

# Managing Home Dialysis: The Client Perspective on Independent Treatment

Polaschek, N. (2006). Managing Home Dialysis: The Client Perspective on Independent Treatment. *Ren Soc Aust J* 2(3) 53–63

Submitted April 2006 Accepted September 2006.

## Abstract

**Aim:** This study describes how one group of renal clients using dialysis at home view their therapy.

**Methodology:** This qualitative study used a critical interpretive methodology. Twenty clients from one renal department in New Zealand, who used either haemo or peritoneal dialysis at home, were interviewed for an hour each in November 2004 and January 2005. The audiotaped interviews were analysed to produce a thematic description of the common client perspective for the group. This represents one dimension of the client discourse, in contrast to the dominant professional discourse in the renal setting.

**Results:** Several interrelated themes were identified from the set of texts:

- Confidence in their own competence in self-care treatment;
- Independent modification of their therapeutic prescription;
- Influence of their life situation on their commitment to therapy;
- Ambiguous relationships with renal health professionals.

**Discussion:** One interpretation of the client perspective is that individuals negotiate the required treatment into their lifestyle to enable them to live with their chronic condition. In these terms the role of nurses who work with people living on dialysis could be conceptualized as a professional participation in their process of negotiation. To do this effectively nurses need to understand the client perspective on renal replacement therapy.

## Introduction

Renal replacement therapy requires significant cooperation from people with end stage renal disease (ESRD). For renal clients, using this complex treatment for their chronic condition, involves a regular dialysis program, fluid intake and dietary restrictions, and medication regimen.

Those who perform their own dialysis at home have greater control of their therapy and more responsibility for it than people who attend a dialysis clinic. Not only is there no direct professional supervision of their treatment, there is less intensive monitoring of the efficacy of their therapy. Failure to comply

## Key Words

Renal patients, haemodialysis, peritoneal dialysis, renal nursing, compliance, negotiation.

with the therapeutic prescription is commonly viewed as a significant problem by renal health professionals. In order to effectively address the issue of renal clients' therapeutic behaviour it is necessary to understand the attitudes of people using dialysis towards renal replacement therapy. However little is known about the renal client perspective on treatment. This paper reports a study that sought to describe how one group of renal clients using dialysis at home view their therapy.

## Background/Literature

There is an extensive literature about renal clients' failure to comply with the therapeutic prescription (Leggatt et al. 1998, Bleyer et al. 1998, Hailey and Moss 2000, Morgan 2000, Kovac et al 2002, White 2004), focussing on alteration of the dietary and fluid intake restrictions (Sensky et al. 1996, Lee and Molassiotis 2002), and shortened and missed dialysis sessions (Rocco and Burkart 1993, Gordon et al. 2003). Previous research sought to identify stressors, as well as strategies used to cope and adapt to therapy (Lok 1996, Cormier-Daigle and Stewart 1997, Keogh and Feehally 1999, Mok and Tam 2001, Welch and Austin 2001, Tsay et al. 2005).

## Authors

Nick Polaschek RN PhD is Programme Manager, Clinical Services Directorate, Ministry of Health, Wellington, New Zealand and Research Associate, Whitireia Community Polytechnic, Porirua, New Zealand.

## Correspondence to:

Dr Nick Polaschek, Clinical Services Directorate, Ministry of Health, PO Box 5013, Wellington, New Zealand 6001.  
Nick\_Polaschek@moh.govt.nz

## Managing Home Dialysis: The Client Perspective on Independent Treatment

---

There is a growing literature, using various methodological approaches, that seeks to understand the experience of living with renal failure (Gregory et al. 1998, Nagle 1998, Caress et al. 2000, Lindqvist et al. 2000, Faber, 2000, Curtin and Maples 2001, Hagren et al. 2001, King et al. 2002, Polaschek 2003, Jablonkski 2004). These studies are focused almost exclusively on the dialysis clinic setting. Generally these studies reveal the difficulties that renal clients face in seeking to maintain their normal lifestyle when living on dialysis. A few refer in passing to client attitudes towards therapy. Clients in Faber's (2000) study viewed attending the dialysis clinic as a form of "work". Curtin and Mapes (2001) found the healthcare management strategies of long term dialysis survivors included both monitoring and influencing the care provided by staff at the dialysis clinic. To date no research has focussed on the client perspective towards therapy.

The lack of studies about attitudes of renal clients towards therapy is understandable in a context where treatment is necessary for survival and usually provided for the client by renal staff at the dialysis clinic. But the efficacy of renal replacement therapy is dependant on the cooperation of the individual receiving treatment. This is the source of the studies about the professional problem of non-compliance. Developing an understanding of the client perspective on therapy may assist renal staff in seeking to improve its efficacy. It may also raise questions about the relationship between the efficacy of treatment and the wellbeing of individuals using it.

