfrågan kunde förändras över tiden med patients försämrade tillstånd. Attityder kunde förändras både till en mer positiv och till en mer negativ inställning till att avslutning av behandling. Resultaten visar att tankar och känslor relaterade till död och döendet är betydande och komplexa för dessa patienter.

**Delarbete III** hade till syfte att beskriva och belysa innebörder av att vara närstående under livets slut för en svårt sjuk familjemedlem som behandlades med hemodialys. Fjorton retrospektiva kvalitativa intervjuer genomfördes med närstående till en avliden patient som hade behandlats med hemodialys. Deltagarna rekryterades via tre dialysavdelningar. Intervjuerna genomfördes vid 3-13 månader efter det att deras

familjemedlem hade avlidit. Intervjuteksten tolkades med fenomenologisk-hermeneutisk metod vilket resulterade i det övergripande temat *att sträva efter balans och välbefinnande följande den sjuke familjemedlemmen på vägen mot livets slut*. Vid analysen framkom sex teman av innebörder av att vara närstående i denna situation; att sträva efter att stödja och vara hjälpsam utan att skada den sjukes jag, att balansera viljan att hjälpa med den egna styrkan och resurser, att balansera viljan att hjälpa med det egna pågående livet, ökande ansvar innefattande dilemman, strävan efter ett gott liv tillsammans i nuet samt att leva med medvetenhet om döden. Av resultaten framkom att när närstående strävar efter balans och välbefinnande när de följer en familjemedlem mot livets slut så har stöd av och kommunikation med vårdpersonal stor betydelse. En bristande kommunikation kan då ge en känsla av att vara övergiven.

**Delarbete IV** hade till syfte att beskriva livets slut för patienter som behandlades med hemodialys utifrån de närståendes perspektiv. Intervjuteksten från 14 retrospektiva intervjuer med närstående (se studie III) analyserades med kvalitativ innehållsanalys. Resultaten av intervjuer med närstående visade att patienternas sista månader innebar en gradvis försämring med tilltagande frekvens av akuta tillstånd och komplikationer som medförde akuta inläggningar på sjukhus. Denna tid innebar ett minskat livsutrymme med ökande komplexa vårdbehov med flera sjukdomar och med symtom som ej alltid var väl hanterade. De sista månaderna kunde innebära att resa fram och tillbaka mellan akutavdelning, hemmet, sjukhem och dialysavdelningar. Fyra månader före döden levde fortfarande 11 patienter hemma men endast en patient dog hemma. Patienterna beskrevs ge uttryck för uppgivenhet, men också glädje i livet. Tre mönster av de sista veckorna i livet framkom; osäker antecipation av döden när livet gradvis avtar; att invänta döden efter upphävande av dialysbehandling; samt en plötslig men inte oväntad död efter intensiv vård. Resultaten visar komplexitet gällande beslut om avslutande dialysvård vilket oftast beskrevs som ett självständigt beslut fattat av den sjuke men föranlett av en fråga från läkaren. Närstående beskrev känslor av att frågan om avslut var ställd med för kort reflektionstid. Även känslor av att vara ställda inför ett ultimatum framkom. Patientens beslut om dialysupphävande beskrevs också som ett sätt för denne att återfå kontroll och självbestämmande. Resultatet visar att efter beslut om upphävande av dialysbehandling så kunde de sista veckorna vara en betydelsefull och värdig sista tid av livet tillsammans, där livet och



den döendes person blev mer framträdande än döden, men även lidande framkom under denna tid.

**Sammantaget visar resultaten** att patienterna lever i ett gränsland av att leva och att dö, ett gränsland som delas av deras närstående. Patienterna och deras närstående fokuserar på livet och nuet när de i detta gränsland i flera dimensioner lever nära döden. De lever ett osäkert liv med sjukdom och uppehållande av livet med hemodialysbehandling. Denna osäkerhet innebär komplexitet i förhållande till medvetenhet om döden vilket också utmanar kommunikation och interaktion mellan berörda parter; patient, närstående och vårdpersonal.

Resultaten visar vikten av att vårdpersonal på hemodialysavdelning kombinerar teknisk skicklighet med kommunikationsfärdigheter och i samtal öppet lyssnar på patienters och närståendes levda erfarenheter, deras lidande, och deras förståelse av sin situation. Samtal om livssituation och tankar om framtiden bör erbjudas tidigt med efterföljande kommunikation. På så vis ges patient och närstående en möjlighet att tala om prognos, hur livets slut kan se ut med och utan dialysbehandling, och om olika vårdmöjligheter, vilket kan ge dem en möjlighet att planera och förbereda inför livets slut.

Resultaten från de fyra delstudierna påvisar vikten och värdet av en integration av WHO's palliativa vårdfilosofi (med dess fokus på symtomlindring, teamarbete, kommunikation och relation tillsammans med stöd till involverade familjemedlemmar) i verksamheten på hemodialysavdelningar. Filosofin kan hjälpa och stödja vårdpersonal på dialysavdelningar, och andra vårdenheter, med syftet att förbättra vården av svårt sjuka patienter som behandlas med hemodialys, både i en tidigare fas och när de strävar efter välbefinnande inför livets slut.

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