Living with automated peritoneal dialysis

Part 1: Literature review (15 ECTS on level 41-60 Swedish credits)
Part 2: Empirical study (15 ECTS on level 61 – 80 Swedish credits)

Master Thesis 30 ECTS
Caring Science
No: HAL- 2005:06

Author: Ann-Christin Karlsson, R.N.
Supervisor: Karin Holmén, Dr. Med. Sc.  
Examiner: Sirkka-Liisa Ekman, Prof.
Abstract

Living with dialysis treatment means disturbance and adjustment in one’s life and it is important for health care professionals to share persons’ personal understanding and experiences in order to provide good nephrology nursing care. A comprehensive understanding is lacking of the experiences persons with end-stage-renal-disease have of automated peritoneal dialysis (APD) and of the conditions influencing these experiences.

The thesis consists of two studies, where the first is an integrative literature review of scientific articles with the aim to describe every day life with APD treatment. The review showed that patients on APD had significantly more time for work, family, and social activities as compared to continuous ambulatory peritoneal dialysis (CAPD). Mental health was found to be better in APD than compared to patients on CAPD. Findings even suggested that the use of APD to treat elderly patients was effective. Not one study was found from the APD patient’s perspective.

The second study is an empirical part where six adults volunteered to be interviewed for their lived experiences of APD treatment. Using the latent content analysis the result is presented out of the themes; choice of dialysis modality, transfer to automated peritoneal dialysis, effects on daily living on dialysis, living and everyday life on dialysis, and thoughts about future. The implications for nursing research are discussed with focus on nursing empowering the chronically ill to maintain and improve the quality of life. Maximizing the individual’s power resources facilitates the individual’s ability to cope with chronic illness.

Keyword: end-stage-renal-disease, automated peritoneal dialysis, every day life, coping
# CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td></td>
</tr>
<tr>
<td>ABBREVIATIONS/DEFINITIONS</td>
<td></td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>BACKGROUND</td>
<td>2</td>
</tr>
<tr>
<td>HISTORIC FLASH-BACK</td>
<td></td>
</tr>
<tr>
<td>TYPES OF PERITONEAL DIALYSIS</td>
<td>3</td>
</tr>
<tr>
<td>Continuous ambulatory peritoneal dialysis</td>
<td></td>
</tr>
<tr>
<td>Automated peritoneal dialysis</td>
<td></td>
</tr>
<tr>
<td>Patient’s lived experience with renal replacement therapy</td>
<td></td>
</tr>
<tr>
<td>CHRONIC KIDNEY DISEASE</td>
<td>4</td>
</tr>
<tr>
<td>Symptoms of chronic kidney disease</td>
<td></td>
</tr>
<tr>
<td>End-stage renal disease</td>
<td></td>
</tr>
<tr>
<td>Incidence and prevalence of chronic kidney disease</td>
<td></td>
</tr>
<tr>
<td>OVERALL AIM</td>
<td>6</td>
</tr>
<tr>
<td>PART 1: Literature review</td>
<td>7</td>
</tr>
<tr>
<td>AIM</td>
<td>7</td>
</tr>
<tr>
<td>METHOD</td>
<td>7</td>
</tr>
<tr>
<td>INTEGRATIVE REVIEW</td>
<td></td>
</tr>
<tr>
<td>RESULTS</td>
<td>10</td>
</tr>
<tr>
<td>LIFE STYLE</td>
<td>10</td>
</tr>
<tr>
<td>QUALITY OF LIFE IN PATIENTS ON APD</td>
<td>11</td>
</tr>
<tr>
<td>COMPLICATION</td>
<td>13</td>
</tr>
<tr>
<td>COMPLIANCE</td>
<td>14</td>
</tr>
<tr>
<td>NUTRITION</td>
<td>15</td>
</tr>
<tr>
<td>APD AND AGE</td>
<td>16</td>
</tr>
<tr>
<td>PATIENT PREFERENCE AND SELECTION</td>
<td>17</td>
</tr>
<tr>
<td>DISCUSSION</td>
<td>18</td>
</tr>
<tr>
<td>METHODOLOGICAL CONSIDERATIONS</td>
<td>18</td>
</tr>
<tr>
<td>RESULTS</td>
<td>20</td>
</tr>
<tr>
<td>CONCLUSION</td>
<td>22</td>
</tr>
</tbody>
</table>
PART 2: Empirical study 26

INTRODUCTION 26

CONCEPTUAL FRAME 26

AIM 28

METHOD 28
PARTICIPANTS 29
DATA COLLECTION 30
THE QUALITATIVE INTERVIEW 31
THE INTERVIEW 31
DATA ANALYSIS 33

ETHICAL CONSIDERATIONS 36

RESULTS 37
CHOICE OF DIALYSIS MODALITY 37
One’s own informed choice

TRANSFER TO AUTOMATED PERITONEAL DIALYSIS 39
More or less one’s own informed choice

EFFECTS ON DAILY LIVING ON DIALYSIS 40
Modifying the environment at home
Adjusting to in course of the disease

LIVING AN EVERYDAY LIFE ON DIALYSIS 42
Social activities
Life that cope with dependence of dialysis treatment
Role disturbance and social relationships
Social network’s understanding of dependence

Compliance to treatment
Contacts with health care professional
Adapting and planning to carry on daily living
Avoiding and giving up

THOUGHTS ABOUT THE FUTURE 55
From relief and gratitude to fear

DISCUSSION 56
METHODOLOGICAL CONSIDERATIONS 56
RESULTS 57
CONCLUSION 62
## ABBREVIATIONS / DEFINITIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>APD</td>
<td>Automated peritoneal dialysis. Refers to all forms of peritoneal dialysis that use a mechanical device to assist in the delivery and the drainage of the dialysate from the peritoneal cavity.</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic Kidney Disease. Persisting, long-lasting renal pathologic process often associated with loss of kidney function.</td>
</tr>
<tr>
<td>Clearance</td>
<td>A quantitative measure, expressed in mL/min, of the rate at which waste products are removed from the blood by the kidney, peritoneal membrane or artificial kidney.</td>
</tr>
<tr>
<td>CAPD</td>
<td>Continuous ambulatory peritoneal dialysis. A manual treatment carried out by the persons in his or her home. This treatment is kept up 24 hours a day and is similar to that of the normal kidney.</td>
</tr>
<tr>
<td>Cycler</td>
<td>A machine used to infuse and drain dialysate from the peritoneal cavity.</td>
</tr>
<tr>
<td>Dialysate</td>
<td>A mixture of water, electrolytes and dextrose that takes up toxic products and excess fluid from the blood.</td>
</tr>
<tr>
<td>ESRD</td>
<td>End Stage Renal Disease. Term used for complete or irreversible loss of kidney function, the last stage of chronic renal failure.</td>
</tr>
<tr>
<td>GFR</td>
<td>Glomerular filtration rate. The amount of glomerular filtrate formed per minute is referred to as glomerular filtration rate (GFR), and is in the average healthy person approximately 125 mL/min.</td>
</tr>
<tr>
<td>HD</td>
<td>Hemodialysis. A process of removing chemical substances and water from the blood by passing it through an extracorporeal, artificial kidney composed of semi-permeable membranes. Is usually performed at a dialysis unit at a hospital.</td>
</tr>
<tr>
<td>Peritoneal cavity</td>
<td>From the Greek word 'peritonaion' meaning to stretch around and has a surface area of 2 m². The peritoneal cavity is the space between the parietal membrane, which lines the abdominal cavity, and the visceral membrane, that is the inner layer closely covering the organs and includes the mesenteries.</td>
</tr>
<tr>
<td>Peritonitis</td>
<td>Inflammation of the peritoneum.</td>
</tr>
<tr>
<td>RRT</td>
<td>Renal Replacement Therapy. Hemodialysis therapy, peritoneal dialysis therapy, or renal transplantation.</td>
</tr>
<tr>
<td>Semi-permeable membrane</td>
<td>A membrane with pores that is permeable to some small molecules, but not to large molecules.</td>
</tr>
<tr>
<td>Ibid.</td>
<td>Latin abbreviation for <em>ibidem</em>; in the same place. Used in footnotes and bibliographies to refer to the book, chapter, article, or page cited just before.*</td>
</tr>
</tbody>
</table>

Source: Sorkin & Diaz-Buxo, 1988

*Collins English dictionary
INTRODUCTION

My working experience, and my pre-understanding, as a registered nurse working with renal care is the major background for this thesis. In 1995, after 10 years working with hemodialysis, as renal replacement therapy, I changed over to peritoneal dialysis treatment. It emerged as a new experience for me considering the difference between the two groups of patients. The hemodialysis patient came to the dialysis unit usually three times a week receiving dialysis treatment for four to five hours at a time. There was a potential risk for the staff to ‘take over’ the patients’ responsibilities in a gentle way of being helpful, instead of using the potential within each patient to carry out what ever he/she could perform on their own. Of course, some patients who could not accept their situation, what ever the cause might be, found it convenient to stretch out their arm towards the nurses to place needles into – like ‘take care of my arm, but leave the rest of my body and soul out of whatever you do to me.’

Only a short time after my change of working commitments I saw that the patients with peritoneal dialysis treatment, who performed their modality at home every day seven days a week, had agreed with self-care from the start and had a totally different view on their lives. These patients usually wanted to take a more active part in their disease, treatment, and every day life. I say ‘usually’ because it could preferably be seen in patients who had taken an active part in choosing modality already from the start, where peritoneal dialysis was their first choice of treatment modality.

This experience pointed out that I, as a nurse, had to act more like a coach ready to support the patients in their daily life with their choice of modality, giving them the tool of knowledge – ‘tricks of the trade’ – in order to perform their treatment instead of me ‘taking over’. I found out that the way to succeed in establishing a long-standing relation with a patient was to remove the “professional” and distancing role and instead try to become a partner with the patient.

My interpretation is that I have become interested in the patient perspective by being close to the patient’s world and this has become my perspective for this thesis.
BACKGROUND

HISTORIC FLASH-BACK
The initial concept of peritoneal dialysis progressed from a novel treatment developed in the early 1740’s by Christopher Warrick, who was a surgeon in England. Warrick treated a woman suffering from ascites (a collection of fluid in the peritoneum). He decided to install Bristol water and claret wine - hoping the wine would have an antibacterial effect - into the patient’s peritoneum through a leather pipe. The therapy was discontinued after three treatments because the patient reacted violently. The story tells that the woman did recover from the ascites in a period of weeks, and according to Warrick, was capable of walking seven miles in a day without difficulty.

In 1923 the first clinical use was performed in Germany by Georg Ganter, a clinical investigator. The first patient treated was a woman suffering from renal failure following childbirth and they installed 1 to 3 litres of a solution into the peritoneal cavity, containing proper amounts of electrolytes with dextrose added for fluid removal. The solution was placed in large bottles that were boiled to insure that the bacteria had been killed, and was then installed through a simple hollow needle, with rubber tubing serving as the channel between the bottle and the needle into the peritoneal cavity. The patient was treated until the blood chemistry became acceptable and was then sent home. The patient died, and new knowledge was gained – the therapy had to be continued in order to keep patients alive.

Up to the 1950’s the methods and techniques involved inventive improvisation. The first chronic patient successfully treated was in the 1960’s in the United States. The patient survived for 6 months, after which she refused further treatment. In 1976 the concept of ‘continuous ambulatory peritoneal dialysis’ got its origin, and was at first called a ‘portable/wearable equilibrium dialysis techniques’ (Gokal, 2000).

In the late 1970’s a new technique of automated peritoneal dialysis was developed called continuous cycling peritoneal dialysis. This technique consists of automated delivery of dialysate by a cycler while the patient rests at night (Diaz-Buxo et al., 1981).
TYPES OF PERITONEAL DIALYSIS

There are two types of peritoneal dialysis. One is continuous ambulatory peritoneal dialysis (CAPD), and the other is automated peritoneal dialysis (APD).

In order to perform the treatment a soft tube, known as a catheter, is surgically placed through the abdominal wall. Sterile dialysis solution (2-3 liters) will flow into the peritoneum through the catheter. Through the process of diffusion, waste products are removed from the blood. Excess fluid is removed by the process of osmosis, using a hypertonic glucose solution. Both waste products and excess fluid are transported across the peritoneal membrane into the dialysis solution. The used dialysis solution is drained from the peritoneal cavity and replaced with new solution (Sorkin & Diaz-Buxo, 1988).

Continuous ambulatory peritoneal dialysis

This type of self-dialysis is done seven days a week on a 24-hour-a-day basis. Four to five exchanges of new solution are done each day. During an exchange, which takes about 30 minutes, the solution that was inside the peritoneal cavity is drained and new solution is installed. The new solution remains in the cavity for 4-6 hours; this is called the dwell time. The last evening’s exchange dwells overnight to allow for an uninterrupted night’s sleep (ibid.).

Automated peritoneal dialysis

This modality refers to all forms of peritoneal dialysis that employ a mechanized machine to assist the delivery and drainage of dialysate. Automated peritoneal dialysis has become the fastest growing modality of renal replacement therapy. Limitations with continuous ambulatory peritoneal dialysis, (i.e. high risk of peritonitis, treatment fatigue, increased intra-abdominal pressure) have indicated this change (Gokal, 2000).

Dialysis begins at bedtime when the patient connects to a cycler machine that automatically will replace the solution in the patient’s peritoneal cavity with fresh dialysis solution while the patient sleeps. In the morning the patient disconnects from the cycler, sometimes with a prescribed volume of dialysis solution left in the cavity. This technique frees the patient from the need to perform manual CAPD changes (Sorkin & Diaz-Buxo, 1988). As the APD machine performs the changes automatically, it leaves the patient free from dialysis related activities until it is time to reconnect to the machine the next night (Diaz-Buxo, 1996).
Patients’ lived experience with renal replacement therapy
The treatment of chronic kidney disease has developed and changed from a theory to a way of living in order to prolong the life span for patients requiring renal replacement therapy. Patients receiving long-term therapy, such as continuous ambulatory peritoneal dialysis and automated peritoneal dialysis, are subject to permanent procedures. The treatments may be stressful on a more constant basis due to the responsibility a patient must take for their health and well-being (Diaz-Buxo, 1981).

Rittman et al. (1993) described in a phenomenological study the meaning of living with chronic renal failure as described by patients’ experiences from hemodialysis. The highlight is that understanding patient’s lived experience is central in balancing the advantages of technology and the need to maintain human connections with the patients. It is also important for health care professionals to understand the experience of living with renal replacement therapy from the patient’s perspective in order to assist patients to live with this chronic illness (ibid.).

A qualitative study by Lindqvist et al. (2000) described the perceived consequences of illness and treatment among end-stage renal disease patients. Data collection was obtained by unstructured interviews with a group of 86 people living on different modalities of renal replacement therapy. An overall theme “wishes for independence and normality” was identified. The sub themes were; “wish for normality”, “wish to manage one’s own life”, “deprivation of one’s “normal” life”, and “concerns” (ibid.).

This study concludes that the perceived consequences of being an end-stage renal disease patient involve several aspects of everyday life. The authors also emphasize the importance for nurses to appreciate the patient’s view of illness as well as his/her perceived stressors and expectations and use that knowledge in nursing assessment in planning and implementing nursing care (ibid.).

CHRONIC KIDNEY DISEASE
Symptoms of chronic kidney disease
The normal function of the kidneys is to maintain homeostasis of the internal environment, and chronic kidney disease represents a progressive, irreversible decline in glomerular
filtration rate. This causes an irreversible loss of the kidney’s capability to excrete waste products, produce hormones, and regulate electrolyte and water balance (Aurell, 1997). When the glomerular filtration rate falls to 10-25 mL/min, the patient develops advanced chronic kidney disease.

At this stage the following symptoms of chronic kidney disease occur: hypertension, anaemia, fatigue, loss of muscle mass, calcification in joints and tissues, cramps, itching, increased risk of infection, food and drink not tasting the way it used to, loss of appetite, nausea and vomiting, impotence, amenorrhea, infertility, nervous system dysfunction, and sleeping disorder.

In this phase medical treatment along with dietary protein restriction is given in order to slow down the progression of the chronic kidney disease (ibid.).

**End-stage renal disease**

When the glomerular filtration rate is 5-10 mL/min the patient enters a phase called end-stage renal disease and the patient has major symptoms of chronic kidney disease along with severely disturbed electrolyte and water balance.

End-stage renal disease occur when nephrons are lost, and the retention of metabolic waste products, salt, and water is potentially fatal unless renal replacement therapy is started. When the residual renal function is less than 5 mL/min a life threatening condition arises and individuals with end-stage renal disease must choose a dialysis treatment. For the majority of individuals, the choice includes either hemodialysis performed at a dialysis unit or at home, or peritoneal dialysis performed at home by the patient. Transplantation is the treatment of choice, but the number of donor kidneys is limited and transplants may fail (ibid.).

**Incidence and prevalence of chronic kidney disease**

In Sweden, the incidence and prevalence of chronic kidney disease has increased, especially in the group of elderly people, and today the majority of patients are over 65 years of age. The annual growth has been approximately 5 %, and the number of incidence is about 125 per million inhabitants per year.

The primary kidney diseases that cause chronic kidney disease are for example glomerulonephritis, interstitial nephritis and polycystic kidney disease. The secondary causes are for example diabetes mellitus, renal and systemic atherosclerosis, systemic
vasculitis, amyloidosis and myeloma. As of the year 2002, the leading causes of chronic kidney disease in Sweden were diabetic nephropathy and glomerulonephritis.

