

**Pictures and perspectives: A qualitative descriptive study
of the experience of living with fluid restrictions for
people undertaking haemodialysis in a community
setting**

Submitted for the requirements of a Master of Philosophy (Nursing)

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Statement of Originality

The thesis contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository**, subject to the provisions of the Copyright Act 1968.

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Peter Sinclair

List of publications and conference presentations

Publications

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Abstract

“Fighting nature is like fighting yourself, and it takes strength”

People undergoing haemodialysis are required to follow a complex treatment regimen that includes dietary and fluid restrictions. Fluid restrictions are reported to be the most difficult component of self-management for people with end stage kidney disease. Historically, research into interdialytic weight gain, a marker for fluid restriction adherence, has focused on interventions devised by clinicians and utilised quantitative methodologies. There has been little consideration given to how people experience fluid restrictions.

This study set out to understand what it was like for people with end stage kidney disease, who were undergoing haemodialysis, to live with the restriction of fluids and in particular to answer the research question: What is the experience of fluid restriction for people receiving haemodialysis in a community based setting? The study used a qualitative descriptive design, in-depth interviews were conducted to explore the experience of living with fluid restrictions in a group of six women and one man who received haemodialysis. Participants were invited to use artefacts to support their story telling. The study was conducted in a community based dialysis unit in a large regional city in New South Wales, Australia. Data were analysed using an iterative process of comprehending, synthesising, theorising and recontextualisation to identify emergent themes.

Themes identified were magnitude of loss, constant struggle and accepting. Accepting fluid restrictions was not a linear progression to understanding and adherence but a multifaceted, tortuous struggle unique to each participant. Over time participants were able to develop and consolidate coping or management strategies into their lives. In varying degrees, these strategies assisted them with managing their fluid restrictions more effectively, but the reminder that they could no longer drink freely as they once did, was always present. In time, participants described that they had come to terms with accepting fluid restrictions in their lives yet acknowledged that they were fallible and prone to times when the temptation to have an additional drink became too much.

Successful adaptation to fluid restrictions was largely dependent on support, the acknowledgement that their lives were worth living, and the understanding that the outcomes of not following prescribed restrictions had both short and long term physiological consequences. However, accepting fluid restrictions and engaging in surveillance and maintenance behaviours, did not ameliorate the constant struggle or the magnitude of loss that each participant faced.

Overall, participants described the unnaturalness of not being able to drink spontaneously. Consequently, adhering to strict limitations of fluid intake was *“hard, very hard.”* While previous research has identified the effect of end stage kidney disease on peoples’ lives, this study has contributed to a deeper understanding of the inescapable and omnipresent nature and influence of fluid restrictions on these peoples’ lives. This is the first study that has focused on describing the experience of living with fluid restrictions for people receiving haemodialysis

Prologue

I have spent the last few years engaged in this study and writing these chapters. Each day, or night I would sit at my desk with a cup of coffee, or a bottle of water. When I needed a break I would take the dog for a run or go for a ride on my bike to clear my mind. During this time I could drink up to two litres of water. When I returned home I would drink more water to refresh me and restore the fluids I had just used. Some days I spent eight to ten hours writing and reading and would easily drink two to three litres of fluid in that time. I get thirsty, so I drink; I go out with my friends, and I like to have a drink with them. How would I manage if I developed end stage kidney disease and restrictions were imposed that prevented me from drinking when I wanted to, or if I was thirsty?

Chapter 1 Introduction

The incidence of End Stage Kidney Disease (ESKD) is increasing, particularly in older adults. In Australia, there has been an approximate increase of 14% in the number of people receiving dialysis therapy since 2006, with a total of 10, 590 people on dialysis at the end of 2010 (Grace, Hurst, & McDonald, 2011). People with ESKD have a higher risk for complications and death than the general population and many have concomitant and pre-eminently fatal co-morbidities. Cardiovascular disease and withdrawal from treatment are the top two causes of death in this patient population (McDonald, 2011).

Well-being, quality of life and the avoidance of complications, is dependent on successful self-management (Wong, Chow, & Chan, 2010) and in particular, the restriction of fluid intake. Often, there is an expectation by Health Care Professionals (HCPs) that people with ESKD will 'comply' with mandated fluid restrictions. However, such self-management is not easy and causes significant disruption and burden to peoples' lives. In addition, the embodied understanding of their being is challenged. What was once considered normal and beneficial in maintaining physical health (i.e. water) is now restricted.