A number of studies have recognised that people living with a chronic illness sometimes autonomously alter their prescribed therapeutic regimens (Adams et al. 1997, Van Wissen et al. 1998, Anderson and Funnell 2000). These authors suggest that conceptualising individual's response

to chronic illness in terms of compliance is inadequate (Playe and Keeley 1998, Kyngas et al. 2000, Thorne et al. 2000, Murphy and Canales 2001, King et al. 2002). Several studies have recognised an ambiguity in professional attitudes, where clients with ESRD are expected to take responsibility for managing their chronic condition but, at the same time, to comply with the medical orders (Horne and Weinman 1994, Faber 2000). A few authors have proposed that attitudes towards their therapy among people living with a chronic condition are better understood as a process of negotiation (Thorne 1993, Hernandez 1995, Polaschek 2003a, Russell et al. 2003). This review of the literature suggests that interpretations of renal clients' therapeutic behaviour need to be based on studies seeking to understand their attitudes towards renal replacement therapy.

### Methodology for the study

This qualitative study used a critical interpretive methodology to describe the perspective of one group of people using self-care dialysis towards their therapy. The critical interpretive approach is a form of hermeneutic enquiry that recognises that any individual's understanding arises from interpretations made within a social context characterised by several contrasting interpretive perspectives (Thompson 1990, Benner 1994, Allen 1995). For the critical interpretive approach in this study concepts derived from the work of Michel Foucault (1975, 1977, 1980) are used. Foucauldian ideas have been found useful because they facilitate delineation of relationships between the different social roles in the highly specialised settings of contemporary medicine (Cheek and Rudge 1997, Lupton 1997, Bevan 2000). The disciplinary technology of renal replacement therapy can be conceptualised as creating a distinctive social context made up of several interrelated 'discourses'. Individual's understanding is shaped by these discourses, which reflect

different positioning of various social roles within the renal setting.

The dominant professional discourse, the basis of the renal setting, is primarily articulated in the therapeutic techniques of renal replacement therapy. It is also expressed in professional attitudes, especially in assuming the efficacy and value of renal replacement therapy and, consequently, expecting full compliance with the therapeutic prescription from people who use dialysis. In the renal setting commercial and political discourses are also influential (through research, product marketing and policy) in the way that this form of therapy is understood. There is also a client discourse in the renal context, which is expressive of the perspective of those who experience renal replacement therapy (Polaschek 2005). This client discourse is obscure in the renal context because the 'renally replaced' life is dependent on the dominant renal discourse; the client perspective is 'structurally silenced' by the dominant professional viewpoint (Sloan 1999). By discerning the distinctive shared interpretations among one group of people living on dialysis, from within their statements typically reflecting their socialisation by the language and ideas of the dominant professional discourse, this study aimed to describe their characteristic attitudes towards their therapy, one dimension of the client discourse in the renal setting.

Ethical approval for the study was obtained from the relevant health authority. The 'positioning' of the researcher in relation to the group of participants was important (Finlay 2002). He worked in the renal department that supported all of them, but was not directly involved in the care of anyone using dialysis. The invitation to individuals was made by staff rather than the researcher, ensuring their free

# Extraneal™ (7.5% icodextrin)

## The solution for the long dwell

*"It is likely that a more gradual and even control of fluid status throughout [a] 24-hour period is beneficial to the maintenance of residual renal function." Davies 2003<sup>1</sup>*

**For sustained ultrafiltration (UF)<sup>2</sup>, maintenance of urine volume<sup>1</sup>, and enhanced solute clearance<sup>3</sup>, choose Extraneal for the long dwell.**

Please review the full Product Information before prescribing (available on request from Baxter Healthcare).

™ Baxter and Extraneal are registered trademarks of Baxter International Inc. Marketed in Australia by Baxter Healthcare Pty Ltd, ABN 43 000 392 781. Marketed in New Zealand by Baxter Healthcare Ltd. REFERENCES: 1. Davies SJ et al, J Am Soc Nephrol 2003; 14: 2338-2344. 2. Posthuma N et al. Perit Dial Int 2000; 20(Supp 2): S106-S113. 3. Woodrow et al. Nephrol Dial Transplant 1999; 14: 1530-1535.