There are an increasing number of patients and approximately 756 per million inhabitants suffer from end-stage renal disease in Sweden. Around 1 100 persons will need renal replacement therapy due to chronic kidney disease every year. At the end of year 2002, 2 434 patients received haemodialysis and 781 patients received peritoneal dialysis in Sweden (SRAU 03).

According to Polaschek (2003) there are many quantitative studies examining renal patients’ quality of life, adaptation, stressors, and coping mechanisms, and his opinion is that few of these studies try to understand the experience of living on dialysis in a qualitative way of research. Polaschek continues by stating that the quantitative studies mostly investigate ways to improve the outcomes of renal replacement therapy for renal patients and that these studies need to be complemented by qualitative research that seeks to describe the human experience of living while using renal therapy (ibid.).

**OVERALL AIM**

The overall aim was to describe life with automated peritoneal dialysis from the patient’s perspective.

Part 1 Out of an integrative literature review highlight everyday life with automated peritoneal dialysis treatment.

Part 2 Out of an interview study illuminate patients’ lived experiences of automated peritoneal dialysis treatment on daily living.
PART 1: Literature review

AIM

The aim was to highlight everyday life with automated peritoneal dialysis treatment out from an integrative literature review.

METHOD

INTEGRATIVE REVIEW

An integrative review (Beyea & Nicoll, 1998) was carried out in order to sum up and draw overall conclusions on past research according to the aim of this thesis. To perform a literature review is essential in order to understand the gathered facts about the topic being reviewed. The integrative review consists of reading, analyzing, and summarizing academic materials of a specific topic (ibid.) – in this case; the patients’ everyday life with APD-treatment. Performing integrative reviews has been expressed by Kirkevold (1997) as an “important strategy to further the development of nursing science and nursing practice”. It is also a way to make knowledge based on research more reachable to clinical nurses and is “thereby reducing the current gap between nursing theories and nursing research” (ibid.).

A systematic computerised literature search in the electronic databases CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Medline; the primary database of NLM (National Library of Medicine), and PsycINFO (American Psychological Association) was carried out in February 2004, with PubMed as the search motor (Willman & Stoltz, 2002).

The keywords used were: automated peritoneal dialysis, continuous cycling peritoneal dialysis, tidal peritoneal dialysis, nocturnal peritoneal dialysis, nursing, nephrology nursing, quality of life, patient perception, patient attitude, patient experience, everyday life, lived experience.

The different keywords were then combined with each other (Table 1:1).
Limits for the database search: All Adults: 19+ years, English language, Human, Only items with abstracts. No restrictions to gender, nationality or to date of publication was taken.

The articles were to be primary source material, evaluated through the peer-review process and published scientifically. To be noted is that the PsycINFO could not map the term automated peritoneal dialysis or continuous cycling peritoneal dialysis, tidal peritoneal dialysis, or nocturnal peritoneal dialysis, resulting in no hits in combination with the rest of the keywords.

Table 1:1. Number of abstracts per database and keyword.

<table>
<thead>
<tr>
<th>PubMed</th>
<th>Hits</th>
<th>Identified and scanned abstracts</th>
<th>Saved abstracts</th>
<th>Abstracts not included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limits: All Adult: 19+ years, English, Only items with abstracts, Human.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD*</td>
<td>134</td>
<td>23</td>
<td>15</td>
<td>8</td>
</tr>
<tr>
<td>APD* AND nursing</td>
<td>91</td>
<td>26</td>
<td>7</td>
<td>19</td>
</tr>
<tr>
<td>APD* AND nephrology nursing</td>
<td>10</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD* AND quality of life</td>
<td>189</td>
<td>61</td>
<td>19</td>
<td>42</td>
</tr>
<tr>
<td>APD* AND patient perception</td>
<td>16</td>
<td>4</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>APD* AND patient attitude</td>
<td>26</td>
<td>4</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>APD* AND patient experience</td>
<td>215</td>
<td>18</td>
<td>2</td>
<td>16</td>
</tr>
<tr>
<td>APD* AND everyday life</td>
<td>2</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD* AND lived experience</td>
<td>1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SUMMARY</strong></td>
<td><strong>136</strong></td>
<td><strong>47</strong></td>
<td><strong>89</strong></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CINAHL</th>
<th>Hits</th>
<th>Identified and scanned abstracts</th>
<th>Saved abstracts</th>
<th>Abstracts also in PubMed Not included</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limits: English, Abstracts</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD*</td>
<td>293</td>
<td>15</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>APD* AND nursing</td>
<td>63</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>APD* AND nephrology nursing</td>
<td>61</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD* AND quality of life</td>
<td>19</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>APD* AND patient perception</td>
<td>81</td>
<td>10</td>
<td>0</td>
<td>10</td>
</tr>
<tr>
<td>APD* AND patient attitude</td>
<td>1</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>APD* AND patient experience</td>
<td>82</td>
<td>7</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>APD* AND everyday life</td>
<td>88</td>
<td>9</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>APD* AND lived experience</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SUMMARY</strong></td>
<td><strong>49</strong></td>
<td><strong>10</strong></td>
<td><strong>39</strong></td>
<td></td>
</tr>
</tbody>
</table>

*) APD = automated peritoneal dialysis OR continuous cycling peritoneal dialysis OR tidal peritoneal dialysis OR nocturnal peritoneal dialysis as keywords searched for together.
For subheadings to CINAHL see Appendix 1:1.

In order to keep the material organized Beyea & Nicoll (1998, p. 878) points out that a ‘suitable method’ should be established to keep the hard copies organized. Here the Matrix Method (Garrard, 1999) was used as it is both a structure and a process.

Selection of relevant documents followed three steps according to the Matrix Method.

1. **Reviewing the Abstracts**
   Reading the abstracts to decide its relevance to the aim of the study.
   Abstracts were read and used in order to:
   - alert to more recent studies.
   - provide leads to discover other studies

2. **Skimming the Document**
   Briefly examining the original article, and deciding whether or not to keep a copy of the document for inclusion in the integrative review.

3. **Photocopying the Document**
   A copy of relevant articles was printed out.

A total of 185 abstracts were identified as relevant for the aim of the study, picked out and scanned. The number of articles was then reduced once more because some abstracts appeared in both databases. The 57 abstracts that remained were picked out and read in full text. After reading the abstracts in full text another 46 of them were excluded and the remaining 11 articles were considered to be relevant for the integrative review and were used for the result.

The main reason for exclusion was because the articles were not performed as studies or performed at a molecular level of medicine.

The Review Matrix, which is a box with rows and columns, was then used to create a structured order in a 3-step process (Garrard, 1999, pp.114-118).

1. **Organizing the documents**
   Chronologically arranging the sources from the oldest to the most recent by year of publication.

2. **Choosing topics**
   Deciding which topics to use in the Review Matrix.
3. Abstracting the documents

Reading and abstracting each document in chronological order, from the oldest to the more recent.

Using this Matrix Method (ibid.) each of the eleven articles was evaluated in ascending chronological order using the structured abstracting form with eight topics; author, title and journal identification; year; purpose; study design; participants; and results, as shown in Appendix 1:2.

RESULTS

LIFE STYLE

The obvious lifestyle advantage for automated peritoneal dialysis (APD), as compared to standard continuous ambulatory peritoneal dialysis (CAPD), was that it required two rather than four procedures daily (Diaz-Buxo et al., 1981). APD gave the patients the opportunity for uninterrupted daytime activities, assuming that fewer than two diurnal exchanges were utilized (Liberek et al., 1999). APD was also an obvious benefit to those in full-time employment where daytime CAPD exchanges could be a disruption (Brunkhorst et al., 1994). The group where the lifestyle advantages of APD have been an increasing consideration is in the elderly (Kadambi et al., 2002) and infirm, who are dependent on relatives or other caregivers to do their dialysis for them (King et al., 1992).

The advantages of a modality requiring only a morning and evening intervention were obvious for the busy relatives of elderly dialysis patients. There was also a flexibility afforded by the fact that the more tiring and time consuming cycler set-up for the coming night’s treatment could be done at any time during the day concerned. In the case of a patient living alone, a relative or caregiver could visit and set up the cycler in the daytime and the patient was required only to attach and to detach from the cycler and to deal with alarms that occur (Viglino et al., 1995).

There were other lifestyle factors that led to CAPD being preferred by some patients.
One was the fact that APD involved the use of a machine. For some patients the principal advantage of CAPD was its relative simplicity and unobtrusiveness, so a cycler could be perceived as undesirable (Diaz-Buxo et al., 1981; Brunkhorst et al., 1994).

Another lifestyle consideration was the requirement for APD patients to stay attached to the cycler for eight to ten hours nightly. This situation may be a problem for patients who sleep poorly and who like to wander at night time (ibid.).

Brunkhorst et al. (1994) showed in their study that only a smaller proportion of their patients found this to be a problem. Since the patients had the material at home and the knowledge to perform CAPD as well as APD, the patients had a free choice between both methods. Most patients decided in favour of APD in this study (ibid.). It could similarly be seen as an issue by patients who were parents of young children or who were caregivers for elderly relatives, and who therefore wished to feel free to get up a number of times during the night to give assistance (Diaz-Buxo et al., 1981; King et al., 1992; Brunkhorst et al., 1994; Viglino et al., 1995; McComb et al., 1997; Liberek et al., 1999).

**QUALITY OF LIFE IN PATIENTS ON APD**

De Wit et al. (2001) were surprised that quality of life (QOL) on APD patients has rarely been studied. In their MedLine literature search they only found four studies that had incorporated APD patients. Two of them were found in this literature review: McComb et al. (1997) and Bro et al. (1999).

McComb et al. (1997) assessed the impact of a portable APD system on Health-Related Quality of Life (HLQOL) of 26 patients on CAPD, using the RAND 36 item Health Survey instrument (measures physical functioning, role limitations (physical and emotional), social functioning, emotional well-being, pain, energy, and general health perceptions). The authors wrote about convenience of APD treatment that made it more suitable for patients who were employed or had young families. It was also of benefit in allowing a more active lifestyle in younger patients and helping them come to terms with renal replacement therapy.
The reduced number of procedures required to perform APD made them of great value where a helper performed or assisted with treatment in patients affected by neuromuscular disorder, blindness, low intelligence or in poorly compliant patients. The study showed that APD may be indicated for social reasons due to the convenience of having to perform only a single connection and disconnection from the dialysis catheter. This could help with employment and lifestyle for younger patients, and in older, more debilitated patients, it could enable a helper to perform dialysis at home in patients unable to do CAPD themselves. The results showed an improvement in the pain score ($p=0.079$), although this was not reaching statistical significance in the overall sample. No other statistically significant differences were found overall in the domains of HRQOL. The improvement in pain score reflected the capacity of newer cyclers to switch from drain to fill, leaving the patient empty for less of the time. The significant improvement in the scores of dialysis adequacy suggests that easier setup of the cycler might result in better patient compliance.

The few statistically significant changes in HRQOL could have two reasons, according to McComb et al. First of all, the RAND 36-item health survey may not be sufficient sensitive to measure a treatment change of this nature, and second, the authors think that the lack of statistical significance may be related to the small sample size (ibid.).

The purpose of the study by Bro et al. (1999) was to compare APD and CAPD treatment with respect to quality of life and clinical outcomes in relation to therapy costs. This was, according to the authors, the first prospective, randomized multicenter study performed. The study lasted for six months and 17 patients were allocated to APD and 17 patients to CAPD after randomization. Medical and biochemical parameters were evaluated at monthly controls. Quality of life (QOL) parameters were assessed at baseline and after 6 months by self-administered short-form SF-36 generic health survey questionnaire supplemented with disease and- and treatment –specific questions. Therapy costs were compared by evaluating dialysis-related costs. It was 25 out of the 34 patients enrolled who completed the study (i.e. 26 % drop-out rate).

The QOL study showed that significantly more time for work, family, and social activities was available to patients on APD compared to those on CAPD ($p< 0.001$). Although the difference was not significant, there was a tendency for less physical and emotional
discomfort caused by dialysis fluid in the APD group. Sleep problems, on the other hand, tended to be more marked in the APD group.

Any positive effect of APD compared to CAPD on dialysis-related hospital days or complication rates could not be confirmed. The authors discussed that with a larger patient sample it would be possible that a significant difference might have been achieved. Upon completion of the study, all patients on APD were free to choose between APD and CAPD treatment. They all preferred to continue on APD. The CAPD patients were not free to choose between APD and CAPD for reasons of economy.

The conclusion from the authors was that if APD treatment can help to keep selected patients vocationally or socially active, paying the extra cost seemed reasonable (ibid).

de Wit et al. (2001) analyzed health-related quality of life (HRQOL) in a convenience sample of 37 APD and 59 CAPD patients matched for total time on dialysis. In a multivariate analysis, the mental health was found to be better in APD patients than compared to CAPD patients. There were indications that APD patients tended to be less depressed and anxious than CAPD patients. One explanation from the authors was that treatment selection could have played a role, because patients with higher anxiety levels may not have chosen the APD technique because they found it unpleasant and frightening to be attached to a machine while sleeping.

No differences between APD and CAPD patients were found with respect to the physical aspects of HRQOL. The authors concluded from this study that the HRQOL of APD patients was almost equal to HRQOL of CAPD patients (ibid.).

**COMPLICATIONS**

Peritonitis (inflammation of the peritoneal cavity) is a major problem in CAPD and is a frequent cause of interruption or ending of treatment. Adult patients treated by APD have shown significantly lower rates of peritonitis than in CAPD, and numerous factors have been proposed to explain this. One is the reduced numbers of connections to, and disconnection from, the abdominal catheter (Diaz-Buxo et al., 1981; Brunkhorst et al., 1994).
The rate of peritonitis with APD treatment has a lower incidence because the number of manual connections between the peritoneal catheter and the system is reduced to two per day. Also, all connections in APD take place at a convenient time and location, which improves the patient’s concentration and minimizes the patient’s fatigue (Diaz-Buxo et al., 1981; McComb et al., 1997).

Viglino et al. (1995) pointed out that improved patient technique due to performance of all connections in the same environment, less patient fatigue due to performance of fewer connections and assistance of a helper could help reducing peritonitis rates. APD could sometimes be preferred to CAPD for mechanical reasons such as back pain, hernias, or recurrent dialysate leaks and according to Liberek et al. (1999) could APD be successfully used in patients with hernias or fluid leak problems in whom excessive rise of intra-abdominal pressure during dialysis in standing and sitting positions was contraindicated. The remaining option would otherwise be change of renal replacement therapy into hemodialysis (ibid.).

**COMPLIANCE**

Bro et al. (1999) found that there was a tendency for APD patients to have less emotional and physical discomfort. This could, according to Bernardini et al. (1998), contribute to the increased patient compliance with the treatment prescription seen with APD therapy compared to CAPD (ibid.).

Bernardini et al. (1998) developed a method to measure compliance with prescribed exchanges in CAPD and APD, through an inventory of the patient’s home supplies. They emphasized the fact that the quantity of dialysis actually delivered to a patient depended on the level of patient compliance with the prescribed regimen. A total number of 49 patients on CAPD and APD were openly enrolled, but they were not told that the home visits inventories were to verify compliance. The patients completed a self-evaluation about how often they missed out on exchanges; what they thought the consequences of missed exchanges were, and how they felt about the medical care received. The staff also evaluated the patient’s compliance independently.
The results from this study showed that 35% were noncompliant with prescribed exchanges based on the supply inventory. About 40% of CAPD patients were noncompliant compared with 20% of APD ($p=0.15$).

There was no difference in compliant and noncompliant patients by age, race, gender, time on peritoneal dialysis treatment, measured-to-predicted creatinine ratio, number of comorbid conditions, or incidence of diabetes. There was no difference in attitudes about the consequences of non-compliance. Only two patients (4%) admitted to non-compliance.

The number of days hospitalized was higher in noncompliant patients, and the peritonitis rates were higher in noncompliant patients, compared with compliant patients.

Staff evaluations of PD patient compliance in the current study were highly inaccurate.

The authors discussed that home visits to conduct supply inventories provided an excellent method of monitoring compliance, but that further studies were needed to verify the frequency of non-compliance with prescribed exchanges.

Because of the small number of patients the authors were not able to identify measures that convert noncompliant patients to compliance with the PD prescriptions.

According to the authors the study was not able to prove an increased risk of death in noncompliant patients, which the authors thought was because of the small sample size and the short follow-up of only one year.

Bernardini et al. (1998) thought the issue of compliance was important because non-compliance did not make the patient feel worse in the short run and when the patient felt ill later on, he/she did not think the symptoms were results of non-compliance (ibid).

**NUTRITION**

Abdo et al. (1993) conducted a study for six months looking for the answer whether there was a difference in nutritional status and adequacy of dialysis between CAPD and APD treatment or not, because renal patients are disposed to malnutrition and especially patients on peritoneal dialysis because of the loss of protein in the dialysate. The authors pointed out that nutrition is a major concern because morbidity and mortality are increased in malnourished patients.
The study included 13 patients on APD and 19 patients on CAPD and nutrition was assessed by weight change, dietary intake (using a questionnaire), degree of peripheral oedema, and laboratory analysis.

Statistical analysis was conducted using Student’s two-tailed unpaired t-test or chi-square test where appropriate $p$-value < 0.05 was considered statistically significant. The results from the study showed that no significant weight change or edema difference was found between the two groups.

Questionnaire on dietary intake showed that the CAPD group had experienced more appetite change than the APD group, but the APD group showed significantly more gastrointestinal symptoms. The reason for this was unclear, but the authors said it was perhaps related to the raised intraperitoneal pressure in the lying position experienced more by the APD patients than by the CAPD group.