Chronic illness that disrupts or causes the loss of bodily functions encroaches on a person's understanding of self. It is often characterised by adjustment to new forms of knowledge, high levels of uncertainty (Mishel, 1990) and challenges to a person's understanding of their own identity (Seymour, 1989). Turner (1996, p. 220) suggested that "disease which entails a loss of self is the most proximate and universal form of human estrangement". Chronic illness requires individuals to revise their sense of self and their relationship to the world (Seymour, 1989). The individual uses this process to find meaning in the transformation from their old self to their new self. This is particularly relevant for people with ESKD who must implement fluid restrictions into their lives.

The successful adherence to fluid restrictions necessitates a heterogeneous array of adaptations to entrenched behaviours and health beliefs (Kaveh & Kimmel, 2001).

Behavioural based adherence is a multidimensional phenomenon influenced by health beliefs and attitudes, patient-health provider relationships, knowledge, social support structures, coping skills and relationships, self-efficacy, locus of control, and satisfaction with factors influenced by treatment regimens (Brown & Fitzpatrick, 1988; Cameron, 1996; Lindberg, Wikström, & Lindberg, 2007; Mok & Tam, 2001).

The concept of adherence within the context of fluid restrictions and the consequences of poor management must be made relevant to patients in order for them to understand its importance (Kaveh & Kimmel, 2001). Any suggestion that fluid restrictions are the sole responsibility of the patients is questionable. Fisher et al., (2006) suggested that repeated episodes of fluid overload may negatively impact on staff-patient relationships. The potential for staff to label patients as 'non-compliant' can create a confrontational and tense clinical environment (Casey, Johnson, & McClelland, 2002). Relatively little is known regarding the adverse impact of non-adherence of fluid restrictions on the psychosocial wellbeing of patients as well as on the attitudes and behaviour of HCPs towards these patients. Possible feelings of despair, frustration, alienation and anger may impair the therapeutic relationship and minimise the likelihood of positive outcomes for people receiving Haemodialysis (HD) and the provision of quality care by HCPs.

In order to support people living with ESKD it is necessary to understand the personal meaning of disruption and the nature of their experience of living with kidney disease. It can be argued that health professionals do not understand this very well. Some research has identified that nursing staff tend to make assumptions about understanding the life experiences of those they care for (Bahrami, Parker, & Blackman, 2008; Berg, Idvall, Katajisto, & Suhonen, 2012; Molzahn, Northcott, & Dossetor, 1997). An improved understanding of the experience of the patient as a person, will assist HCPs to translate this knowledge into more person centred and meaningful support strategies. This understanding will inform nursing practice and provide direction for future research.

1.1 A background on chronic kidney disease, end stage kidney disease and renal replacement therapy

There has been a change recently in the terminology used to describe disorders related to the kidney. There has been a transition in the literature from the terms chronic renal failure and acute renal failure to chronic kidney disease (CKD) and acute kidney injury or dysfunction respectively. These changes in terminology reflect the changes in our understanding of both the illness trajectory and pathophysiology of kidney disease and recognises that there is a disease process occurring and not merely 'renal failure'.

The sub-types of kidney disease are described as either acute, chronic or end-stage.

Acute kidney injury is characterised by a rapid onset of symptoms that are potentially reversible with prompt intervention that addresses the initial cause of the injury.

Chronic kidney disease by contrast, is a largely silent disease that presents as an insidious, irreversible decline in renal function. Some literature uses the terms CKD and ESKD interchangeably, however this is incorrect as the final stage of CKD, when the glomerular filtration rate falls below 15ml/min, is defined as ESKD to denote the terminal phase of the disease trajectory (P.M Sinclair & Bennett, 2011). It is at this stage that the person must choose either a renal replacement therapy (RRT) or to withdraw from active treatment. Renal replacement therapy consists of three modalities, peritoneal dialysis (PD), HD or kidney transplantation.

The progression from CKD to ESKD requires the individual to make profound adjustments to their accepted way of living (Curtin, Mapes, Petillo, & Oberley, 2002). As people approach the terminal phase of the kidney disease trajectory, most renal departments in Australian hospitals provide them with a choice between PD or HD if a pre-emptive kidney transplant is not possible. Patients are required to make this choice and the decision process is often made with lifestyle, medical, economic, social and family factors in mind (Harwood, Wilson, Sontrop, & Clark, 2012; Just et al., 2008; Morton et al., 2012). People who choose to undertake HD, depending on service availability and medical suitability, may undertake home, community (also known as satellite) or hospital based dialysis. In Australia, community based HD accounts for 50% of all treatments compared with hospital based HD (22%), PD (20%) and Home HD (9%) (Briggs, Hurst, & McDonald, 2011). Home based dialysis offers clear

physiological, economic, social, and quality of life benefits over hospital or community based dialysis but may not be suitable for all people requiring dialysis (Masterton, 2008).