**Baxter Healthcare Pty Ltd**  
Tel. (02) 9848 1111  
www.baxterhealthcare.com.au

**Baxter Healthcare Ltd**  
Tel. (09) 574 2000  
www.renalinfo.com

**Extraneal Abridged PI:** *Indication:* Extraneal™ (7.5% icodextrin) is indicated for use as an alternative osmotic agent in dialysis solutions for the long dwell exchange in patients treated with peritoneal dialysis. *Contraindications:* Extraneal should not be used in patients with a known allergy to starch based polymers and/or icodextrin and in patients with maltose or isomaltose intolerance or patients with glycogen storage disease. In patients with a history of abdominal surgery in the month preceding commencement of therapy or in patients with abdominal fistulae, tumours, open wounds, herniae or other conditions which compromise the integrity of the abdominal wall, abdominal surface or intra-abdominal cavity. *Warnings:* Blood glucose management with Extraneal must be done with a glucose-specific method to avoid interference resulting in unrecognised hypoglycemia. If non-specific glucose test methods (GDH-PQQ) are used, loss of consciousness, neurological damage and death may occur. *Precautions:* Extraneal associated skin reactions, including rash and pruritus, are generally mild or moderate in severity. Occasionally, these rashes have been associated with exfoliation. In the event of this occurring, and depending on the severity, Extraneal should be withdrawn at least temporarily. Refer to PI. *Adverse Effects:* Adverse reactions reported with an incidence of > 5% and at least as common on dextrose control included pain, asthenia, exit site infection, infection, back pain, hypotension, diarrhea, vomiting, nausea/vomiting, anemia, peripheral oedema, hypokalemia, hyperphosphatemia, hypoproteinemia, hypervolemia, arthralgia, dizziness, dyspnea, skin disorder, pruritus. Refer to PI. *Dosage and administration:* Extraneal is recommended for use during the longest dwell period, that is in CAPD usually overnight and in Automated Peritoneal Dialysis (APD) for the long daytime dwell. Adults: By intraperitoneal administration limited to a single exchange in each 24 hour-period, as part of a CAPD or APD regimen. Elderly: As for adults. Children: Not recommended for use in children (less than 18 years). Available dosage forms: 2500mL flexible PVC container available for standard single bag and twin bag.

**PBS Information:**  
Extraneal is not listed  
on the PBS.

**PBS Information:** S100. Private hospital authority required. Treatment of anaemia requiring transfusion, defined as haemoglobin level of less than 100 g per L, where intrinsic renal disease, as assessed by a nephrologist, is the primary cause of the anaemia.

PLEASE REVIEW FULL PRODUCT INFORMATION BEFORE PRESCRIBING, AVAILABLE ON REQUEST FROM ROCHE PRODUCTS PTY LIMITED. NeoRecormon® Epoetin beta, rch (recombinant human erythropoietin). **References:** 1. Choukron G *et al.* Subcutaneous injection (SCI) of Epoetin beta (EB) is less painful than Darbepoetin alfa (DA): A randomized cross-over trial in healthy volunteers (HV). Poster presented at XL-II ERA-EDTA 2005. 2. Locatelli F *et al.* *AJKD* 2002; 40:119-125. 3. Weiss L *et al.* *Nephrol Dial Transplant* 2000; 15:2014-2019. 4. NeoRecormon Approved Product Information, December 2005. **Indications:** Treatment of anemia associated with chronic renal failure in patients on dialysis and treatment of symptomatic renal anemia in patients with chronic renal insufficiency not yet undergoing dialysis. **Dosage and Administration:** May be administered by intravenous (IV) or subcutaneous (SC) injection, however, SC should be considered where possible since lower doses are required. The usual aim of treatment is to increase the PCV to 30%-35% whereby the weekly increase should be at least 0.5 vol%. A value of 35 vol% should not be exceeded. The target PCV should be determined individually in the presence of cardiovascular, cerebrovascular or peripheral vascular diseases. **Correction Phase:** Initial SC dose 60 IU/kg/week, in 1-7 divided doses; may be increased every 4 weeks by 60 IU/kg/week if PCV is not adequate. Initial IV dose 120 IU/kg/week, in 3 divided doses, administered over 2 minutes. Dose may be increased to 240 IU/kg/week after 4 weeks; further increments at 60 IU/kg/week, at monthly intervals.



**Maintenance Phase:** Reduce dosage to half the previously administered dose then adjust at 1-2 week intervals until the maintenance dose is achieved. Patients stable on SC once weekly dosing may be switched to once every 2 weeks administration. Maximum dose should not exceed 720 IU/kg/week. **Use in Children:** On average, the younger the patient, the higher the NeoRecormon dose required. However the recommended dosing schedule above should be followed as the individual response cannot be predicted. **Contraindications:** Poorly controlled hypertension; known hypersensitivity to NeoRecormon. **Precautions:** Anaphylactoid reactions observed in isolated cases. Skin or injection site reactions may occur rarely. Monitor blood pressure, serum potassium, phosphate, iron, ferritin and total iron binding capacity. Effectiveness is reduced by folic acid, vitamin B12 deficiencies, and severe aluminium overload. An increase in heparin dose is frequently required during therapy. Use with caution in the presence of refractory anemia with excess blasts in transformation; epilepsy; thrombocytosis; and chronic hepatic failure. As with all growth factors there is a concern that epoetins could stimulate the growth of any type of malignancy. In isolated cases, anti-erythropoietin antibody-mediated Pure Red Cell Aplasia (PRCA) associated with epoetin beta therapy has been reported. If PRCA develops therapy must be discontinued and patients should not be switched to another erythropoietin. Clinical results thus far do not indicate any interaction with other substances. Pregnancy Category B3; use with caution in lactation. **Adverse Effects:** Hypertension; upper respiratory tract infection; menstrual disorders; headache; decrease of ferritin values and transferrin saturation. **Presentation:** NeoRecormon is available as pre-filled syringes in the following strengths: 1,000 IU/0.3 mL (PBS dispensed price: \$147.00); 2,000 IU/0.3 mL (PBS dispensed price: \$272.00); 3,000 IU/0.3 mL (PBS dispensed price: \$351.00); 4,000 IU/0.3 mL (PBS dispensed price: \$447.00); 5,000 IU/0.3 mL (PBS dispensed price: \$556.50); 6,000 IU/0.3 mL (PBS dispensed price: \$660.60); 10,000 IU/0.6 mL (PBS dispensed price: \$1,037.00); 20,000 IU/0.6 mL (PBS dispensed price: \$2,040.00); 30,000 IU/0.6 mL (PBS dispensed price: \$502.50). **Date of Preparation:** 3 March 2006. © Registered Trademark. Roche Products Pty Limited ABN 70 000 132 865 ACN 000132 865. 4-10 Inman Road, Dee Why 2099. Saatchi & Saatchi Healthcare HRN0110 08/06. 