There was no statistical difference between CAPD and APD according to dialysis adequacy. Aldo et al. (1993) stated the fact that the small sample size of 32 patients made it more difficult to find statistically significant correlations, but the authors found that the nutritional status of APD patients in this study, conducted in their own centre, was similar to the CAPD patients. The serum albumin variable used to assess nutritional status revealed that both groups were mildly malnourished (ibid.).

APD AND AGE

Kadambi et al. (2002) conducted a study in order to review the experience of APD in elderly patients ($\geq 65$ years of age) and to compare the technique failure rates, peritonitis rate, and overall quality of life in older patients with younger ($< 65$ years of age) patients on peritoneal dialysis modality. A total number of 493 patients were reviewed and the present study suggested that elderly patients with end-stage renal disease could be successfully treated with APD and that complications of dialysis in this population were not higher than in younger patients.

They found that technique failure rates, peritonitis rates, and general quality of life measures were not different in older ($\geq 65$ years of age) versus younger patients with end-stage renal disease. Their findings suggested that the use of automated cyclers to treat
elderly patients was effective, well accepted, and did not increase the risk of complications or technique failure. The authors emphasized that age alone should not be a barrier to APD therapy and that referral for consideration to renal replacement therapy should be encouraged in elderly patients.

Another conclusion from this study was that APD is a modality for the elderly, especially those who are frail or debilitated with neuromuscular or visual impairments. These patients often need a partner for assistance if they are going to perform home dialysis. The technical assistance needed for APD occurs in the morning or late in the evening, decreasing the burden on the patient’s partner or caregiver. It was also proven advantageous for patients in skilled nursing facilities, as it was convenient and simple for busy staff to perform necessary connections (ibid).

PATIENT PREFERENCE AND SELECTION
Viglino et al. performed a study in 1995 in order to measure the impact of automated peritoneal dialysis on the peritoneal dialysis program. The study was performed as a retrospective examination of treatment results for a time period of 12 years. The patients starting peritoneal dialysis treatment during the first study part of five years were assessed from both clinical and psychological, social, and aptitude points of view, to identify indications and contraindications for peritoneal dialysis treatment. The second part of the study lasted for seven years and selected patients with help from a protocol that was drawn up for patient selection including a clinical assessment made by the doctor and a social, psychological, and aptitude assessment carried out by the nursing staff with the support of a psychologist and the involvement of the patient, the family through group meetings and home visits.

The results showed that APD increased from about 3 % to 15 % between the two periods being studied. In the second part APD was chosen on clinical grounds for about 27 %, while for the remainder the choice was determined by distance, advanced age, and work. The main reason for choosing APD was the need for a partner in performing dialysis.
Patients changing modality from CAPD to APD did it due to inadequate dialysis, problems caused by increased intraabdominal pressure, recurrent peritonitis, and social-aptitude grounds (need for partner, compatibility with work commitments).

This clinic had a selection protocol that considered APD second choice to CAPD and it turned out that an increase was seen in the use of APD over the years studied. The nonclinical grounds on which APD was preferred to CAPD were related to the time required by and the timing of the dialytic procedure. This was important when work commitments during the day were involved, or when dialysis needed to be performed with an assistant, especially if the assistant was not a member of the family.

The psychological problems in assessing one’s body image due to the presence of liquid in the abdomen made APD favourable to avoid treatment drop out. Finally this clinic’s experience was that APD has contributed to limiting the PD drop out rate and allowed wider use of APD, but the authors hoped for an APD system at a reduced cost that would allow APD to be considered as an alternative to, or integrated with, CAPD on the basis of clinical, psychological, and social-aptitude assessments (ibid.).

**DISCUSSION**

**METHODOLOGICAL CONSIDERATIONS**

This first part of the study has been performed as an integrative review, with the intention to understand and gather facts about the topic being reviewed. The literature review consisted of reading, analyzing, and summarizing studies (Beyea & Nicoll, 1998; Garrard, 1999) of the patients’ everyday life with automated peritoneal dialysis treatment.

The review was selective, i.e. limitations have been made. The study included adults over the age of 18, minors were excluded, only items with abstracts and about humans written in English were searched for. There was no limitation on gender or time for publication. To include children would not have been in accordance with the aim of the study as minors (less than 18 years of age) are in a different context than adults and may need to be spoken for. No restrictions to date of publication were made because peritoneal dialysis has only been a renal replacement therapy since 1976, and as it is a narrow field, especially for nurses, there was a potential risk to miss out on relevant articles.
The choice of keywords was not easy, also because of the narrow field, and as the database search went on it turned out to be necessary to include the different subforms of APD (i.e., continuous cycling peritoneal dialysis, tidal peritoneal dialysis, and nocturnal peritoneal dialysis) as keywords.

A second reminder is that the PsycINFO could not map the term automated peritoneal dialysis or continuous cycling peritoneal dialysis, tidal peritoneal dialysis, or nocturnal peritoneal dialysis, resulting in no hits in combination with the rest of the keywords.

It was not difficult to find quantitative studies, but to find qualitative studies was more difficult, no one was found. Either this was due to an incomplete search of the published literature, using the incorrect keywords, or that articles in other languages than English exists, or that unpublished or incorrectly indexed studies have not been found and were therefore not included. There was no Swedish study found, and the only Nordic study came from Denmark.

The eleven chosen articles for the integrative review turned out to be quantitative and covered a span of 20 years (Appendix 1:3). Only two of the articles showed clearly in print that they were written by nurses (McComb et al., 1997; Bernardini et al., 1998).

The purposes of the examined studies covered issues like: impact and cost of APD treatment, biochemical and medical aspects, serological and clinical parameters, nutrition, health-related quality of life, compliance, and experience of elderly on APD treatment. All these issues are important, but the fact remains that research was very focused on parameters measured by figures and numbers.

Though peritoneal dialysis has become an established form of renal replacement therapy, the number of long-term peritoneal dialysis (over eight years) is limited to a small percentage of patients because of dropout to hemodialysis for complications of peritoneal dialysis, transplantation or death (Gokal, 2000). That could explain the difficulty of long-term studies – patients may not be able to remain in a study due to change of renal replacement therapy.

Some studies reported high mortality but one should bear in mind the fact that in many cases it was due to negative patient selection, i.e., patients had comorbid conditions or were patients who were not able to use any other form of dialysis than peritoneal dialysis.
That is also probably why four of the eleven articles collected data retrospectively. Only one study (Bro et al., 1999) was performed as a prospective, randomized multicenter study, and this study was the only one from the Nordic countries (Denmark). The rest of the articles came from USA (3), Canada (2), The Netherlands, Poland, Germany, Italy, and United Kingdom.

Six of the eleven studies enrolled both APD and CAPD patients, with varying sample sizes ranging from 10 patients to almost 500 patients. The large sample size was due to a review of APD and the elderly for a period of six years (Kadambi et al., 2002). Most authors reflected upon the study findings and its limitations due to the small sample sizes and should, according to the authors, be interpreted with caution. Small sample sizes seem to be a characteristic concern in studies of patients with peritoneal dialysis and a high drop out rate caused by changes in treatment modalities due to progression of the disease, and concomitant diseases.

The studies were also varying in time period ranging from six months to twelve years. In two of the studies were the time period not mentioned at all. The studies compared issues like cost-effectiveness, nutritional status, impact of APD, quality of life and clinical outcomes related to therapy costs, and health related quality of life between APD patients and CAPD patients. One of the studies (Diaz-Buxo et al., 1981) had not defined a purpose at all.

The drop out rate was not reported in six of the eleven studies (54.5%). In the remaining five studies varied the drop out rate from 26 % to 49 %. The cause of drop out was for example transfer to hemodialysis treatment (due to peritonitis, low clearances, intraperitoneal bleeding), kidney transplantation, and death (due to cardiac failure, septicaemia). The study design was quantitative in all eleven studies and four of them were retrospectively performed. Only one study (Bro et al., 1999) had a prospective, randomized design.

**RESULTS**

This integrative review confirmed what Polaschek (2003) stated, namely that there are many quantitative studies examining renal patients’ quality of life and that there are few
studies trying to understand the experience of living on dialysis in a qualitative way of research (ibid.).

Further, this integrative review states that qualitative studies examining APD patients’ experiences and every day life with automated peritoneal dialysis is lacking and opens up a trigging field for further research.

It can take many years to develop obvious symptoms of chronic kidney disease and the outcome of chronic and degenerative diseases is classified by the World Health Organization (WHOQOL Group, 1995) as impairment (physical status), disability (physical functioning) and handicap (social functioning). The amount of disability from chronic illness depends not only on the kind of condition but also on the implications it holds for the person (ibid.). The altered lifestyle may relate to the individual patient’s view of the impact of the disease on self to the specific disease (Lubkin, 1995). This could be represented by changes in life patterns required of patients on renal replacement therapy. Lubkin (1995) also states that chronic illness is never fully cured or prevented and that there is a risk for collapse of cultural, economic, emotional and social factors which all affect physical integrity (ibid.).

Working in a clinical setting meeting patients with end-stage renal disease confirms this last statement from Lubkin. Patients often talk about this as their ‘hidden handicap’ – it does not show on the outside what is happening on the inside – suffering from a chronic disease with fatigue, changed role patterns, etc.- and still your environment does expect everything, including yourself, to be as ‘normal’ as always and as possible. As there is a lack of qualitative studies on APD treatment, a look around for studies on other ‘hidden handicaps’ came up with a qualitative study by Mendel et al. (1997) conducted for the purpose to describe the impact of dizziness on daily living from the patients’ perspectives. Nine open interviews were audio taped and transcribed verbatim and then analyzed inspired from grounded theory. Four themes emerged from the text analysis; vulnerable reactions, affirmation and non-affirmation, ways to carry out daily living and expressing the need for health care support. The study gave evidence of the need to develop the patients’ capability to cope and handle daily life activities. It also showed that living with dizziness causes severe limitations in life and that attention should be paid to development of support programs (ibid.).
Another qualitative study from Ebbeskog & Ekman (2001) was found looking at elderly persons’ experiences of living with venous leg ulcer. 15 persons were interviewed and the text was analyzed using a phenomenological-hermeneutic approach inspired by Ricoeur. The authors wrote in their background that living with chronic illness means disturbance and adjustment in one’s life and how important it is to understand the person’s perspective on chronic illness experience – it is only the person himself who understands the meaning of that experience.

Four themes emerged in their study; emotional consequences of altered body image, living a restricted life, achievement of well-being in connection with a painful wound and bandage, and struggle between hope and despair with regard to healing process. The authors think that the challenge for caregivers is to understand each individual’s specific need within the perspective “of their daily life, balanced against the ongoing disruptions which cause their ability to live a reasonable life” (ibid., p. 242).

CONCLUSION

The conclusion of the integrative review is that despite the increasing number of patients being treated with APD, there is up to the present moment little data on the patients’ lived experiences on daily living with APD treatment in a qualitative way of research.

The quantitative studies mostly investigate ways to improve the outcomes of renal replacement therapy for renal patients and these studies need to be complemented by qualitative research that seeks to describe the human experience of living while using – in this case- automated peritoneal dialysis.

Most studies combine the results for CAPD and APD. Still it is clear that the need for renal replacement therapy has an impact on life expectancy and the psychosocial life of the patient and many studies disclose that the choice of APD is generally performed by social issues or the development of complications on CAPD.

The traditional approach used for evaluation of the peritoneal system relies on clinical experiences gathered by different centers. The typical report uses chemical profiles,
complications of therapy, and morbidity as the primary parameters in the evaluation of performance, and survival as the ultimate standard of quality.

The significance of such observations is weakened by variation in the selection criteria utilized for choice of therapy, duration of uremia, and the severity of the complications affecting different populations.

The advantages of APD include the capacity for an increased dialysis prescription, increased freedom and quality of life and a decreased risk of peritonitis and intra peritoneal pressure related problems.

A number of studies have attested to the clinical and social benefits to be obtained from APD – these include increased delivery of dialysis as measured by weekly dialysis doses, urea and creatinine clearances, increased ultrafiltration rates, decreased glucose absorption and protein losses, a decreased incidence of peritonitis and a reduction in intraabdominal pressure related problems such as hernias or subcutaneous leaks. A reduction in hospital admission rates and an improvement in patients’ sense of well-being and quality of life have also been reported.

There seem to be two major groups of patients who benefit from APD rather than CAPD. The first category is social – patients who find that their quality of life or that of their carers’ is significantly improved on APD. These include those in full time education or with demanding jobs and the elderly patient who may be dependent on relatives or other carers to perform their dialysis for them. The second group comprises those who could be regarded as CAPD failures, for example patients who can no longer achieve adequate dialysis.

The APD machine performs the changes automatically, leaving the patient free from dialysis related activities until it is time to reconnect to the machine the next night.

APD is a dialysis technique which may benefit certain groups of patients with end-stage renal disease. The APD treatment has the flexibility of prescription to enable the delivery of adequate dialysis dose and can increase the quality of life and social rehabilitation of patients while they wait for a renal transplant, which remain the optimum treatment for individuals suffering from end-stage-renal-disease.

Perhaps comparative studies are complicated to perform due to loss of patients to transplantation or because of change of modality or because of death.

A priority for the years ahead should be randomized comparisons of CAPD and APD strategies in a variety of subgroups of patients.
One has to take into consideration the fact that the number of patients and events in almost all studies are low that no proper statistics could be applied for a comparison between APD and CAPD.

Data on APD is sparse and still is quality of life an important parameter when advising patients on renal replacement modality selection. The introduction of a machine to assist the patient with his dialysis exchanges can potentially improve his quality of life in different ways.

For example, first, the machine can reduce the time the patient has to dedicate daily to his treatment. If the patient opts for APD, the number of daytime exchanges can be substantially decreased. This allows many patients to remain employed.

Secondly, with APD, the fill volumes during the day in the peritoneal cavity can be reduced along with the intra-abdominal pressure which enables the patient to go about more freely, decreasing the risk of hernias.

One of the disadvantages of APD relative to CAPD is its higher costs and the extra expense consists of the cycler itself, plus the extra day-to-day cost of the additional dialysis solution and tubing that is required in APD (Liberek et al., 1999). Bro et al. (1999) calculated that in Denmark, operation costs were 20-25 % higher in APD as compared to CAPD.

Another side of the cost is the fee for hospital admission due to APD treatment. Bernardini et al. (1998) could show that the number of days hospitalized was higher in noncompliant patients who had 1 016 per 100 patient years in opposition to 908 days per 100 patient years in compliant persons ($p<0.04$).

There is also evidence that more patients on APD as compared to CAPD are vocationally active which has financial consequences (Bro et al. 1999).

**ADVANTAGES OF APD**

- APD is a home-based therapy predominantly performed during the night.
- APD can be administered at home while the patient sleeps, providing more free time during waking hours.
- APD may be favoured by employed patients or older patients.
• APD reduces the risk of peritonitis and mechanical complications compared to CAPD.
• APD may have a positive influence on compliance.
• APD may be the preferred therapy for patients who require assistance.

There is a need to let the voices from the individuals suffering from end-stage renal disease to be heard, not by using predetermined variables as in a quantitative study, but instead using a qualitative approach with the qualitative research interview as an instrument using open questions giving a possibility for deeper understanding of the patients’ life situation.
PART 2: Empirical study

INTRODUCTION

Results from part one, the integrative literature review based on scientific articles between the years of 1981 to 2002, showed that patients on automated peritoneal dialysis (APD) had significantly more time for work, family, and social activities as compared to continuous ambulatory peritoneal dialysis (CAPD). Also mental health was found to be better in APD than compared to patients on CAPD. There were indications that APD patients tended to be less depressed and anxious than CAPD patients. Findings even suggested that the use of automated cyclers to treat elderly patients was effective. The integrated review also revealed that renal patients’ experiences concerning automated peritoneal dialysis treatment have not been studied according to a qualitative approach, which was the intention with this study, part two.

CONCEPTUAL FRAME

Chronic illness transforms the lives of afflicted individuals and their families and over a prolonged time the afflicted lose what their lives had once been (Miller, 2000). They live with irreversible changes and must learn to live and function with a less efficient and dependable body. Medical regimens and monitoring symptoms fill time once occupied by more pleasurable and productive activities. Previously held expectations for the future must be reshaped into plans that incorporate the illness. Chronic illness puts the individual in front of psychosocial challenges and demands of adaptation. To live with a chronic illness means insecurity for the future prospects with a constant anxiety and emotional stress for the future (ibid.). In individuals with a chronic disease, for which cure is not a realistic goal, it is a fact that they live under a constant contempt of death. For individuals with chronic renal failure there are treatment modalities available to artificially take over the kidney function, such as peritoneal dialysis (Gokal, 2000).
Antonovsky a medical sociologist, developed the salutogenic model to explain why people remain healthy during times of extreme stress (Antonovsky, 1985). Sense of coherence (SOC) is the central concept of the health oriented salutogenic model. The model focuses on the predictors of health outcomes and serves as a major coping resource for the preservation of health. A person’s social, cultural, and historical contexts are fundamental factors that act as resources in striving towards health. The SOC concept is built up by three components: comprehensibility, manageability and meaningfulness, and is defined as; “A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence (1) that the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable and explicable (comprehensibility); (2) the resources are available to one to meet the demands posed by these stimuli (manageability); and (3) these demands are challenges, worthy of investment and engagement (meaningfulness)” (Antonovsky, 1987, p. 19).

The component comprehensibility is the extent to which one perceives the world as ordered and the problems one faces as understandable and clear. Manageability is the component for the extent to which one believes that the requisite resources for coping successfully are at one’s disposal or at the disposal of others on whom one can reply. The third component meaningfulness is the extent to which one feels that the problems and demands posed by living are challenges worthy of commitment and engagement (Antonovsky, 1985; Antonovsky, 1987).