**With minimal injection site pain,<sup>1-4</sup>  
patients will be tickled pink.**

Injection site pain is equivalent to physiological saline.<sup>1</sup>



# Renal Nursing can be a Pain in the Back!



Thompson MaxiLift

Australia's widest range of Dialysis chairs are available for demonstration by calling:

*for you and your Patient.*

*Features include:*  
Power Operated Recline  
Battery Operation  
Patient Lock-out Switch  
Height Adjustable.....No Bending  
Full Trendeleburg Position  
CPR in the chair  
Casters with Brakes  
Easy to Clean  
Rugged Construction



Todd Full PowerRecline for Satellite & Home Use

**Reduce the Pain....and the Strain**

  
**Artistic**  
HEALTHCARE SEATING



Optional Fold-Out Tray Armrests

[sales@artistic.com.au](mailto:sales@artistic.com.au)

**1300 889 330**

[www.artistic.com.au](http://www.artistic.com.au)

## Bard Dialysis Catheters

Catheters that You Can Count On for Extreme Performance in Haemodialysis

**BARD**  
ACCESS SYSTEMS

*Niagara*<sup>TM</sup>  
**Slim-Cath**<sup>®</sup>

*Niagara*<sup>TM</sup>

*HemoGlide*<sup>®</sup>

*HemoSplit*<sup>®</sup>



Call 1800 257 232 for further information or contact your BARD Territory Manager

## Managing Home Dialysis: The Client Perspective on Independent Treatment

---

participation. He guaranteed participants that no information they shared in the interviews would be given to their clinical teams and their anonymity would be protected in any use of the research.

A group of 20 male and female participants using self-care dialysis, 15 haemodialysis (HD) and 5 peritoneal dialysis (PD) were selected from the dialysis population in one regional renal department in New Zealand. The majority had initially spent a short period of time at the dialysis clinic. They used a range of variants of therapy. For HD these included three 5 hour dialysis sessions each week or alternate nightly 8 hour treatments. No participants were using daily HD or a PD cyclor. Most of those using HD and all using PD performed dialysis at home by themselves without a helper present. The form of therapy participants used was determined firstly by their clinical need for dialysis efficacy, secondly by their own choice to better fit their life situation, and finally by the availability of therapeutic options.

Participants had been established successfully on dialysis for at least six months. They had not had to attend the dialysis clinic because of problems with their dialysis and were viewed as competent by the renal staff supporting them. The researcher interviewed each participant for an hour in their own homes in November of 2004 and January of 2005. He used a semi-structured format that encouraged them to share freely their own views on a variety of topics related to their therapy. A range of questions facilitated discussion around the following topics: the extent to which they consider they control the therapy; reasons for difficulties in meeting the requirements of the therapeutic prescription; identifying aspects of the therapy they modify; their view of their relationships with renal health professionals supporting them.

The audiotaped interviews were analysed in terms of the critical interpretive approach. Within participant's statements distinctive expressions dissonant from the dominant professional viewpoint were distinguished from those reflecting it. Similar concepts in these distinctive expressions were identified across the set of texts. These were collated into various categories, to produce a number of themes that describe the common client perspective towards their therapy, in contrast to the dominant professional viewpoint in this renal setting. This thematic description of a key dimension of the renal client discourse, reported below, is illustrated by examples and sometimes verbatim comments from participants.

The adequacy of this type of qualitative study is based on its 'trustworthiness' (Emden and Sandelowski 1998, Koch and Harrington 1998, Clarke 1999, Seale 2002, Tobin and Begley 2004). This is demonstrated firstly by the consistency of the methodology, design and process in the study. Secondly it is shown by the utility of the study in the clinical setting. This is being examined through feedback to the local client group and through presentation and publication for renal health professional groups.

### Results

Four themes were produced from the analysis of the audiotaped interviews which summarise the characteristic attitudes in this group of self-care renal clients towards their renal replacement therapy. This construct, representing one dimension of the renal client discourse, expresses the common perspective of people using self-care dialysis in this particular context. The four themes are an interrelated set as described below.

#### **Theme one: Confidence in their own competence in self-care treatment**

Participants were confident in their own competence to manage their renal replacement therapy. They had no difficulty

with the sequence of actions involved in performing their dialysis treatment. A number of them had memories of times of anxiety in the first months of treatment and, for HD, some stories of losing blood while connected to the dialysis machine. Now well established on dialysis, they had overcome these concerns and typically noted that their treatment was automatic, "*second nature*", to them. They never needed to attend the dialysis clinic because of problems with their dialysis treatment. They felt positive about being in control of their own care, in contrast to their experience of being dependent on the dialysis clinic. They could ensure their treatment suited them, rather than having to risk variable experiences of treatment because of the attitudes or different levels of expertise of the nurses caring for them in the dialysis clinic.

Participants recognised the ongoing potential for unexpected problems during their HD treatment but were confident in their own expertise to manage these. They typically handled occasional technical complications near the end of treatment, especially significant clotting or air in the blood lines, by terminating the treatment, because the time required for corrective action made this the sensible thing to do. Managing hypovolaemia ("*going flat*") due to fluid loss during treatment remained a minor concern, but they had learned to minimise this potential problem in various ways, in particular by varying the rate of fluid removal during treatment. One participant and his partner had become expert at discontinuing treatment when periodic unpredictable power failures occurred. Those using PD were confident in their ability to manipulate the "*strength*" of their bags to increase or reduce the rate of fluid removal as necessary. Occasional problems with their vascular access on HD or tenckhoff catheter access on PD, which interfered with their treatment and required admission to hospital, were

## Managing Home Dialysis: The Client Perspective on Independent Treatment

---

frustrating rather than major concerns that destabilised their confidence in their self-treatment at home. Because of their confidence in managing problems during treatment, participants' adherence to their treatment regimen was not influenced by issues related to the technical performance of the treatment.

Participants described a growing awareness of their own body over time on treatment, in particular changes in their blood pressure or fluid status. Those using HD felt a "need" for dialysis, especially after any unusually long break due to an alteration of their treatment regimen. One said, *"I'd feel the extra day; now my body tells me I need the dialysis machine"*. This heightened sensitivity enabled them to control their own therapy more effectively. According to the dominant professional discourse renal replacement therapy can be efficaciously managed by patients themselves; the client discourse emphasises their confidence in their capacity to manage their own treatment at home.

### **Theme two: Independent modification of the therapeutic prescription**

Participants modified some aspects of the therapeutic prescription. They generally followed professional recommendations about treatment, knowing this was necessary to remain well. However commonly, after beginning regular dialysis, they experimented with their therapy to find out whether what the doctor had ordered was really necessary for them. Most often they shortened their treatment hours or did not limit their drinking to the recommended daily intake. Two participants had autonomously ceased treatment (because they felt worse on treatment) for a period of months without any adverse clinical effects. As one man said, *"I missed a day,*

*then missed another day, I didn't feel any worse for not dialysing"*. Generally, worsening of their symptoms eventually made clear to them the need for treatment.

Confident in their own competence, a number of participants considered some autonomous alteration of their therapeutic regimen necessary to address limitations of treatment, specifically to manage symptoms caused by the treatment itself, and also to fit the treatment into their regular pattern of activities. Participants established a personal pattern of dialysis treatment, commonly a variation on what had been prescribed, that best enabled them to maintain their lifestyle. Some did shorter sessions during the week when they worked, and a longer session at the weekend. Others did sessions running into the night to maximise their "free" time during the day. One person said, because of the *"lack of freedom, the regimentation of dialysis, I'm always trying to maximize the hours available [to do other things], because you spend so much time on the machine"*.

Some participants also periodically altered their own modified regimen in various ways. They shortened treatment hours on occasion, sometimes to limit worsening symptoms during treatment (severe headache, cramping, dizziness), sometimes to allow them to meet a specific work commitment or enable participation in some unexpected social situation. A few lengthened treatment hours on occasion to facilitate higher than usual fluid removal or to manage symptoms such as *"restless legs"*. Several participants using PD periodically omitted their midday bag exchange, one woman noting they were *"time constrained"*, in order to enable them to meet work commitments.