These three components could be anticipated to be found in the participant’s narratives from the interviews.

A sense of coherence is an enduring perception that one’s life has worth, meaning, and purpose. A feeling of being in control is part of coherence, as is confidence that “things will work out well”. Coping resources are those that are available to help persons master, tolerate, or reduce a problem or demand (Antonovsky, 1985).

A strong SOC is required to cope effectively with the ever-present stressors of living and to maintain health. Based on this concept, persons with a stronger SOC should be more able of selecting the best available coping resources and have better quality of life. Antonovsky means that life experiences from childhood through to the end of life are sources of SOC and the greater the consistency of life experiences, the more the individual’s life becomes predictable and understandable (Antonovsky, 1987). The degree
of success depends on the individual’s capacity, knowledge and skills in managing the stress facing them, which in turn leads to extra strengthening of SOC. It was suggested that as a person grows older the SOC should be strengthened, and therefore they may be less likely to perceive events as stressful. Even though SOC does not refer to a specific type of coping strategy it comprises factors that may be regarded as a basis for coping with stressors (ibid.).

According to Antonovsky’s model (Antonovsky, 1985), the relationship between SOC and movement along the health continuum is indirect and is mediated by the role that SOC plays in the management of tension. In tension states, a strong SOC will help to uphold effective coping and resolve tension. If not, the tension leads to stress and a decline toward health breakdown. The stronger the sense of coherence, the more likely is it that a person will successfully cope and the degree of sense of coherence is an indicator of an individual’s coping capacity. A strong sense of coherence enables a person to handle more stressful situations more readily (ibid.).

**AIM**

The aim for the study was to illuminate patients’ lived experiences of automated peritoneal dialysis treatment on daily living out from an interview study.

**METHOD**

When describing a phenomenon from the emic perspective, as in this case the patient’s lived experience of automated peritoneal dialysis treatment on daily living is a qualitative method of use. Qualitative approach can help to describe how people live or how they cope with daily life and thereby provide understanding for a group of people. The qualitative
method has a wide perspective (Morse & Field, 1995), where the participants are able to extend their answers more in detail about their experiences.

**PARTICIPANTS**

A purposeful sampling strategy was used to identify persons treated with automated peritoneal dialysis.

The inclusion criteria were:

- Persons who were 18 years of age or older.
- Persons treated with automated peritoneal dialysis for at least three months.

The participants were recruited from Swedish nephrology units, where they first had been trained to take care of their peritoneal dialysis treatment. As the treatment thereafter was performed in the participants’ homes, they only came to the nephrology units for scheduled visits at individual intervals or in case of emergency.

One of the inclusion criteria was that persons should have over three months of treatment with automated peritoneal dialysis. It is a nursing experience that the first months of therapy can be a period to endure discomforts and limitations when the sequence of problems and upsets can seem persistent. The time usually required to get adjusted to the modality is three months.

The sample consisted of six persons: two women and four men who all had active treatment with automated peritoneal dialysis at the time for the interviews.

The time on peritoneal dialysis of the participants is shown in Table 2:1. All participants had started their renal replacement therapy on continuous ambulatory peritoneal dialysis before switching over to automated peritoneal dialysis. The reasons for change of modality were inadequate dose of dialysis (n = 4 persons) and the patient’s own preference (n = 2 persons).

The time on automated peritoneal dialysis ranged from nine months to five years. One of the participants was working, four participants were retired due to age and one participant had disablement pension. The fact that all participants had undergone continuous ambulatory peritoneal dialysis prior to automated peritoneal dialysis made this group their own group of reference, i.e., each participant was able to personally compare the two different modalities of renal replacement therapy even if it was not specifically asked for.
Table 2:1 Time on peritoneal dialysis of the interviewed participants  
\( n = 6 \) persons, A-F

<table>
<thead>
<tr>
<th>Participants</th>
<th>Time on CAPD</th>
<th>Time on APD</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>108 months</td>
<td>9 months</td>
</tr>
<tr>
<td>B</td>
<td>6 months</td>
<td>60 months</td>
</tr>
<tr>
<td>C</td>
<td>6 months</td>
<td>18 months</td>
</tr>
<tr>
<td>D</td>
<td>10 months</td>
<td>14 months</td>
</tr>
<tr>
<td>E</td>
<td>20 months</td>
<td>10 months</td>
</tr>
<tr>
<td>F</td>
<td>24 months</td>
<td>12 months</td>
</tr>
</tbody>
</table>

CAPD = continuous ambulatory peritoneal dialysis  
APD = automated peritoneal dialysis

DATA COLLECTION

At each of the nephrology units one of the nurses specialized in peritoneal dialysis was asked to select persons who were articulate and interested in describing their experiences of automated peritoneal dialysis treatment on daily living. The selection of the participants was also to be in accordance to the inclusion criteria. Written information (Appendix 2:1) and consent (Appendix 2:2) was handed out by the nurses to a total of eight persons who met the above criteria. The written information described the purpose of the study, the data collection method including the use of a recorder. It also contained information of the participant’s right to at any time withdraw from the study, as well as the information that anonymity would be preserved as well as confidentiality. A prepaid envelope was included and the persons were asked to reply within two weeks. All the eight persons who received the written information countersigned the information and gave their consent to be contacted on the telephone by the interviewer. Interviews were performed with only six of the eight persons because of lack of time. The two persons not being interviewed received a thank-you-letter with regrets that the interview unfortunately could not take place. A week after their reply the six persons were contacted on the telephone by the interviewer and meeting arrangements was set up at their own preference. Five interviews took place in a hospital setting, and the sixth took place in the interview person’s home.
Prior to each digitally recorded interview were all persons asked of their consent and they were again assured of anonymity and confidentiality. The chosen nephrology units gave their oral consent to the interviewer to perform the interviews for the study.

**THE QUALITATIVE INTERVIEW**

Taking part in a dialogue is a basic form of human interaction (Kvale, 1996) and a conversation of daily life in a professional way called ‘qualitative research interview’, is defined by Kvale as “an interview whose purpose is to obtain descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena” (ibid., p. 5-6). The qualitative interview was used as a tool trying to understand and to unfold the meaning and experiences from the subject’s viewpoint of the lived world. The performed interviews were looked upon as an inter change of views in a conversation between individuals over a theme they both share interest for. “If you want to know how people understand their world and their life, why not talk to them?” (ibid., p. 1).

The purpose of the qualitative interview for this study was to describe the lived experience of automated peritoneal dialysis treatment on daily living from the patient’s perspective. The purpose of this qualitative interview was not to aim at quantification, but to seek qualitative knowledge expressed in normal language, which means that this method allowed the persons being interviewed to express their situation from their own perspective and in their own words.

The interviews were carried out in the form of a dialogue related to lived experiences of automated peritoneal dialysis treatment. The interviews focused on each interview person’s reactions and feelings to living with automated peritoneal dialysis treatment. The participants were also, in accordance to Kvale (1996), encouraged to put words to their viewpoints on their lives and worlds.

**THE INTERVIEW**

An interview guide was set up in order to have an outline with suggested questions to keep the dialogue going and stimulate the participants to talk about their experiences.
The interview guide consisted of three main research areas. The interview consisted of two opening questions, four head questions, two sub questions and three closing questions (Appendix 2:3).

The questions were designed to the purpose of the study with a descriptive disposition in order to gain understanding of the phenomenon of living with automated peritoneal dialysis treatment. It was important to allow the persons to tell their story in a narrative and naturalistic way that ended up in an interview that was conversational in nature and interrupted as little as possible (Kvale, 1996).

A short briefing was performed before the start of the interview about the purpose of the study, how the data was to be used, the use of a recorder, as well as a check for any questions from the interview person to be answered. According to Wärneryd (1993) is our memory like a network of associations where we forget things that have few connections or associations to events or knowledge. The information you once learned is permanently stored in the memory, but not all of the information is available. Forgetfulness is thereby the inability to access the information once stored in the memory (ibid.). This strengthened the intention to start with general opening questions, like a grand tour, in order to refresh the person’s memory that would help to recall stored memories, details or experiences of the automated peritoneal dialysis treatment. The two opening questions from the interview guide were, ‘When did you start dialysis?’ and ‘Whose choice was it to start automated peritoneal dialysis treatment?’

It was important to allow the interviews to take the time needed and according to Wärneryd (1993) an interview is not tiring and of negative effect if it does not last more than 1½ hours.

The interviews were rounded off with the interviewer’s summarization in order to give the interviewed person a chance to debrief or to add something forgotten to the story already being told. The interviewed persons were also asked if the interviewer had left out any questions they anticipated to be asked (Morse & Field, 1995). Further questions were used to obtain clarification or more detail.

All dialogues were digitally recorded and the average lengths of the dialogues were approximately 56 minutes (range 28-69 minutes).

With the questions from the interview guide the descriptions ended up in a voyage through the start of peritoneal dialysis to present time. Several themes emerged from the
descriptions given by the participants. Even though the participants experienced the phenomena in their own unique ways, commonalities existed.

DATA ANALYSIS

Transcribing interviews

According to Morse & Field (1995, p. 30) it is important to “become extremely familiar with the data”. All recordings were therefore taped and listened to at the same day they were performed. The interviews then were transcribed verbatim directly into the computer and then checked against the discs for accuracy. Identifying information was left out during transcription and the transcribed interview participants were identified from A - F. Only the interviewer had access to the identities. The discs and identities were stored in a safe.

After collecting the verbal data and the verbatim transcriptions were made, the phase of content analysis entered. Downe-Wamboldt (1992) states that qualitative content analysis is designed to describe phenomena of interest for a certain purpose. Content analysis is frequently used methodology in nursing research (Cavanagh, 1997; Graneheim & Lundman, 2003) and is an analysis by topic where each interview is segmented into categories where a separated segment could consist of a paragraph or of some lines (Morse & Field, 1995). According to Cavanagh (1997) content analysis is an established technique to deal with a wide range of nursing questions.

The content analysis can be either manifest or latent (Fox, 1982; Morse & Field, 1995; Graneheim & Lundman, 2003). The manifest content analysis is strictly bound to what the interviewed persons said and nothing is to be read into or assumed about it (Fox, 1982). The latent content analysis on the other hand, which was chosen for this study, is an analysis of what the text talks about (Graneheim & Lundman, 2003) and the researcher tries to go further than transcription of what is said and tries to see what was implied or meant (Fox, 1982). The method includes analysis in different steps resulting in identification of categories and possibly themes. The latent content analysis can be presented as themes expressing what the text talks about (Graneheim & Lundman, 2003).
The first step of the latent content analysis began by reading the interview texts over and over again in order to get a sense of the whole. Then the text was categorised by extracting participants’ experiences of their treatment and every day life from the transcribed text according to the questions in the interview guide (inspired by Heikkilä, 2004). This extracted text was thereafter looked upon as the unit of analysis. The next step was to divide the extracted text into meaning units; constellations of words or statements that related to the same central meaning, with the attempt to find themes in order to fulfil the aim of this empirical part of the thesis. The meaning units were condensed and coded in order to shorten the text without loosing its core messages. Through the steps of analysis of the text some meaning units were moved back and forth to establish their belonging to what code was most appropriate. The various codes were compared on the basis of similarities and differences and sorted into a scheme. Themes appearing throughout the analysis, which were interpreted as underlying messages of the abstracted meaning units were identified. At the same time the narratives about the experiences were compared with how the experiences were reflected upon by the participants.

The first superficial interpretation was that the narratives dealt with the aspects of coping with and living with a chronic renal disease and its treatment. During the analysis it has been important to put aside personal understanding of individuals living with dialysis treatment from working experience and just letting the text speak for itself. All the data was handled in the computer and in the Swedish language.

As an example of the analysis procedure, one part of the latent content analysis is outlined in table 2:2.
Table 2:2 Part of a latent content analysis, an example.

<table>
<thead>
<tr>
<th>Meaning units</th>
<th>Interpretation</th>
<th>Subtheme</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When I had it explained to me, I understood it to be more of a free life than hemodialysis because you can handle it yourself.”</td>
<td>Wish for a free life and independence.</td>
<td>Wishes to live a normal everyday.</td>
<td>Choice of dialysis modality.</td>
</tr>
<tr>
<td>“My partner was checked up for transplantation, but didn’t match and then they more or less advised me against it. They probably think I’m strong enough to handle this treatment for my age….I have not insisted on it, I think this works out pretty well.”</td>
<td>Realizing that life will never be the same as before and adjust to it.</td>
<td>Coping to live a life on dialysis.</td>
<td>Effects on daily living on dialysis.</td>
</tr>
<tr>
<td>“I try not to let the dialysis run life completely…We were away yesterday afternoon and came back around five-six, but then I don’t do the bag exchange right away…I wait until after dinner.”</td>
<td>To handle the treatment and live as normal as possible using various strategies.</td>
<td>Taking part in their own treatment.</td>
<td>Living an everyday life on dialysis.</td>
</tr>
</tbody>
</table>

A high validity has been aimed for in the study by clearly describing the different phases of the study and also to fulfil the aim of the study from a scientific approach. Quotations have been used for validation in the descriptions of the result. The quotations can be shorter or longer, and aims at increasing the understanding of the meaning of the quotations, reflecting the results.

The result is presented out of CHOICE OF DIALYSIS MODALITY, TRANSFER TO AUTOMATED PERITONEAL DIALYSIS, EFFECTS ON DAILY LIVING ON DIALYSIS, LIVING AND EVERYDAY LIFE ON DIALYSIS and THOUGHTS ABOUT FUTURE.
ETHICAL CONSIDERATIONS

The protection of the individual is of greatest importance and forms the basis of ethical considerations in research. The value of the research and the protection of the individual must always be weighed against one another. There are four basic ethical principles applying to research that have been drawn up to protect the individual (Vetenskapsrådet, 1990).

Information requirement: The researcher must inform the participants of the aim of the research and the terms of their participation. They must also be informed that participation is voluntary and that they have the right to abstain from participation.

Consent requirement: Individuals participating in research have the right to decide, on their own, if they wish to participate, for how long and on what terms. Therefore, the researcher must obtain approval from the participants. Participants must also be able to abstain from participation, without this resulting in any negative consequences. If a participant decides to abstain from participation, he or she may not be subjected to attempts at persuasion.

Confidentiality requirement: Data concerning individuals who participate in research must be subject to the strictest confidentiality and stored so that unauthorised persons cannot access the data.

Limitation requirement: Data collected for research purposes may only be used for research purposes.

The interview persons were informed both in writing and orally of the aim of the study and the method that would be used, prior to and after the interview. They were also informed that their participation was voluntary and that they had the right to leave the study at any time and without having to give an explanation. All interview persons had to give their written consent to be included and contacted by the interviewer. To protect the interview person’s right to privacy, confidentiality and integrity, the verbatim transcribed interview texts were coded and only the interviewer had access to the key to the code system. The digital discs with the interviews on were stored in the interviewer’s safe.

The study was approved by Blekinge Institute of Technology, School of Health Science in Karlskrona, Sweden.
RESULTS

CHOICE OF DIALYSIS MODALITY
One’s own informed choice

Some of the participants knew of their impending renal failure years prior to the actual start of dialysis.

*I know my doctor told me for several years...about dialysis and transplantation...but he never talked seriously that I was headed for dialysis...but still I came quite fast and got this treatment. In good time so to say.*

Other participants had little or no warning of their renal failure:

*I came to the hospital because of heart failure and fluid overload...a loss in kidney function was found... I was taken by surprise and it was a great adjustment for all of us. Everyone was unprepared.*

Wishes to live a normal every day life

When facing the fact that renal replacement therapy was needed the participants’ alternatives were either hemodialysis or peritoneal dialysis. They all expressed a need to maintain a sense of normalcy in their everyday life after the onset of dialysis treatment. Selecting peritoneal dialysis prior to hemodialysis was perceived by the participants as a minimum of disruption of their everyday lives as this treatment was performed in ones home in contrast to hemodialysis at a dialysis unit in the hospital for at least three times a week. All participants had been given information in advance prior to choice of modality. The pre-dialysis information was given both individually and at group sessions, referred to by the participants as “The Kidney School”.

*It is important and useful to join a pre-dialysis group... to get information from different angles. I found it valuable.*

The most important factor for the informed choice of dialysis modality was the concept of freedom and the ability to perform the treatment on ones own.

*...when I had it explained to me, I understood it to be more of a free life than hemodialysis because you can handle it yourself*
I chose it...I could make a choice at the counselling meetings...

I could make a choice and then I chose it because of its freedom...getting stuck to the hospital for three days a week didn’t attract me.

The participants’ views were on a personal level and included questions that could be resolved only over time. Familiarity with alternatives did not always resolve concerns. The information from individuals already attending dialysis treatment alongside the information from hospital health care professionals had an impact in choice of modality.

... of course one wasn’t sure of what model to choose and I wanted hemodialysis from the beginning because I wanted to handle it myself... I interviewed some patients on hemodialysis about what they thought...put needles into yourself and manage it by yourself...that is what I felt for then but I also felt that I maybe didn’t have all the knowledge to make a decision about that or peritoneal dialysis...at that time I didn’t think of the machine at all.

Support of formal and informal information

After the participants had started their own treatment they did not hesitate to tell others about their disease and dialysis treatment in order to help new patients to decide what their treatment modality would be. They felt it necessary to help others in their situation as they had been helped themselves once upon a time. The participants felt that the information coming from the patients had been equally valuable, sometimes more, as the information from the health care professionals.

I can’t say that I did not get enough information. Afterwards when I look in the fancy folders I laugh at the pictures with the nice machine standing next to a bed – they never said anything about all the cardboard boxes and the bags that comes with it...

They never said anything about a manual exchange in the daytime as a complement to the treatment with the machine...I never thought of it to be needed...we never talked about all the time needed for the treatment itself and time for preparation. We never talked about practical matters...
TRANSFER TO AUTOMATED PERITONEAL DIALYSIS

More or less one’s own informed choice

All of the participants transferred over time from continuous ambulatory peritoneal dialysis treatment to automated peritoneal dialysis. The transfer was in some cases attributed to medical reasons, e.g. fluid retention and inadequate dialysis, and in two remaining cases to the participants’ own request. In order to come to terms with the medical reasons the four manual bag exchanges per day had to increase to five manual changes.

_It doesn’t work out...3½ hours between bag exchanges...look at the watch...when is it time for the next exchange?...and I still didn’t do well, because it was not enough so I had to have the machine...it was not a choice of my own. I never really wanted the machine if four exchanges a day would have been enough. Then I never had chosen the machine._

Another option for increasing the dialysis dose was to transfer to the machine and then some of the participants perceived that they no longer had a choice of their own but to transfer to automated peritoneal dialysis.

_It was not enough with four bag exchanges a day and then I didn’t have a choice ...it is better to do it at night, of course, and be free in the daytime. Now I only have one exchange in the daytime. I’d rather have the machine ... especially now when it has functioned and is reliable._

…it was worth a try…it solved many other concerns, you are free in the daytime…you don’t have to be punctual…it has worked out so far ... otherwise the machine is supreme, you can’t be more comfortable. I was horrified the first time I saw the machine with all tubes ...Now it is nothing!

Possibility to keep one’s freedom in daily living

Their first choice of daily manual bag exchanges had now become a new issue to adapt to. The use of a machine performing the treatment at night was not asked for but remained as a possibility to keep ones freedom. Not transferring to the machine would mean a transfer to hemodialysis at a renal unit. For some of the participants it was not a big change or issue because their main goal was to transfer to the machine as soon as possible already from the start of peritoneal dialysis treatment.
... I had almost counted with the machine from the start...it was part of the condition that there was something called “the machine” and that you didn’t need to change bags in the daytime... I just thought it seemed so flexible.

We discussed already from start that I wanted the machine...I’ve been so enthusiastic, I wanted the machine, so I can’t look negatively upon it. When I first read the folders I thought: “this is probably the best solution”. I don’t know if it was a desire, I’d say it was a demand...that’s what I wanted from the beginning.

It has to do with the sense of freedom ...you may not need an exchange at all but only the machine at night...

One positive outcome and experience after the transfer to the machine was the fact that all the participants were already experienced with manual bag exchanges. That gave them a possibility and freedom to alter between the two modalities if needed.

... I had the bags...but I gave notice about the machine which I had looked at and that’s what I wanted to have in the spring when the golf started because then I wanted to be free in the daytime until autumn. And that is how it turned out. Now I can chose either or, but one choice is when you say it is OK to start dialysis treatment in the first place.

From the onset of dialysis treatment was the independence expressed as freedom in their choice of modality but the modality per se also included dependence, i.e., scheduled time for the manual bag exchanges and later on the transfer to the machine. The freedom in the day from manual exchanges with the machine was over time not possible to maintain due to the need for increased dialysis dose, ending up in one or more manual exchanges as a complement to the dialysis regimen at night, which required some planning for most of the participants. Still this alternative was mostly expressed as the best alternative compared to transfer to hemodialysis.

EFFECTS ON DAILY LIVING ON DIALYSIS

Modifying the environment at home

Glucose solution is needed in order to carry out automated peritoneal dialysis treatment and was delivered directly home to the participants from the pharmacy. At the beginning the deliveries were every two weeks, but for reason not known by the participants, the
deliveries were changed to every third week and it was a decision they felt unable to influence. Some comment on the pharmacy was:

*The pharmacy is the worst company. They don’t know what service is. They have taken that out of the assortment.*

**Delivering and arranging space for boxes at home**

The amount of dialysis solution was individually prescribed by the doctors. Depending on the manufacturer of the dialysis solution did one cardboard box contain either two bags with five litres of solution or two bags with six litres. This meant a delivery for the participants of 20 to 45 boxes every third week. The amount of cardboard boxes delivered included practical matters to be solved, for instance one had to stay home until the delivery was made because the participants knew which day the delivery was due but not at what time it was scheduled for.

*One has to wait for them coming...I’ve asked them to come in the morning because I want to be free in the afternoon.*

Also it meant adjustments at home arranging and making space for the boxes to be stored;

*I hide them under the beds. First I keep them in the hall, and then we carry them around.*

*I have a corner in my room in the wardrobe... I close the curtain and then they are gone...*

*I think it’s OK with the cardboard boxes compared to my partner. XX doesn’t like it at all...we had to redo at home to store it all.*

The delivery of dialysis solution meant a lot of garbage/disposal to be taken care of.

...it is garbage every day... we share the garbage can with our neighbour so I can’t fill it up just with my bags...so you live in a world of garbage. You have garbage around you all the time ... it is wearing with all the garbage and all these cardboard boxes.

*I had to order a bigger garbage can...but I live in a house so there is plenty of room.*

Strength was needed to fold the boxes together before disposal;

... my hand aches and I can’t manage to lift up the bags ... the cardboard boxes are the worst, having to take them out... it is easier when one of the grandchildren comes by”. 
Adjusting to in course of the disease

Coping to live a life on dialysis
Realizing that life will never be the same as before the kidney disease had progressed to a state where dialysis was unavoidable was something the participants tried to cope with. It was something very intense to live with, not only for the participants but also for those people living with them. Life on dialysis was expressed as a psycho-social impact where they felt that they had to learn not to take anything for granted. Nothing was obvious – eating, travelling, not being tired, even life itself. The normal things one did prior to dialysis treatment had become more or less issues, and they may not even change back to normal until after a renal transplantation. But then the fact remained that their age prevented some of them from transplantation.

My partner was checked up for transplantation, but didn’t match and then they more or less advised me against it. They probably think I’m strong enough to handle this treatment for my age. But I’m at such an age that the kidneys that are available usually go to younger persons. I haven’t insisted on it, I think this works out pretty well.

LIVING AN EVERYDAY LIFE ON DIALYSIS

The disturbances in basic drives, including things like sleep, hunger, sexuality and activities was expressed. As automated peritoneal dialysis treatment took place primarily at night for the participants was sleeping expressed in many different ways.

I’m rather tired when I wake up. It could depend on that one doesn’t sleep that well, one slumbers first early in the morning...

...sometimes it is hard to fall asleep- you lay there listening to those sounds – it sounds a little when it drains and fills...then it is quiet for a while in the phase of dwell...

...sometimes it is hard to fall asleep... One has to get to bed early... and I have to start the machine in good time in order to get up in the morning.

Sometimes the machine alarms even though you don’t lie on the catheter, it’s not funny...but then again I sleep like a log...
Sometimes it feels like I can’t sleep at all…I have a special weekend-program which is a little longer and I get to sleep longer. Then you’ve slept so much in the week-ends that you have trouble sleeping another night in the week… I can’t turn on the light and read because then I’ll wake up my partner … I would like to get up and sit and read a book or do a crossword or watch a movie.

On the whole I sleep well and it feels good to have that possibility…when the alarm on the machine goes off I turn around and go back to sleep again.

Eating as a basic drive was not always experienced as satisfying or pleasurable, and therefore participants could have difficulty eating.

One has this odd taste in the mouth. Food doesn’t taste what you are used to. One gets heartburn, one suffers from indigestion, lots of gas and belching. One can’t eat that much either because it feels like you are already full.

The appetite is not what it used to be…my eyes wants food but I don’t want to eat when food gets on the table. I have lost my sense of taste.

The basic drive of sexuality was expressed by some participant as a concern regarding younger patients.

It must be harder for younger people considering love life…having the catheter - but I am so old that I have already come over that.

The machine was perceived as noisy and disturbing by some of the participants, but also for their partner.

…you can’t share bedrooms with someone, and then both will be disturbed so I have my own bedroom now. I found a machine that is more silent running than the one I had before. It is worse for my partner who probably suffers more than I do...

The fact of separate bedrooms could be read between the lines as a disruption in sexual life. The capacity to participate in physical activities and athletics was expressed as somehow limited, but still there was a strong need for those who had already been performing their favourite sports to continue doing so.
I stopped playing tennis after the catheter operation, but they told me I didn’t have to...sometimes I think I’ll pick it up again. I would probably have been more active if this hadn’t happened...

Social activities

The social activities varied amongst the participants, but there was a concern to combine leisure activities with treatment modality, such as travels, sports and other social activities for the participants. The importance of sport activities was illustrated by a participant who altered between continuous ambulatory peritoneal dialysis for five months a year and automated peritoneal dialysis for the remaining seven months due to the interest in playing golf. Organizing holidays were considered problematic for some participants because of the need to arrange for inclusion of equipment and other supplies necessary for treatment. The ability to travel was expressed in both negative and positive experiences. It was perceived easier to travel within the country than abroad for some participants, mostly because of more planning in advance was needed. The treatment regimen occasionally prevented participants to participate in enjoyable family activities. Long walks with the partner had become shorter and less frequent, staying over night in the boat was impossible because the need of electricity to the machine, going abroad to friends was energy consuming.

Restrictions in travelling or late night activities were sometimes overcome by the fact that all participants were initially trained for manual bag exchanges before the change of modality to automated peritoneal dialysis. This left them flexible in these situations.

Between the need to plan activities around dialysis and time commitments for treatment and rest, participating in “normal” living was a focal challenge for them. Performing one’s activities often meant reordering time and adjusting schedules to cope with to much or too little time that occurs when trying to manage dialysis regimen alongside other activities. Their day-to-day living was configured to accommodate the technology of treatment. Dietary control and fluid balance, drug management, and self-monitoring for secondary effects of illness and treatment shaped their life patterns. The overall impression emerged that all participants had been able to cope over time in a positive way despite some lifestyle adjustments required by dialysis.
Feelings of exhaustion
The symptoms of chronic renal disease were perceived uncomfortable at times and had an impact on daily living. Fatigue and weakness were described as disturbing symptoms and were at times limiting the individual’s activities. This unpredictability made it difficult for the individual to make plans for activities and may decrease social life. Although the individual wanted or had planned to participate in certain activities, the physiological status sometimes limited the individual from doing so.
In the participants’ descriptions of the effects of treatment some expressed a sense of physical and psychosocial exhaustion.

...I had problems with the catheter and the machine...you look all over for the problem...you don’t find it. It screams a lot, but there is nothing wrong with it and I just let it be and it goes on...sometimes all the bags have to be swapped out...

...having four bag exchanges a day was nothing...not a bother at all, but doing five was trying...even more trying with the machine in a way...Preparing it every night. That you can’t get up at night because of all the tubes...I was so afraid of getting a gastric flu...if you have to go to the bathroom. Sometimes there is a hole on the bag in the heating chamber...the alarm on the machine goes off...you dry it up and re-start. Sometimes it’s not possible to re-start so it has to be a manual exchange...having the dialysis fluid on the floor is like having syrup – it’s sticky.

I used to love my mornings, to rise to a new day...now I have to struggle up in the mornings...and then there is for a fact that it occurs something in the body all the time so you end up like a wrung out piece of rag. I think that is a very, very big difference compared to before. It takes me a while to get up and I can’t really jump out of bed. It’s a difference that affects every day life.

Strength is not what it ought to be. It has taken some years to admit it is not what it used to be. It’s the most difficult- to admit it to yourself. If you have been used to take care of yourself, you consider being able to manage everything and you find yourself sitting there unable to do anything...

I sometimes think of ending it all, to quit treatment...but then one sobers up, so to say, one knows it won’t work, I have to continue...
For some participant the future plan for transferring to hemodialysis was seen as a true relief.

...I’m starting hemodialysis in two months and I really look forward to be able to lay just as I want to in the bed and turn around whenever I want...I thought hell on earth was hemodialysis, but one can change one’s mind... then it’s planned for transplantation. Now I really have that to look forward to...it’s not a bed of roses either to be transplanted...all the side effects...

Life to cope with dependence of dialysis treatment

Dependence of the machine and dialysis procedure
There were times when the participants felt controlled by the dialysis procedure and the dialysis machine. Once dialysis treatment was started, the participants had possibilities to stop it, if a visit to the bathroom was needed for example. Otherwise the treatment took place for seven – nine hours where the participant was connected to the machine, and more or less had to stay in bed.

Malfunctioning of the machine caused both worries and anger. Uncomfortable symptoms during dialysis, such as restless legs, nausea, and pain in the stomach were experienced.

But no matter how uncomfortable or inconvenient dialysis was perceived from time to time, all participants had coped over time and realized and were aware of the fact that in order to prolong life then the dialysis treatment had to take place.

It’s hard being connected to the machine all night...then I have to go to bed already at ten o’clock...even if I’m really tired I still have to wait until ten o’clock otherwise the treatment is finished too early in the morning. I do not want to go up that early. Then you have this catheter...you lay on your back in bed, then I have to turn over on my side because I can’t turn around and lay on my face because that’s where the catheter is...then the alarm on the machine can go off.

I’m little too positive, I know...you are free all day...you can come and go where and when ever you want...but you have to be punctual when you go to bed because I wake up so early in the morning. I don’t want to lay awake and wait for it to get finished...the machine disturbs at night...it is difficult before you fall asleep, but one gets used to it, it is the sounds from the pump. I used to wake up as soon as anyone got into the bedroom...but now, when I am at sleep anyone could come or go as they want to, I don’t wake up...
I have considered getting back to the manual procedure, but I will probably give the machine a chance after all...with manual exchanges you only get sitting around at home doing nothing...just look at the watch and consider when it’s time for the next exchange. It’s no meaning leaving home because I have to get back in another hour or so...

...it’s no work with the manual procedure, but if I’m going to be outdoors doing sports from April until October then it feels good to be free after all. Then you can put up with the trouble with the machine anyhow...it suits me very well...one is grateful for the opportunity for dialysis to start with...and this form of dialysis is actually supreme and then I mean both the manual exchanges and the machine...I have the machine for seven months and the manual exchanges five months a year. This modality is a natural way of living for me since I started with it. So there is no problem at all. It is natural. I know how to do it.

Trying to find a life-style that cope with the dialysis

The need to be connected to a machine had its disadvantages and certain limitations on social activities and family activities.

... I spent only one night in the boat this summer – I had manual exchanges...the machine is not to consider when spending nights on the boat. It’s a difficulty - you need electricity. I went home every night while the rest of the family slept on the boat. XX had to give me a ride home and then come back for me again the next morning. You get tied up to the machine to sleep at home...it is really a limitation. It is.

...sometimes we go to close friends...then you have to bring the machine in its big suitcase and all the cardboard boxes, it’s enough to fill the trunk of the car...

...the airline company had missed that you can’t bring the machine onboard...you have to bring it as hand luggage because it is fragile...they had no space to keep it... we got away anyway. You are prevented from going away because it takes space and the cardboard boxes are heavy and even if you go away in your own car there are other things to be packed as well.

I don’t travel anymore. Perhaps we go to X-land for the weekend...you leave in the evening, spend one day in X-land and go back at night...on that occasion I skip the dialysis...that’s nice! We had our house fixed and we went to X-land and stayed for a whole week. I had the cardboard boxes delivered from the pharmacy and it worked out just fine...that’s the only time I’ve done this but it is
important to know that it is possible to do it... you have to plan for it...

Travelling sometimes meant dealing with unpredictable situations and adapting to it.

*We are going to Europe and we pack the car full of boxes... We did a similar journey in Sweden and met with opposition in one place...they had no drain so I had to put the drainage tube out of a window into the garden...it worked out too!*

*It’s difficult to perform a journey. The range is very limited, so to say. Twelve hours range or you have to bring along a crazily amount of cardboard boxes.*

*I’ve been on holiday and it has worked...of course, it needs planning...it takes some time but is possible to solve. I have plans on going abroad and drag the machine along...next spring...it is the lack of courage since I became sick not to dare. The strength is not what it ought to be either.*

The presence of a chronic condition complicated the conception and completion of goals and dreams. The individual might need to make use of most inner resources to cope with the condition.

**Role disturbance and social relationships**
Because of the illness were experiences expressed concerning role disturbances and what it felt like not being able to fulfil role expectations. This inability to perform expected role behaviours could be interpreted as a possible threat to the individual’s self-esteem.

*My partner is retired now and wants us to go travelling...I can feel once and again that I make every possible effort when I’d rather do something else...that’s what life is like, you have to stand by each other, but I’m afraid to be in his way...*

*It is mentally stressing because you experience to be a bother all the time.*

Some participant expressed a decreased libido and how the dialysis catheter interfered with sexual intimacy. The results indicate that these participants perceive more or less control over family relationships and activities than before the illness. Maintaining normal family and social role commitments were mentioned as important, as expressed by some participant.
It works out just fine for me having the dialysis at home ...I can help XX in the morning and I’m at home when XX returns ...It is easier when you are alone, but having someone who is depending on you being at home is not that easy. It is important that it works out socially.

Concerns for their wives or husbands and their ability to cope with the changed life situation were also expressed;

*It is worse for my partner, XX probably suffers more than I do... XX doesn’t approve of it being like a hospital at home. Not everyone can cope with that– for me it is nothing at all. XX worries a little. It is probably worse for the person standing at the side of.*

Also attitudes and reactions from the social environment were taken into consideration.

*...I don’t know...people around ...There is a totally different attitude when they know you’re ill... they don’t know how to handle the situation. People are more careful, always alert. It cuts both ways...*

The general impression was that social life had not changed much over all, which was considered as an important factor with the treatment by the participants.