In managing their own fluid balance, some participants increased their target 'dry' weight following HD treatment, to

avoid symptoms of dizziness and feeling *"washed out"* after treatment. One noted, *"At my target I feel on the border of being disoriented. I function better with a bit of fluid on"*. However a few of them had sometimes attempted to 'dry' themselves out by completing their treatment below their recommended target weight (despite the risk of hypovolaemia) to allow them to drink more in a particular social situation. Commonly they tended to avoid habitual social situations, as they did not feel they could participate fully without drinking and did not wish to feel socially isolated. When they did choose to attend such occasions they knew they would drink beyond their assigned daily fluid intake limit. Likewise, while they generally adhered to their dietary restrictions, they found the need to check the composition of food available in social situations tedious and simply avoided obviously problematic foods.

Despite modifying their prescribed treatment regimen in various ways in order to manage better, participants did not change their therapy arbitrarily. Although some found variability in their sense of wellbeing interfered with their activities after treatment, and many acknowledged the tedium of the routine of therapeutic regimen, this did not affect their performance of dialysis. As one man said, *"It's a routine, I don't want to do it sometimes, but you know you've got to do it. But it feels like a waste of time, 5 hours sitting on a machine"*. They coped with these inescapable effects of treatment by accepting dialysis and its consequences as part of their usual pattern of activities, by 'normalizing' it (Gregory et al. 1998, Nagle 1998).

Some participants made it clear that having capacity to vary their treatment regimen was important for them, both in enabling them to integrate the therapy into their regular pattern of activities in

## Managing Home Dialysis: The Client Perspective on Independent Treatment

---

order to maintain important aspects of their normal lifestyle, and also to manage the ongoing routine of treatment. A number contrasted this with the sense of constraint they felt in being dependent on the inflexible schedules at the dialysis clinic for treatment. As one said, *"In hospital [the dialysis clinic] you're at every one's beck and call; you do it when they want you to do it, because they have a business to run. At home I can do it at my own leisure."* Although full compliance with the therapeutic prescription is necessary to maintain their health status according to the dominant professional discourse, by contrast, in the client discourse some variation in their treatment regimen is necessary in order to maintain their lifestyle while living on dialysis.

### **Theme three: Influence of their life situation on their commitment to therapy**

Participants' commitment to continuing to complete the requirements of therapy was influenced by certain important aspects of their life situation. If they had close family relationships, especially a partner or dependent children, this motivated them to continue to carefully perform their treatment, in order to be able to sustain these relationships. Likewise if their work was important to them they had a strong reason to maintain the discipline of therapy in order to function well in their work. Their personal attitudes towards life (religious views or other personal convictions) also influenced their commitment to meet the ongoing demands of the therapeutic regimen. One man summed up having come to terms with dialysis, *"It's all part of the experience of living."* By contrast, those without a partner or dependent children or unemployed often lacked motivation to maintain the discipline of therapy. Several noted that following the end of a relationship or loss of their job

their commitment towards treatment diminished. As one man who had had several relationships while living on dialysis said, *"Dialysis is a stress in your life that's easier to manage if you are in a relationship"*.

The examples participants gave during the interviews revealed that they found it easier to maintain the discipline of treatment when they had some positive motivation from their lives; the discipline was harder to maintain without such a motivation. As one participant said, *"When life is going well dialysis is easy"*. A positive perception of certain aspects of their life situation encouraged commitment to their therapy; a lack of these undermined their commitment. As one put it, *"Who cares, why bother now, it's too much effort, what does it matter anyway."* Some indicated that, given the difficulties of treatment for them personally, without the motivation they found (in relationships, their work or their beliefs) they might wonder whether it was worth carrying on with treatment. Thus while participants had often initially experimented with treatment and subsequently modified the therapeutic prescription in order to manage better within their own lifestyle, how well they adhered to their modified regimen depended on their perception of their wellbeing in their own life situation.

Participants' comments showed that they were not motivated to continue to meet the demands of treatment by a desire to maintain their health status, but rather by their own life situation. This is shown very clearly by some participants whose desire to improve their current difficult life situation by receiving a transplant provided motivation to maintain the discipline of therapy. For this group of participants their current problems while living on dialysis were not demotivating. Their hope of a transplant enhanced

their commitment to careful treatment, due to a conviction they needed to ensure they were always *"ready"* (by being well dialysed), both to enhance their likelihood of being offered an organ that became available and also of the graft being successful. As one said, *"It would break my heart if a transplant came along and my bloods were up the shoot and they decided to give it to someone else"*. While in the dominant discourse renal client behaviour is assumed to be motivated by a desire to maintain their health status, in the client discourse, by contrast, ongoing commitment to therapy is influenced by various aspects of individual's life situation which affect their general wellbeing.

### **Theme four: Ambiguous relationships with renal health care professionals**

Participants had ambiguous relationships with renal health care professionals. They generally viewed their relationships with renal staff very positively, often in contrast to other health professionals they had to deal with. They felt supported by renal nurses in undertaking their own treatment. But, although they discussed managing some clinical problems with them, they did not generally discuss the autonomous modifications they made to the therapeutic prescription. One noted, *"Certain things you keep to yourself. I don't want to offend people. They do their best for you. Now it's passed over to me I'm doing the best for me"*.

They were clear that only those using dialysis can understand what it is like, in particular the impact of treatment on their lives. They also recognised a clear expectation on the part of professional staff that they comply with the treatment as prescribed. Because of this they did not feel they could discuss with staff any modifications to what was considered clinically optimal treatment. As one said, *"They can only look at it from the clinical side, not from the patient's side, how they're*

## Managing Home Dialysis: The Client Perspective on Independent Treatment

---

*feeling. You've got to have guidelines, they give you guidelines, they've got to treat everyone equal, some need a regimented approach but I think there's room for flexibility".*

When faced with the difficulties caused by treatment participants, oriented to managing their own care independently, sometimes chose to modify the therapeutic prescription beyond professional recommendations, in order to cope better with treatment in their lives. One man stated, "*Whether it's right, wrong or otherwise it's my technique*". In accord with this independent approach they did not consider it essential to tell staff everything about their treatment, and also did not wish to create issues that might impact negatively on their relationships with staff.

Interestingly, the participants' major concern was not being fully informed about their ongoing clinical situation by health professionals. As one said, "*I think they should be more honest from the beginning*". While this might seem at odds with their own reluctance to talk openly to staff about their own modifications to their treatment regimen, this further ambiguity may reflect their own awareness of the asymmetry (due to the difference in knowledge and power) in the relationship between renal clients and health professionals. These participants' views can be interpreted as reflecting the obscure client discourse that is 'structurally silenced' (Sloan 1999) by the dominant professional discourse.

### **Discussion: Negotiating therapy into their lives**

Autonomous alteration of the therapeutic prescription by renal clients is presumed to be problematic in the dominant professional discourse, as studies about lack of compliance show (Hailey and Moss 2000, Morgan 2000). By contrast the client discourse in this study indicates

that, while acknowledging the need to adhere to the treatment regimen, renal clients sometimes independently modify their therapeutic prescription in order to maintain their normal lifestyle. They rationalise this by noting their competence to successfully manage their treatment, reflecting the views generally found among clients with other chronic conditions towards their therapy (see for example attitudes towards medication in general in Pound et al. 2005, or attitudes of people with diabetes, Hernandez 1995). Although objectively suboptimal treatment may have consequences in the long term (for example regular fluid overload leading to heart failure), participants viewed their approach as necessary to manage the requirements of the regimen within their own lifestyle.

Studies about compliance assume that renal clients' primary goal is to seek to maintain their good health (Leggatt et al. 1998, Kovac et al. 2002). By contrast the client discourse in this study shows that their life situation influences their commitment to continuing to complete the requirements of the therapeutic regimen. Given a positive perception of their life situation they are motivated to manage their therapeutic regimen in order to maintain it. If their perception is less positive their motivation to continue to meet the demands of a complex and ongoing therapy is limited. Maintaining their health status through compliance with the therapeutic regimen is a means to an end, the primary goal of maintaining their general wellbeing. Changes in their life situation, such as loss of a partner or a job can significantly affect their adherence to their regimen. The relationship between the demanding therapy, necessary for survival, and their own life situation is complex, and can only be indirectly influenced by health care professionals.

Frustration with renal health professionals who do not listen to them and a consequent sense of powerlessness is a theme in the literature of the renal client experience (Bevan 1998, Nagle 1998, Curtin and Mapes 2001). This reflects the contrast between the dominant professional discourse and the obscure client discourses within the renal context. Such a sense of inequality is not a feature of this study, perhaps because its setting is self-care rather than the dialysis clinic, making it easy for participants to manage their interactions with renal staff. A negative dimension in their relationship with renal staff does not improve adherence to the therapeutic regimen; it can make the client experience, already often difficult, worse.

One interpretation of their approach to treatment is that renal clients negotiate therapy into their lifestyle to enable them to live with a chronic condition (Thorne 1993, Polaschek 2003a, Russell et al. 2003). From their perspective, their initial experimentation with treatment, subsequent modifications in their therapeutic regimen and even their varying adherence according to their changing life situation, are not aberrations. They are necessary activities, part of their process of negotiation of therapy into their lifestyle. Management of their own treatment at home allowed the participants in this study a greater capacity for variation in treatment patterns than in the dialysis clinic. These clients can only alter their therapy by actually missing treatments or seeking to shorten them by claiming various symptoms (Rocco and Burkart 1993, Gordon et al. 2003). By moving beyond professional assumptions about therapeutic behaviour in terms of compliance, to acknowledge the client perspective in a model of negotiation, renal staff can engage with the distinctive client discourse within this chronic care setting.

# Managing Home Dialysis: The Client Perspective on Independent Treatment

## Limitations of this study

This research is limited in presenting one variant of one dimension of the client discourse. Participants in the study were drawn from one renal department in New Zealand and used a limited range of self-care treatment modalities. A minority used PD, none used PD cyclers. Clearly the results reflect, to an indefinable extent, the institutional culture of the specific renal context in which they were produced.