**Social network’s understanding of dependence**

The participants’ social environment often gave verification of a difference between how these participants appeared to others and their ability to function because of their renal disease. The expectations of family, friends and even society itself were sometimes unrealistically high.

*My partner uses to say that you always intend to be so blasted brave. Say what is bothering you with this and don’t try to give a better picture of it then what it is, because then you’ll get the wrong signals.*

*Many of our friends are moving abroad... ‘Come and visit. We’re going to do this and that’... They really don’t realize that I maybe can’t come along doing all those things because I still have to struggle along with the machine...it doesn’t show on the outside that I’m sick.*
The participants often felt that people around them did not always believe that they had a medical problem. They could understand that kind of reaction because nothing wrong appeared on the outside indicating anything seriously wrong.

*People spontaneously come up to me and say: You look healthy and fit...They remember what I looked like two years ago...looked washed out and a lot worse...and how much better I’ve been ...But actually one is a little weaker in the muscles and has less power, that is obvious, it’s a lot worse...maybe because you are over 70 and not 40...that’s the road we all have to go.*

Some participants were more or less dependent on others to give them a hand at home in their daily life. It was important to be accepted for one’s needs and to have flexibility from the family members or from friends regarding those special needs. All of the participants described their family members as very understanding and supportive and that they would never have managed without them.

*It’s lucky that my partner is so experienced by now. In the small everyday life it is good to really know each other. Otherwise I doubt if it would work out. XX hasn’t said a single sound yet, it’s me having a sense of guilt realizing how much trouble it is ...and worrying on XX behalf.*

**Contacts with health care professionals**

**Professional treatment in health care**

The contacts with the health care system were described as important but sometimes even perceived as too frequent. Affirmation from health professionals was important, as one participant expressed;

*Here we have a very good treatment; it works out so well in the contacts with the staff. That is what is the most important. And the most important part was when I came here for the very first time...I’ll never forget it...I didn’t have dialysis yet then... ...but then I have to come here often. I’m here at least once a month.*

*The staff at the dialysis unit is fabulous...I have been well taken care off...they have been like rocks to me considering how sick I have been – I wouldn’t have made it without the girls. I have had support all the way...they didn’t only call me at home to check up on me, they even came by in their free time. Without the security at the dialysis unit it wouldn’t work at all in the same good way. You wouldn’t trust in yourself in the same way if the support was not to be found here.*
Interaction with the staff at the renal unit played a large role and the fact that nurses working with the peritoneal dialysis patients had a lot of knowledge made the participants feel secure and well looked for.

Contacts with the health care system were also described as difficult, because the disease was not always affirmed in a positive way when the participants acutely had to go to the hospital, mostly because of peritonitis (inflammation in the peritoneal cavity). If the participants ended up at the emergency admission the lack of knowledge for this group of patients was perceived as obvious. One participant who went to the hospital because of peritonitis experienced a long wait in the emergency room while being in severe pain.

...then I had to wait for eight hours in the emergency room at the hospital...there was some kind of misunderstanding...first I called my dialysis unit but they were busy and redirected me to the emergency...it was unnecessary many hours to lay there in pain...eventually I got an injection of morphine and was transferred up to the ward.

The lack of affirmation was interpreted by the participants as a lack of interest but also as incompetence medically spoken, as one participant explained:

...there are few people who know what peritoneal dialysis is. Not even health care knows what it is. There is a lot of misunderstanding and lots of trouble when you are at the emergency and you need to do a bag exchange laying there waiting...they don’t know what you are talking about..."you have to make a call to the dialysis unit so they can come down and make a bag exchange"- it’s the same confusion every time! The negative thing is the ignorance of the health care staff. You get surprised because you expect them to know at least as much as I do. And there are very few who can accept good advice from a patient. It is difficult to get them to listen to you as patient.

The need for accurate information and the need to know as much as possible about the reasons for the disease, as well as its outcomes, was described as important. It was important to be recognized and listened to by the health personnel and to be cared for in a professional way.

The participants described a feeling of relief when seeing their own doctor or nurse for consultation, because they then felt that their symptoms and their renal problems were recognized and affirmed as being real. The participants wanted to see themselves as partners in care as opposed to recipients of care.
Compliance to treatment

Knowledge – a sense of power and less dependence
Carrying out and being compliant to the dialysis treatment according to the prescribed regimen was information the participants had been told as being important for the outcome of health. Some of the participants had used the opportunity to have days off from treatment – with approval from their doctor – which meant a greater freedom and less limitations in their daily living The patients who appeared most successful, in the sense of making the most of a life that is being sustained, were those who remained a sense of control over their treatment rather than being at the mercy of their situation. A sense of control over the treatment situation included the knowledge and ability to ‘bend the rules’ within safe limits from time to time. It could for example be excluding an exchange in order to attend a special event or knowing how to overstep the dietary restrictions for a special occasion without risking fluid overload. As hospitalization often results in a great loss of control for an individual, one thinks that the opposite occurs performing one owns treatment at home – a sense of power and freedom to – within given restrictions – be able to make one’s own decisions. Being able to adjust the time interval between bag exchanges, knowing that it will not do any harm; being able to run private errands without looking at the clock all the time.

I can be without dialysis for two or three days. So if I go away for a shorter period of time I don’t have to bring all the bags. It’s good in that way. You are freer so to speak.

They have told me that once in a while I can skip the machine and that is a comfort when the machine doesn’t work when you go to bed and you can’t get it started. Then you can put a manual bag on the heater.

Taking a day off meant that one could alter the regimen and switch over to manual bag exchanges and skip the machine in order to increase freedom and flexibility.

If I skip the machine, which I can do, I haven’t done it that many times...then I take a manual bag in the morning and perhaps another one in the afternoon and then I connect to the machine at night...that works out too. I know how to do and I have even brought a bag with me at six o’clock so I can perform an exchange to where I’m going. One day I’ll do it this way and another time I just skip it.
Some participant was totally unaware of the possibility;

\[ I \text{ haven’t done it… I have not heard that I can do that… It just hasn’t come up. Sometimes I skip the afternoon exchange for practical reasons if I’m not at home.} \]

**Adapting and planning to carry on daily living**

The most important aspect of daily life was to be able to continue life like it was before the onset of the renal disease and the dialysis treatment. In order to avoid restrictions in their daily life they tried to plan ahead and prepare the machine in advance before going to bed or attending evening activities, but most of all they tried to avoid being dominated by their treatment.

\[ \text{When I work at night… I get home at seven o’clock, start the machine at eight o’clock and then when I wake up its done.} \]

\[ \text{I try to live as normal as possible… I stopped playing tennis after the catheter operation, but they told me I didn’t have to… sometimes I think I’ll pick it up again. I would probably have been more active if this hadn’t happened, I think so… sometimes I feel I would like to have more to do… have been used to working everyday… it is a changeover. It is better now; it was terrible in the beginning.} \]

\[ \text{… I live the same life as before.} \]

**Taking part in their own treatment**

To have control over the treatment was a necessity for all participants. One participant in particular found it important to monitor XX’s physiological progress and kept detailed records of blood chemistry values as a way of achieving control and also as a way to take part in XX’s treatment modality. By noting different blood values over time and having a visual representation of the values on a graph the participant found this to be a way, a strategy, to realize and recognize when physiological deterioration was occurring. This worked as a positive feedback for the participant to continue to engage in the therapeutic plan as well as a sign of physiological control.

\[ \text{My attitude is to gain knowledge about my disease. If you are ill, you have to; it’s my body we are talking about so one has to be well-informed. I think it is exciting. It contributes to my well-being to take part in the process.} \]
To handle the dialysis treatment and to live as normally as possible was repeatedly described as important for the participants in this study. Various strategies were used in order to continue with activities of everyday life.

_I try not to let the dialysis run daily life completely... We were away yesterday afternoon and came back around five-six, but then I don’t do the bag exchange right away... I wait until after dinner_

_We get up early at five o’clock in the morning. Then it takes a while to disconnect the machine, twenty minutes at the least. Then I prepare the machine so it is ready for the next night, placing the bags on it and everything... takes away the used tubes._

_...there is always a new problem to solve... one just deal with it as it comes. It is forbidden to sit down and have the blues..._

All of the participants seemed to agree that the treatment allowed them to carry out daily chores, but their time still needed to be adapted to the treatment.

The importance of looking after one’s health, to sleep well at night despite alarms from the machine and to keep free from treatment complications were expressed as strategies to remain as vital as possible. It was important to look after one self physically and to be in good condition.

_I try to get some fresh air and go for walks... and I have noticed that if I go to bed around ten o’clock it’s easier to fall asleep compared to if I go to sleep a lot later._

**Avoiding and giving up**

There were some things that the participants no longer could do with ease, sometimes they perceived they even had to avoid them or to give them up. Specifically mentioned were; one’s own decision for when to go to bed, leisure activities and sports, travelling without planning ahead, and sleeping in the same bedroom as their partner. These concerns could be regarded from perspectives such as physical obstacles, and also be looked upon from the person’s own context where individual reasons or obstacles made it difficult to adapt to or to simply manage.
THOUGHTS ABOUT THE FUTURE
From relief and gratitude to fear

Some reflections prevailed uncertainty about the future, about getting older and perhaps being incapable of carrying out the treatment one’s self. The reflections also expressed relief and gratitude for the existence of the technology of peritoneal dialysis at the same time.

...sometimes you think: what’s going to happen when you get even older and don’t have the strength to struggle with these bags...if you haven’t ended up in hemodialysis, that is. Sometimes one wonders for how long one can survive with this disease...

...the anxiety above all...every time the ambulance arrives... the worry for how it is going to end...I’ve been like a yo-yo in and out at the nephrology clinic....I’ll be happy as long as it works with the peritoneal dialysis.

Waiting for death to come...No, that’s not the way it feels! There is no thinking of that ...I don’t think of the future of things I do not know of.

Fear for the future could mean transfer to hemodialysis.

...they have been nagging for the past year that I need hemodialysis, but I don’t like it. I can’t say why I’m against it. Maybe it’s the blood flying in and out of the arm. Just think about it, lay there for four –five hours every third day – you are completely stuck! As long as the blood tests show good results the doctor told me that it could wait.

...one is aware that if this doesn’t work out one has to transfer to hemodialysis. It is on your mind all the time...

I must say that I have considered many times how to manage all this if you get sick? If you get really sick and can’t keep everything in order...getting weaker and worse – does one manage to handle the machine and perform the exchanges? For as long as you feel fine everything is fine. Another threat hanging over you is hemodialysis...or more bags and longer time at night with the machine...I see more cardboard boxes in the house, more boxes to be torn apart...
DISCUSSION

METHODOLOGICAL CONSIDERATIONS

The aim of the study was to describe patients’ lived experiences of automated peritoneal dialysis treatment on daily living and the results revealed knowledge which would have been hard to obtain by other methods than qualitative. Among the qualitative methods, interviews with a narrative character were found to be most appropriate for the study since it permitted to gain knowledge from people’s life-world experiences.

A problem that may arise in an interview situation was the probable risk of the interviewer directing the interviewee towards particular ways of answering. The interviewer’s aim was to counter this being aware of the phenomenon during the interviews. Another issue to attend to was to create a permissive atmosphere helping the interviewee to feel free to relate in order to prevent insecurity.

The inclusion criterion for age was set at 18 or older, because including children would have meant a different context. The age of the participants per se was not asked for specifically, but it turned out during the interview situation that they were over 60 years old, except one participant in the mid 40’s. The inclusion criterion for age probably had an impact on the results. Younger participants, perhaps being students or employed, and having family with small children, would be in a different context and therefore would possibly have led to other answers than those in these interviews for the thesis. And of course the opposite, if participants would have been more elderly, would also impact on the answers.

The interviewer’s knowledge and experience in the renal field can be looked upon as a positive pre-understanding for what the persons narrated. The interviewees did not know the interviewer and therefore, even if they were encouraged to speak as freely as possible, perhaps they withhold their inner, deeper feelings. Maybe the interviewer’s naïve skills and lack of following up the ‘right threads’ during the conversations had some influence on the interview.

The study was not aimed to produce generalizations, but rather in-depth understanding and knowledge of the phenomena of living with automated peritoneal dialysis treatment, and the results in this study revealed knowledge which would have been hard to achieve by
other methods than qualitative. The sample of interview persons was small and the sampling was done with assistance of renal nurses, who selected participants, which is a possible limitation. However the strength of this approach was that the interviewer could enter the life of the participants and try to grasp their meaning of a lived experience. The dialogues in the study revealed various emotions of the interview persons who freely allowed a glimpse into their life-world and shared fascinating stories. One among other possible limitation was the interviewer’s own awareness of the effect of the previous experiences from working as a renal nurse, but it has been of greatest importance to let personal experiences be detached from those told by interview persons. As Kvale (1996) points out the qualitative research interview is not a conversation between equal partners, because the researcher defines and controls the situation (ibid.). It has been very important to let the dialogues appear for itself with as little interference as possible from the interviewer.

The interviews were conducted during three days, two per day, a couple of hours apart from each other. The interviewer needed time between interviews to reflect and clear the mind in order to be alert for the next interview person.

The fact that the interviewer was a renal nurse working with persons with chronic renal failure could be viewed as both an asset and an obstacle. It was an advantage that the interviewer was able to understand the situations which the participants referred to, and that the participants felt that there was an open climate to discuss their experiences from their treatment. Potential disadvantages were that the interviewer’s practised experiences might have biased the probing regarding what struck the interviewer as important and meaningful in what the participants were saying during interviews. The participants might also have left out information they considered implicit and understood by the interviewer since she works in renal care. In order to reduce the risk of author bias the interviewer used repetition, request for clarification, request for elaboration and confirmation during the interviews.

RESULTS

The lived experiences expressed from living with APD treatment shed light on what every day life is like with this kind of renal replacement therapy. The results showed an
adjustment to daily life, which involved making everyday life easier by adapting to
treatment and using technical aids like the dialysis machine. Worries about starting
treatment and to use the dialysis machine had with time changed to a feeling of freedom
and independence. Despite difficulties that caused strain in everyday life, most participants
had accepted their situation and had tried to make the best of it. Ways of coping had
developed with the changes in life and in relation to the treatment. To live with the changes
and how to live within the new boundaries were expressed. The stories told gave an
understanding of strategies used to carry out daily living in a phase of life where the
chronic renal disease and the treatment could be seen as an uninvited guest.

Existential feelings and concerns became visible during interviews, but issues of practical
matters to take into consideration and to solve in everyday life were more important and
outstanding. This could be interpreted and related to the time on treatment that influenced
the concerns. The participants had had their APD for at least nine months and up to five
years, and prior to that the range of time on CAPD was from six months to nine years, so
the total time on renal replacement therapy varied from two to almost ten years. With so
many years passing by from the onset of treatment the context had altered over time and
probably even the concerns –adjustment to the treatment had become a routine, a way of
living. The interviews showed that they had actively had to learn behaviours that helped
out adapting and to cope to a new lifestyle related to the consequences of the treatment.
Lazarus & Folkman (1984) has stated that, if the nature of the stress changes over time, the
nature of the coping response may also change and then the coping response has to match
the nature of the demands (ibid.). Performing a study with the same interview guide, as for
this study, with individuals three months directly after onset of treatment would be
interesting to perform as a comparison as the concerns were within each individual as a
person with his or her inner capability to cope with life itself. To take life as it comes, to
accept whatever comes by and get used to it – to take life for what it is and not look upon
oneself as a victim of circumstances.

The results from the study showed that coping with and living with APD treatment
involved facing both stressors and challenges in everyday life. Antonovsky (1985) and
Lazarus & Folkman (1984) have stated that an individual’s personal meaning of and
attitudes toward an illness, injury or disability are directly related to coping strategies as
well as a possible mode of control to gain mastery. Coping is, according to Lazarus &
Folkman (1984), the measures taken by the individual in order to handle the situation, i.e. what he or she does or thinks in order to get rid of or to reduce the triggering stressor (ibid.). A person with a strong sense of coherence might be more able to handle stress-related situations in a positive way and that a strong sense of coherence means that environmental stressors are experienced as comprehensible, manageable and meaningful (Antonovsky, 1985).

In this study it was found that the sense of coherence was related to the way in which participants perceived their disease and the way they adjusted to it in everyday life. From the time when receiving the end-stage-renal-disease diagnosis to a new perspective of life, this can, according to Antonovsky’s salutogenic notion of coherence be viewed as a natural biography of the individual (ibid.). The efforts toward creating a meaning out of the disease and to create sense of coherence could be seen as a way to bridge the gap between the time before the diagnosis and the time with APD treatment. Despite difficulties that caused strain in daily life, most expressions were interpreted as an individual acceptance of the situation and that everyone had tried to make the best of the situation. The latent content analysis also revealed a phase of transition with a need of a behavioural change due to the illness. The transition was from the identity of being healthy to being a person with a progressive illness, a process starting when the diagnosis was stated. The transition was from a state of independence in daily living to the dependence on life support treatment.

The APD regimens and the learned skills required to be implemented took time to execute and usually required changes in habits and routines in everyday life, involving physical and psychological stress. The regimen’s difficulty was not only due to the individuals having to learn psychomotor skills such as preparing the dialysis machine for the night’s treatment, but also to the individuals having to cope with psychological reactions to the health problem. The dialysis treatment was perceived as a constant reminder of being different and of having the chronic kidney disease to cope with. According to Lazarus & Folkman (1984) is coping one’s efforts to master demands that are appraised (or perceived) as exceeding or taxing one’s resources It is a process that may consist of behaviours and intrapsychic responses designed to overcome, reduce or tolerate these demands. The two general categories of coping strategies are problem-solving efforts strategies aimed at the regulation of emotions. Problem-focused coping refers to efforts to improve the troubled person-environment relationship by changing things, for instance by seeking information about what to do. Emotional-focused (or palliative) coping refers to thoughts or actions
whose goal is to relieve the emotional impact of stress (for example, bodily or psychological disturbances). Both sets of strategies are brought to bear on most stressful events, problem-solving efforts are especially useful for managing controllable stressors, and emotional-regulation efforts are well suited to managing the impact of uncontrollable stressors. According to Lazarus & Folkman (1984) does everyone employ different combinations of problem-focused and emotion-focused methods to cope with stress. The conditions determining our coping methods in specific situations are complex and likely to depend on the conditions being faced, the options available to us and our personality.

Coping is stimulated in individuals with chronic health problems and chronic illness brings about a confrontation with reality, adaptation and participation in care (ibid.). This study showed that both the individual and the family had to respond to external situations like adhering to the medical regimen in order to complete a treatment such as APD.

Maintaining a sense of normalcy was one way to cope, expressed by the participants with the meaning to live as normal as possible with APD treatment. It could also mean hiding or minimizing the illness, as responding to curious inquiries from others. To feel tired and unhealthy and at the same time to hear how well and fresh one looks emphasized the lack of understanding from friends and relatives. Modifying daily routine and adjusting lifestyle included therapy and symptom control in everyday life as another coping strategy, as was obtaining knowledge and skill for continuing self-care by monitoring effects of therapy. Adjusting to altered social relationships as coping and avoiding loneliness and social isolation was important for everyday life. To care for relationships with family and friends who satisfied dependency needs was also told as important. Another way to cope was to maintain a feeling of being in control, using a decisional control, for example to have a night off treatment if needed. The knowledge obtained and the skill for self-care made this possible. Thoughts were expressed concerning the confrontation of one’s own death and were coped with by maintaining hope despite uncertain or downward course of health.

According to Miller (2000) the way in which a person copes with illness is influenced by the nature of the power resources of belief system (faith and hope), family-social support, psychological well-being, self-esteem, motivation, type and meaning of the illness. Intrapersonal factors affecting coping include age, personality, culture, specific self-care skills, values, beliefs, emotional state, and cognitive capacity. Environmental factors may include presence of a support system, access to health services, physical resources for
The meaning of the illness to the individual affects coping behaviour. Differences in coping can be expected if one individual perceives the illness to be a threat to role functioning and another views the illness as insignificant. Illness may be viewed as a loss or a gain, or of no significance (ibid).

The component comprehensibility, in the sense of coherence concept, is the extent to which one perceives the world as ordered and the problems one faces as understandable and clear (Antonovsky, 1985; Antonovsky, 1987). Knowledge about the end-stage-renal-disease, the treatment modality per se, and knowledge about the complications that might occur seemed to be a source of power for all participants. Knowledge about the illness and its management enabled to make decisions and take actions related to the illness and/or the treatment. The ability to make decisions and act on them gave control over what happened, thereby giving a positive response of participating in the self-care process. Being informed of physiological changes, being confirmed by the health care professionals, positive responses to therapy, and expected results from therapy increased the perception of control and this could be seen in accordance with the sense of coherence concept. Miller (2000) has stated that chronically ill persons’ lack of involvement in their own care develops a sense of powerlessness (ibid.).

After receiving the diagnosis of end-stage-renal-disease there is an interval where patients and their families need information about the illness and the treatment in order to understand and manage the future. It is a period during which valuable preparation can take place. In a situation when feeling loss of control over life, knowledge and information restore a sense of capability (Klang et al., 1999). Pre-dialysis groups have become a method of providing information and reassurance to pre-dialysis patients and their families. Klang et al. (1999) performed a study in order to evaluate the effects of a patient education programme. The purpose of the patient education programme was to inform patients about the basics of conservative renal therapy and about the different modes of dialysis treatment available and thus enable them to make an informed choice. Throughout the programme the patients and their relatives had established contact with the nephrology team, consisting of a physician, a specialist nurse, a clinical nutritionist, a physiotherapist and a clinical social worker. The conclusion was that pre-dialysis group programme enabled patients to choose dialysis modality to achieve an understanding of their illness and its treatment (ibid.). Lack of understanding and knowledge can be major factors contributing to anxiety.
and poor adjustment for individuals with chronic renal failure, as supported by Klang et al. (1998) who found that pre-dialysis patient education resulted in less anxiety and better physical and psychosocial functioning in dialysis patients compared with a non-educated control group (ibid.). According to Miller (2000) is the strategy most frequently used when dealing with the tasks of chronic illness to seek information. Being attentive to the details of care and symptom control, participating in managing requirements of the illness, and raising questions without hesitation are examples of this approach strategy (ibid.).

Nurses can use quality of life information to plan, implement and evaluate interventions for clients with chronic illness, such as end-stage-renal-disease. It is important to recognize the biomedical aspects of a chronic disease, and understanding the illness experience is more prominent when caring for individuals long term. According to Lubkin& Larsen (2002) does chronic diseases as opposed to acute diseases continue indefinitely and often becomes the person’s identity where dependency is a part of the sick role (ibid). This shows the importance for health care professional to ease helping the patient back to independence.

**CONCLUSION**

The data from this interview study is knowledge that is important and could be used in planning patient care. It may also help to direct the focus of nursing towards patient resources and not just towards problems and needs. The results could be used by nurses to plan individualized teaching programmes for patients switching from one peritoneal dialysis modality to another. The study shows how important it is to learn about the amount of time, energy and often discomfort required to carry out APD treatment. By getting insight and knowledge of the subjective reality of APD patients; taking part of their knowledge, feelings, and experiences, the health-care personnel can use that patient perspective to find different answers to the problems the patients face. One example is the issue of compliance where the health-care professionals are focusing on the patient asking; ‘how can we get the patient to be more compliant to the therapy?’ If we organize care from the patient’s perspective then we should rather ask the question; ‘how can we modify the therapy to the particular requirements of this patient?’ So, looking at the problem or the specific situation from a different perspective may not solve the problems, but it will offer new insights and lay foundations in which patients work together with health-care professionals to live their lives as normally as possible. Care and support should be tailored to each individual patient to meet his or her needs at any particular time.
Think beyond the patient and the illness – remember patients are not patients all the time, just as nurses are not health-care professionals all the time.

There are indications that nurses need to recognize and respond to the tremendous emotional impact that chronic illness and its treatment can have on the individual in a time where it is possible to sustain life for years with the help of life support technology.

Nursing interventions for patients on APD treatment could be addressed to enhance the comfort of the psychological environment by reinforcing with the patients that their needs are the first priority of the health team. Lack of information about illness or use of denial as a coping mechanism may lead patients to set goals that they are not able to achieve. Goals that never will be achieved reinforce helplessness, sometimes expressed as lack of time or tiredness.

It is crucial for renal care professionals to understand more about the perspective of kidney patients themselves - to learn and to know what kidney patients really feel and experience. Only then is it possible to provide the care appropriate to the needs of each individual patient. Being dependent on a machine to stay alive is a feeling that is not easy to describe and not easy to understand.

The central focus of nursing empowering the chronically ill is to maintain and improve the quality of life. Maximizing the individual’s power resources facilitates the individual’s ability to cope with chronic illness. In order to improve the individual’s coping nurses could support and assist her/him to take more control of their lives, health and well-being.

For the clinical encounter, results stress the significance of becoming acquainted with patients’ meanings associated with APD experiences. For research, results point to the significance of further studies on interaction between health care and individuals as well as how people make sense of, use, and cope with APD as renal replacement therapy. Future nursing research should focus on interventions and evaluations of support focusing on the perspective of quality of life as well as quality of care.
ACKNOWLEDGEMENTS

I’m deeply indebted to the many people who have contributed to this thesis in so many ways. First of all, to the participants who so willingly shared their knowledge and experiences during interviews to the benefit of other patients and health-care professionals. It would have been absolutely impossible to finish this thesis without my eminent supervisor Karin Holmén, for her expert advice and never ending encouragement. At the Medical Library at Visby hospital there has been lovely support from Birgitta Kopf, Ann-Christin Lindström and Elisabeth Magnusson who never ever gave up or questioned my requests for further articles, and they never blamed me for not returning the literature in due time. I thank you, Monica Rådström. You have been my personal and secret mental mentor making me realize that the road of knowledge sometimes has to be bumpy, but never the less reachable! Finally, but not the least, I gratefully thank Professor Emeritus James MacIntyre, University of British Columbia, Vancouver Canada for linguistic corrections of the text.

Thank you all!
REFERENCES


SRAU 03 (Svenskt register för aktiv uremivård). Aktiv uremivård i Sverige 1991-2002. Dr Staffan Schön, Njurmedicinska kliniken, KSS, 541 85 Skövde, srau.kss@vgvregion.se.


### Subheadings from CINAHL database search.

<table>
<thead>
<tr>
<th>Term</th>
<th>Subheadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Peritoneal dialysis; Peritoneal dialysis, continuous ambulatory.</td>
</tr>
<tr>
<td>2</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>3</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>4</td>
<td>CINAHL unable to map the term.</td>
</tr>
<tr>
<td>5</td>
<td>Include all subheadings</td>
</tr>
<tr>
<td>6</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>7</td>
<td>Clinical nursing research; Nephrology nursing; Nursing care; Research nursing.</td>
</tr>
<tr>
<td>8</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>9</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>10</td>
<td>Patient attitude; Adult.</td>
</tr>
<tr>
<td>11</td>
<td>Include all subheadings.</td>
</tr>
<tr>
<td>12</td>
<td>Patient satisfaction; Adult.</td>
</tr>
<tr>
<td>13</td>
<td>Adult, interviews, qualitative studies</td>
</tr>
<tr>
<td>14</td>
<td>Life experiences. Include all subheadings.</td>
</tr>
</tbody>
</table>
## The Review Matrix inspired by Garrard (1999)

<table>
<thead>
<tr>
<th>Author, title, journal</th>
<th>Purpose</th>
<th>Study design</th>
<th>Participants</th>
<th>Results</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diaz-Buxo, J.A., Farmer, C.D., Walker, P.J., Chandler, J.T., &amp; Holt, L.H. (1981). Continuous Cyclic Peritoneal Dialysis: a preliminary report. Artificial Organs, 5, (2), 157-161.</td>
<td>Undefined</td>
<td>Quantitative. <strong>Time period:</strong> 84 patient months. <strong>Methods:</strong> Equilibration studies, clearance determinations, blood samples, ultrafiltration studies.</td>
<td><strong>Total number:</strong> 14 = 5♂, 9♀ <strong>Age:</strong> 19-72 years <strong>Drop-out:</strong> not reported</td>
<td><strong>Advantages of CCPD:</strong> All patients enjoyed their liberal diets, the convenience of an interrupted day of activities and automated exchanges at night. All but 1 pat remained on CCPD (abdominal surgery and transfer to HD). <strong>Disadvantage of CCPD:</strong> The need for mechanical equipment – on the other hand, it is the machine (cycler) that allows multiple exchanges while the patient rests. A positive patient-machine interaction is ultimately related to the individual’s intellectual acceptance of the machine as an assess to his well-being. The cost of CCPD is higher than CAPD due to cost of the cycler and the disposables required. <strong>Summary:</strong> This study shows that CCPD: 1. Provides excellent clearances 2. Can achieve a high rate of UF 3. Provides a steady physiological state 4. Require fewer connections than CAPD, under aseptic control 5. Allows better utilization of time, since there are no diurnal interruptions and it utilizes automated nocturnal cycles. 6. Provides patients a high degree of freedom and mobility by utilizing portable equipment. <strong>Most important advantage:</strong> the potential for a lower rate of peritonitis.</td>
</tr>
<tr>
<td>King, L.K., Kingswood, J.C., &amp; Sharpstone, P. (1992). Comparison of the efficacy cost</td>
<td>Is APD an efficient and cost effective alternative to CAPD?</td>
<td>Retrospective, Comparative, Quantitative. <strong>Time period:</strong> 2 years (1990-91)</td>
<td><strong>Total number:</strong> 40 = 10 APD + 30 CAPD. <strong>Age APD:</strong> 37-</td>
<td>No significant difference in the biochemical profiles between the APD group and the CAPD group. Average amount of dialysate used each day was for APD 11 L/person (9-14L) and</td>
</tr>
</tbody>
</table>
and complication rate of APD and CAPD as long-term outpatient treatments for renal failure. *Advances in Peritoneal Dialysis, 8*, 123-126.

| United Kingdom | Methods: Biochemical and medical aspects: Peritoneal Equilibration Test (PET), average amounts of dialysate, number of exchanges/day (CAPD) or cycles per day (APD) and the volume of dialysate used was costed per day together with disposable used (disconnect caps, iodine connection shields, Y-sets and cycler sets), peritonitis rates, exit site infection (and their recurrence) rates, costing of peritonitis, the cost of operating a cycler machine. **The psychosocial aspects** were assessed through nurse-patient interaction and by informal interviews – not defined. | 79. Age CAPD: 23-76.  
Drop-out APD: 1 transfer to HD, 1 death, 2 transplants =4/10  
Drop-out CAPD: 4 to HD, 4 deaths, 5 transplants =13/30 | CAPD 6.8 L/person (6-10L). The peritonitis rate was markedly reduced in the APD group (1 in 50 patient months), with no exit site infections (ESI). CAPD group 1 in 12 patient months with peritonitis and 40 ESI. **The costs** of APD and CAPD were similar. All of the **APD patients preferred their treatment** for the convenience of having the day free from performing exchanges and were unwilling to return to the regular CAPD. The **choice and flexibility** of two treatments was a **bonus** e.g. reverting to CAPD for short periods when away from home, or occasionally having a night off dialysis. The study shows that the **investment** in automated PD cycler is **cost-effective** in the long-term; **reduction in complications**, i.e. less peritonitis and ESI. (Sweden leases the machines) All patients expressed **preference for APD**. The patients felt they had more **control** over their lives and treatment. **Self-esteem** was raised through having a small volume day-time dwell whereby the abdomen was minimally distended during the day. APD makes it **easier for a partner** to take charge of dialysis. There is a danger of **selection bias** in short term studies i.e. the “best” patients may select themselves for a new treatment and have good results because they are compliant. According to the authors has APD proven to be an economic, effective and easily managed treatment, which is safe, reliable and readily learned. |
**Quantitative, comparative study.**  
**Time period:** 6 months.  
**Nutritional assessment:** weight change,  
**Total number:** 32=13 CCPD (6♂, 7♀), and 19 CAPD (11♂, 8♀) Been on PD at least 3 months and had no peritonitis 4  
**Nutritional assessment:** No significant weight change, edema difference, no difference in the relative frequency of use of hypertonic dialysis solution, between the two groups. Questionnaire on dietary intake showed that the CAPD group had experienced more appetite change than the CCPD group, |  |  |
patients. *Advances in Peritoneal Dialysis, 9*, 76-79.

**Dialysis adequacy:** collection of 24-hour dialysate and urine. KT/V, PCRN.

**Statistical analysis:** Student’s two-tailed unpaired t-test or chi-square test where appropriate. P-value < 0.05 was considered statistically significant

but the CCPD group showed significantly gastrointestinal symptoms. The reason for this is unclear, but may be related to the raised intraperitoneal pressure in the recumbent (liggande, vilande) position experienced more by the CCPD patients than by the CAPD group.

**Dialysis adequacy:** no statistical difference between CAPD and CCPD using urea kinetic parameters.

**Discussion:** Adequate dialysis is very important for the well-being of patients with end-stage renal disease. With poor dialysis patients retain many of their uremic symptoms, leading ultimately to poor nutritional status and unfavourable outcome.

**Conclusion:** The nutritional status of CCPD patients in this study was similar to the CAPD patients. The serum albumin variable used to assess nutritional status revealed that both groups were mildly malnourished. Adequacy of dialysis was also similar in CCPD patients as compared to CAPD patients.

---

**Germany**


**Quantiative. Retrospective. Time period:** 1989-1993 = 5 years.

**Methods:** Serological and clinical parameters. (24 hour urine collection every third month).

**Statistical analysis:** Mann-Whitney U test for unpaired samples.

**Total number:** 104= 61♂, 43♀ APD

**Age CPPD:** 14-76

**Age CAPD:** 34-75

**Drop-out:** Not defined.

Mean hospitalization for all patients: 10 days/year.

This study demonstrates that APD is able to provide adequate dialysis. APD was associated with a high level of social rehabilitation (not showed), and relatively low rates of peritonitis and technical failure.

The authors mean that a wider use of APD depends on the reduction of the high costs for this kind of renal replacement therapy.