In the critical interpretive approach the client discourse is a response to the dominant discourse. While the dominant discourse primarily reflects the ubiquitous therapeutic techniques of renal replacement therapy, it is also expressed in shared professional attitudes which are somewhat different in each renal setting. For example in the department where this study took place self-care dialysis is common, professional attitudes encouraging clients to view it as a normative mode of therapy. The distinctive features the dominant discourse in this renal setting may have influenced the nature or formulation of the themes derived from the interviews. Studies in different renal settings, presenting other variants, will enable fuller articulation of this dimension of the client discourse in the renal context.

## Conclusion

This study has described how one group of people using dialysis at home view their independent therapy; it has outlined one version of the client discourse in the renal context. The results are suggestive for other chronic care contexts. They show the importance of the client perspective in understanding a chronic condition.

This description of a common client perspective points towards a broader view of the relationship between the efficacy

of therapy and the wellbeing of people who are using the therapy. Optimising the therapeutic prescription may affect their activities, reducing their quality of life. Modifying some aspects of the treatment regimen, within the limits they know are possible, may help them to maintain their normal lifestyle.

One implication of this study is that the role of nurses who work with people living on dialysis can be conceptualized as a professional participation in their process of negotiation. Nurses, recognizing clients have a different perspective, can engage in dialogue that facilitates them in negotiating renal replacement therapy into their own lifestyle. They know that commitment to treatment can vary with their changing life situation, that as nurses they cannot directly influence this but rather support their clients as they seek to manage it themselves. Nurses can work more effectively with renal clients if they develop some understanding of the client perspective in the renal setting.

## References

- Adams S., Pill R. & Jones A. (1997) Medicine, chronic illness and identity: the perspective of people with asthma. *Social Science and Medicine* 45 (2), 189–201.
- Allen D. G. (1995) Hermeneutics: Philosophical traditions and nursing practice research. *Nursing Science Quarterly* 8 (4), 174–182.
- Anderson R. M. & Funnell M. M. (2000) Compliance and adherence are dysfunctional concepts in diabetes care. *Diabetes Educator* 26 (4), 597–604.
- Benner P. (1994) The tradition and skill of interpretive phenomenology in studying health, illness and caring practices. In *Interpretive phenomenology: embodiment, caring, and ethics in health and illness* (Benner P., ed.), Sage, Thousand Oaks, California, pp. 99–127.
- Bevan M. T. (1998) Nursing in the dialysis unit: Technological enframing and a declining art, or an imperative for caring. *Journal of Advanced Nursing* 27, 730–736.
- Bevan M. T. (2000) Dialysis as “deus ex machina”: A critical analysis of haemodialysis. *Journal of Advanced Nursing* 31, 437–443.
- Bleyer A., Hylander B., Sudo H., Nomoto Y., De La Torre E., Chen R. & Burkart, J. (1998) An international study of patient compliance with haemodialysis. *Journal of the American Medical Association* 281, 1211–1213
- Caress A., Luker K. & Owens R. (2000) A descriptive study of meaning of illness in chronic renal disease. *Journal of advanced nursing* 33 (6), 716–727.
- Cheek J. & Rudge T. (1997) The rhetoric of health care? Foucault, health care practices and the docile body – 1990s style. In *Foucault: The legacy* (O’Farrell C., ed.). Queensland University of Technology, Brisbane, pp. 707–713.
- Clarke J. (1999) Hermeneutic analysis: a qualitative decision trail. *International Journal of Nursing Studies* 36 (50), 363–369.
- Cormier-Daigle M. & Stewart M. (1997) Support and coping of male hemodialysis-dependent patients. *International Journal of Nursing Studies* 34 (6), 420–430
- Curtin R. B. & Maples D. L. (2001) Health care management strategies of long-term dialysis survivors. *Nephrology Nursing Journal* 28 (4), 385–394.
- Emden C. & Sandelowski M. (1998) The good, the bad and the relative, part one: Conceptions of goodness in qualitative research. *International Journal of Nursing Practice* 4, 206–212.
- Faber S. (2000) An investigation of life with end stage renal disease: sociocultural case studies analysis. *Canadian Association of Nephrology Nurses and Technicians Journal* 10 (3), 24–34.
- Finlay L. (2002) “Outing” the researcher: the provenance, process and Practice of reflexivity. *Qualitative Health Research* 12 (4), 531–545.
- Foucault M. (1975) *The birth of the clinic: An archaeology of medical perception* (Sheridan Smith A., trans.). Vintage Books, New York.
- Foucault M. (1977) *Discipline and punish: The birth of a prison* (Sheridan Smith A. trans.). Vintage Books, New York.
- Foucault M. (1980) *Power/knowledge: Selected interviews and other writings 1972 – 77* (Gordon C., Marshall, M., Mepham, J. & Soper, K., trans). Pantheon, New York.