---

Viglino, G., Gandolfo, C., Virga, G., & Cavalli, PL. To assess the impact of automated peritoneal dialysis (APD) on the

**Retrospective examination of treatment results.**

**Total number:** 112 HD, 88 PD=78 CAPD

APD increased from 3% to 7.4% between periods I and II in the centre. With PD as first treatment APD was increasing from 3.4%

<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient method selection:</td>
<td>the patients starting on PD was assessed from both clinical and psychological, social, and aptitude points of view, to identify indications and contraindications for this kind of treatment.</td>
</tr>
<tr>
<td>Drop out: 3 patients</td>
<td></td>
</tr>
<tr>
<td>Age: CAPD</td>
<td>47-75 APD 49-75</td>
</tr>
<tr>
<td>+ 10 APD.</td>
<td></td>
</tr>
<tr>
<td>Peritonitis:</td>
<td>abdominal pain, LPK &gt; 100/µL, positive dialysate culture.</td>
</tr>
</tbody>
</table>
| +15.2% between periods I and II. In period II was APD chosen on clinical grounds for 26.6%, while for the remainder the choice was determined by distance, advanced age, and work. The main reason for choosing APD was the need for a partner in performing dialysis. Patients changing modality from CAPD to APD did it due to: inadequate UF, inadequate dialysis, problems caused by increased intraabdominal pressure, recurrent peritonitis, social-aptitude grounds (need for partner, compatibility with work commitments). Only 1 patient dropped out of this APD group. The main reason for using NIPD was insufficient UF, the presence of oedemas in the lower limbs, and the problems related to an increase in IAP. The incidence of peritonitis in APD1 and APD2 was comparable to the incidence in patients treated with CAPD. This clinic had a selection protocol that considered APD second choice to CAPD. There was an increase of APD over the years in part II. The nonclinical grounds on which APD was preferred to CAPD were related to the time required by and the timing of the dialytic procedure. This is important when work commitments during the day are involved, or when dialysis needs to be performed with an assistant, especially if the assistant is not a member of the family. In this sense APD provides greater opportunities for using PD in the near future, considering the aging dialytic population and the high percentage of elderly patients who require assistance in performing dialysis. There are also psychological problems in assessing one’s body image due to the presence of liquid in the abdomen that makes APD favourable to avoid PD drop out. Finally this clinic’s experience is that APD has contributed to limiting the PD drop out rate and allows wider use of APD. But the
<table>
<thead>
<tr>
<th>Italy</th>
<th>Statistical analysis: comparison between groups using the corrected Yates chi-square test for qualitative parameters and the two-tailed, nonpaired Student test for continuous variables. Kaplan-Meier for calculating technique survival, and the log-rank test to compare the probability curves of the two groups.</th>
<th>authors hope for an APD system at a reduced cost that would allow this method to be considered as an alternative to or integrated with CAPD on the basis of clinical, psychological, and social-aptitude.</th>
</tr>
</thead>
</table>
| McComb, J., Ross Morton, A., Singer, M A., Hopman, W M., & MacKenzie, T. (1997). Impact of portable APD on patient perception of Health-Related Quality of Life. *Advances in Peritoneal Dialysis, 13*, 137-140. | Has the introduction of the portable APD system (Home Choice, Baxter) an impact on patient-perceived HRQOL? **Hypothesis:** the technical advantages, from the perspective of convenience, should have a positive impact on the social scores as assessed by the HRQOL tool. **Quantitative.** **Time period:** Not mentioned. **Methods:** RAND 36-item health survey 1.0, which measures physical functioning, role limitations (physical and emotional), social functioning, emotional well-being, pain, energy, and general health perceptions. **Questionnaires** were administered prior to changing to the new system and 3 months later. **Total number:** 26 (11 ♂, 15 ♀). 8 patients had been on CAPD, and 18 had been using other APD systems. **Age:** Mean age 55. **Drop-out:** Not mention | There was an improvement in the pain score (p=0.079), although this did not reach statistical significance in the overall sample. No other statistically significant differences were found overall in the domains of HRQOL. The improvement in pain score may reflect the capacity of newer cyclers to switch from drain to fill, leaving the patient empty for less of the time. The significant improvement in the KT/V score suggests that easier setup may result in better patient compliance. **Discussion:** the few statistically significant changes in HRQOL may have two reasons. 1) The RAND 36-item health survey 1.0, may not be sufficient sensitive to measure a treatment change of this nature. 2) The lack of statistical significance may be related to the small sample size. **Conclusion:** It appears that these
Canada advances have little impact on patient perception of HRQOL. This suggests that health care professionals should continue to assist the patients in other ways in order to provide a successful treatment outcome.


To develop a reliable method to measure compliance with prescribed exchanges in CAPD and CCPD, through an inventory of the patient’s home supplies.

**Methods:**
- A self-evaluation where patients were asked directly about how often they missed exchanges, what they thought the consequences of missed exchanges were, and how they felt about the medical care received.
- **Derogatis Affects Balance Scale (DABS):** a one-page list of 40 adjectives describing how people feel.
- **Staff evaluation,** completed independently by the nephrologists, primary nurse, renal dietician, and renal social worker. A 24-hour dialysate and urine collection, a

| Total number: | 49 CAPD and CCPD patients – not told how many in each group. |
| **Age:** | 37-61. |
| **Drop-out:** | Not mentioned |

17/49 =35% were noncompliant with prescribed exchanges based on the supply inventory. 40 % of CAPD patients were noncompliant compared with 20% of CCPD (p=0.15). There was no difference in compliant and noncompliant patients by age, race, gender, time on PD, measured-to-predicted creatinine ratio, number of comorbid conditions, or incidence of diabetes. Peritonitis rates were higher in noncompliant patients, compared with compliant patients. There was no difference in attitudes about the consequences of non-compliance. Only 2 patients (4%) admitted to non-compliance. The number of days hospitalized was higher in noncompliant patients. Staff evaluations of PD patient compliance in the current study were highly inaccurate. The authors discuss that home visits to conduct supply inventories provide an excellent method of monitoring compliance, but that further studies are needed to verify the frequency of non-compliance with prescribed exchanges. Because of the small number of patients were they not able to identify measures that may convert noncompliant patients to compliance with the PD prescriptions.
To compare APD and CAPD treatment with respect to quality of life and clinical outcomes in relation to therapy costs.

Quantitative: A prospective, randomized multicenter study. (The first according to the authors!)

**Time period:** 6 months.

**Interventions:** 17 patients were allocated to APD and 17 patients to CAPD after randomization for a period of 6 months.

**Medical and biochemical parameters** were evaluated at monthly controls.

**QOL parameters** were assessed at baseline and after 6 months by self-administered short-form SF-36 generic health survey questionnaire supplemented with disease and treatment – specific questions.

**Patients:** 34 patients enrolled; 25 patients 13 = CAPD and 12 = APD completed the study.

- **Age:** CAPD 54-58 APD 50-55
- **Drop-out:** 9/34 =26%

**Results:**

Reasons for patients to terminate prematurely: kidney transplant, change to hemodialysis (oedema of the scrotum, peritoneal catheter dysfunction), sudden deterioration of the general health status, psychosocial factors, inability to handle the cycler.

The QOL studies showed that significantly more time for work, family, and social activities was available to patients on APD compared to those on CAPD (p<0.001). Although the difference was not significant, there was a tendency for less physical and emotional discomfort caused by dialysis fluid in the APD group. Sleep problems, on the other hand, tended to be more marked in the APD group. Any positive effect of APD compared to CAPD on dialysis-related hospital days or complication rates could not be confirmed.

The running costs for APD treatment were US $75 and for CAPD $61 per day.

**Comments:** The authors think that with a larger patient sample it would be possible that a significant difference might have been achieved. Upon completion of the study, all patients on APD were free to choose between APD and CAPD treatment. They all preferred to continue on APD. The CAPD patients were not free...
<table>
<thead>
<tr>
<th>Country</th>
<th>Study Title</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>Therapy costs were compared by evaluating dialysis-related costs.</td>
<td>to choose between APD and CAPD for reasons of economy.</td>
</tr>
<tr>
<td>Poland</td>
<td>To analyse the results and outcome of the APD therapy in a Gdansk centre.</td>
<td>The role of automated peritoneal dialysis in peritoneal dialysis programme: one centre experience. International Journal of Artificial Organs, 22, (11), 734-738.</td>
</tr>
</tbody>
</table>

**Liberek, T., Renke, M., Lichodziejewska-Niemierko, M., & Rutkowski, B. (1999).**

The role of automated peritoneal dialysis in peritoneal dialysis programme: one centre experience. *International Journal of Artificial Organs, 22, (11), 734-738.*

**Conclusion:** If APD treatment can help to keep selected patients vocationally or socially active, paying the extra cost seems reasonable.

**Liberek, T., Renke, M., Lichodziejewska-Niemierko, M., & Rutkowski, B. (1999).**

To analyse the results and outcome of the APD therapy in a Gdansk centre. *Quantitative.*


**Method:** Retrospective analysis of medical parameters.

**Total number:** 17 patients (8 ♂, 9 ♀).

**Age:** 25-86

**Drop-out:** 5/12 (42%).

12/17 were still on therapy at the end of the analysis.

None of the patients were transferred to HD.

It could be argued that the high mortality reported in this study was related to negative patient selection (but it was a retrospective analysis!!). The authors conclude that APD may be used with success in patients in whom continuation of CAPD or HD therapy is very difficult due to its complication or comorbid conditions.

**de Wit, A.G., Merkus, M. P., Krediet, R. T., & deCharro, F. Th. (2001).**


**Method:** Convenience sample. All patients had been treated with their current modality for at least 3 months, were over 18 years of age, had adequate eyesight and understanding of the Dutch language. Data was collected from home interviews by nurses with experience from ESRD treatment. The interview consisted of the administration of four generic questionnaires:

**Total number:** 37 APD patients and 59 CAPD patients matched for total time on dialysis.

**Age:** CAPD 25-80 APD 28-76

APD patients scored equal to or slightly better than CAPD patients on all SF-36 subscales, but that only the difference in social functioning was significant ($p = 0.03$). Compared to CAPD patients, APD patients showed fewer problems in the EQ-5D with mobility, daily activities, and pain, but the differences were not significant. APD patients were less anxious than CAPD patients ($p < 0.05$).

APD treatment appeared to be an independent indicator of better mental health and of the absence of anxiety and depression. Possible, treatment selection played a role. The better social functioning of APD patients might be related to the fact that daytime for these patients are free from treatment, thus facilitating a normal social life. The comparison with a general population sample of the same age, both CAPD and APD patients showed worse SF-36 physical summary scores, but the
The Netherlands

questionnaires, including two
health-profiles
(Short-Form 36
Health Survey
and EuroQOL
EQ-5D) and two
health
preferences
methods
(Standard
Gamble and
Time Trade Off).
Statistical
analysis was
performed.

SF-36 mental summary scores of
patients were similar to those of
the general population.
This study suggests slightly
higher mental QOL of APD
patients than compared to CAPD
patients, and if this is confirmed
by other studies, the higher costs
of APD might be justified.
The authors think that future
studies should be of longitudinal
nature, facilitating better control
for possible differences in
baseline characteristics of
patients' group.

RESULTS: Physical
functioning of both APD and
CAPD patients were impaired
compared with the general
population; mental functioning
was not different. In multivariate
analyses, the mental health of
APD patients was found to be
better than that of CAPD
patients. APD patients were less
anxious and depressed than
CAPD patients.
HRQOL of APD patients is at
least equal to HRQOL of CAPD
patients.

Study in order to
review the
experience of APD
in elderly patients
and to compare the
technique failure
rates, peritonitis rate,
and overall QOL in
older patients with
younger CPD
patients.

Peritonitis rate
was registered.
QOL; SF-36,
Beck Depression
Inventory (BDI),
Patient Related
Anxiety Scale
(PRAS) and a
patient-assessed
QOL. Given to
all patients at 6-
month intervals
– but not sooner
than 3 months
after the start of
CPD treatment.

Total
number: 493
patients
divided into
three groups
based on their
age
Age: Group I
< 50
Group II
50-64
Group III
≥ 65).

The present study suggests that
elderly patients with ESRD can
be successfully treated with CPD
and that complications of CPD in
this population are not higher
than in younger patients.
They found that technique failure
rates, peritonitis rates, and
general quality of life measures
are not different in older (≥ 65)
versus younger patients with
ESRD. Their findings suggest
that the use of automated cyclers
to treat elderly ESRD patients is
effective, well accepted, and
does not increase the risk of
complications or technique
failure.
The authors also think that age
alone should not be a barrier to
CPD therapy and that referral for
consideration of CPD therapy
should be encouraged in elderly
patients.

Kadambi, P.,
Troidle, L.,
Garban-Brennan,
N., Klinger, A
S., & Finkelstein,
APD in the
elderly.
Seminars in
Dialysis, 15
(6), 427-429

USA
## Appendix 1:3.

### Chronological overview of articles for integrative literature review.

<table>
<thead>
<tr>
<th>Authors</th>
<th>Year</th>
<th>Purpose</th>
<th>Study design</th>
<th>Time period</th>
<th>Number of participants</th>
<th>Drop out rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diaz-Buxo et al.</td>
<td>1981</td>
<td>Not defined</td>
<td>Quantitative</td>
<td>84 patient months</td>
<td>14</td>
<td>Not reported</td>
</tr>
<tr>
<td>King et al.</td>
<td>1992</td>
<td>Is APD cost effective?</td>
<td>Quantitative.</td>
<td>2 years</td>
<td>APD 10 CAPD 30</td>
<td>APD: 4/10 = 40% CAPD: 13/30 = 43%</td>
</tr>
<tr>
<td>Abdo et al.</td>
<td>1993</td>
<td>Nutritional status</td>
<td>Quantitative.</td>
<td>6 months</td>
<td>APD 13 CAPD 19</td>
<td>Not reported</td>
</tr>
<tr>
<td>Brunkhorst et al.</td>
<td>1994</td>
<td>Report from clinical results</td>
<td>Quantitative</td>
<td>5 years</td>
<td>APD 104</td>
<td>51/104 = 49%%</td>
</tr>
<tr>
<td>Viglino et al.</td>
<td>1995</td>
<td>Assess impact of APD</td>
<td>Retrospective</td>
<td>12 years divided into two periods</td>
<td>APD 10 CAPD 78 HD 112</td>
<td>3 patients</td>
</tr>
<tr>
<td>McComb et al.</td>
<td>1997</td>
<td>Has APD impact on HRQOL?</td>
<td>Quantitative</td>
<td>Not mentioned</td>
<td>APD 26</td>
<td>Not reported</td>
</tr>
<tr>
<td>Bernardini et al.</td>
<td>1998</td>
<td>Develop method to measure compliance</td>
<td>Quantitative</td>
<td>Started in 1995 – reported in 1998</td>
<td>CAPD and APD =49 patients total</td>
<td>Not reported</td>
</tr>
<tr>
<td>Bro et al.</td>
<td>1999</td>
<td>Compare APD and CAPD treatment, quality of life and clinical outcomes related to therapy costs.</td>
<td>Quantitative</td>
<td>6 months</td>
<td>34 patients enrolled, 25 completed</td>
<td>9/34 = 26%</td>
</tr>
<tr>
<td>Liberek et al.</td>
<td>1999</td>
<td>Analyse the results and outcome of APD</td>
<td>Quantitative Retrospective</td>
<td>Oct 1995 – Dec 1998</td>
<td>APD 17</td>
<td>5/12 = 42%</td>
</tr>
<tr>
<td>de Wit et al.</td>
<td>2001</td>
<td>Explore the HRQOL of APD patients</td>
<td>Quantitative</td>
<td>Not mentioned</td>
<td>APD 37 CAPD 59</td>
<td>Not reported</td>
</tr>
<tr>
<td>Kadambi et al.</td>
<td>2002</td>
<td>Review APD and the elderly</td>
<td>Quantitative</td>
<td>6 years</td>
<td>493 patients</td>
<td>Not reported</td>
</tr>
</tbody>
</table>
Inquiry about participation in a research study

Finding descriptions and information about performing different dialysis modalities is rather simple. It is not as simple to find descriptions about what it is like to live with a renal replacement therapy. The situations or the experiences differ, but everyone’s experiences are important and unique.

You who are treated with automated peritoneal dialysis are hereby asked to participate in a research study. Participation is voluntarily and you have the right to withdraw from participation at any time without further explanation.

The aim of the study is to describe person’s lived experiences of automated peritoneal dialysis treatment on daily living out of an interview study. Collection of data is to be obtained with a recorder at a quiet place of your convenience.

The results from the interviews will be presented in a master thesis in caring science. Information obtained from the interviews will be handled with confidentiality, that is your identity will only be known be my as the interviewer. You will also be anonymous, meaning that single statements will not be able to identify in the final presentation.

The health care and treatment you receive will at no point be affected whether you decide to participate in the study or not.

In order to present oral information, I ask you to return the attached letter in the prepaid envelope within 2 weeks.

Sincere regards

Ann-Christin Karlsson

If more information is wanted, please contact:

**Interviewer**
Ann-Christin Karlsson  
Registered nurse  
Dialysis Unit  
Visby Hospital  
621 84 Visby  
**Phone:** 0498-26 81 22  
070-521 72 47

**Supervisor**
Karin Holmén  
Dr. Med. Sc.  
Sophiahemmet Högskola  
Box 5605  
114 86 Stockholm  
**Phone:** 08-406 28 71

ann-christin.karlsson@hsf.gotland.se  
karin.holmen@sophiahemmetshögskola.se
Consent to personal contact concerning research study

- I have taken part of the written information of the research study.
- I am aware that my participation in the study is voluntary and that I at any time and with no further explanation can withdraw from participation without affects on the treatment I receive.
- I want to be contacted on the phone for oral information by Ann-Christin Karlsson, the responsible nurse of the study.

Date: ___________________________

Name: ___________________________________________________

Phone: __________________________
(Please, do not forget the code number!)
The interview guide

Research areas

- What is the lived experience on daily living with APD treatment?
- What aspects of daily life are most outstanding?
- What strategies are used/developed when living with APD treatment?

Interview

Opening questions

- When did you start dialysis?
- Whose choice was it to start APD treatment?

Head questions

- Can you describe what it is like to have APD treatment?
- Can you describe if, or how, it affects your everyday life?
- Have you had to give something up because of your treatment?
- Do you have any strategies that you use in your everyday life?

Sub questions

- How do you sleep at night?
- Have you had any complications related to the treatment?

Closing questions

What information do you think is of importance before starting APD treatment?
Is there something you would like to add before ending the interview?
Are there any questions that you miss not being asked in this interview?