People who undertake hospital or community based HD are not commonly afforded the luxury of choosing when or where they can undertake dialysis. Consequently, this form of dialysis requires a substantial time commitment from patients which may result in three days of each week being segregated for dialysis alone. Hospital and community based HD is usually undertaken thrice weekly. Dialysis time varies according to individual prescription and is generally between three and five hours per session. Additionally, people need to account for travel time to and from the dialysis setting and may experience time delays associated with machine breakdowns and shifts running behind time. Travel time can be significant depending on the individual's location in comparison to their dialysis setting. Delays may also be experienced if the individual relies on ambulance or community based transport. Consequently, hospital and community based dialysis seriously impacts on their life in terms of time, travel, inconvenience, and dependency.

1.2 Fluid restriction and interdialytic weight gain

Dialysis therapy alone is insufficient to replace the functions of the kidney. People undergoing HD are required to follow a complex, multifaceted and often evolving treatment regimen that includes pharmacological preparations, dietary and fluid restrictions which are often difficult to comprehend. Fluid restriction is reported to be the most difficult component of self-management for people with ESKD (Johnston & Halshaw, 2003; Sharp, Wild, Gumley, & Deighan, 2005). It is suggested that the management of fluid restrictions for people on PD may not be as onerous as those on HD due to the continuous nature of this form of RRT (Wuerth et al., 2002). People on PD are continually undergoing dialysis whereas people receiving conventional HD in hospital or community based facilities receive it intermittently, generally thrice weekly.

Interdialytic weight gain (IDWG), the amount of fluid accumulated between HD sessions, is used as the key marker to measure adherence to fluid restriction. It is easily quantifiable and directly affected by patient behaviour, that is, depending on residual

renal function¹, the more an individual drinks between dialysis sessions the higher the IDWG is likely to be (Christensen, Moran, Wiebe, Ehlers, & Lawton, 2002; Port et al., 2004; Sharp, Wild, & Gumley, 2005). Interdialytic weight gain can be determined by one of two equations: 1. Pre HD weight (kg) minus Previous HD weight (kg) (Kimmel et al., 2000; Port, et al., 2004) or 2. Pre HD weight (kg) minus Ideal weight (kg) (Bots et al., 2004). The second formula assumes that patients achieve their ideal dry weight after each HD session and is unreliable if a patient does not.

Interdialytic weight gain is influenced by numerous environmental, nutritional, behavioural, biological and psychological factors (Hwang, Wang, & Chien, 2007; Sarkar, Kotanko, & Levin, 2006). The potential consequences of high IDWG and associated chronic fluid overload include intradialytic cramping and hypotensive episodes, left ventricular hypertrophy and congestive heart failure, hypertension, acute pulmonary oedema, and increased mortality (Leggat, 2005; Movilli, Gaggia, Zubani, et al. 2007; Oldenburg, Macdonald, & Perkins, 1988; Saran, Bragg-Gresham, Rayner, et al. 2003). These co-morbid burdens further erode the quality of life for people on HD.

Apart from the reduction of fluid intake, the maintenance of adequate IDWG requires people on HD to implement two additional self-care strategies. Firstly, monitoring or measuring their total fluid intake over a 24 hour period and where indicated, the amount of urine output. Secondly, people are required to employ strategies to decrease their thirst drive including limiting dietary sodium intake (Bots et al., 2005).

Sodium plays a significant role in thirst, fluid restrictions and associated IDWG. People drink for one of two reasons, they are either thirsty or they are in a social situation where having a drink may be the norm. The overriding regulatory mechanism for thirst is effective plasma osmolality (Tomson, 2001). The thirst drive is influenced by sodium intake; consequently thirst will be greater if sodium input exceeds sodium output. People with ESKD who are anuric² are unable to regulate sodium output (Charra, 2007), they are also exposed to additional sources of sodium other than dietary in the form of dialysate³ and medication. In view of this, it would be very

¹ The remaining degree of kidney function in a person with end stage kidney disease

² Do not pass urine

³ The fluid and solute solution used in the process of dialysis

difficult for any individual to ignore such an innate physiological stimulus when they feel thirsty.

Studies related to fluid restriction and associated IDWG in people receiving HD have focused on predictors of non-adherence (Leggat et al., 1998), managing the intradialytic consequences of excessive IDWG or interventions to decrease IDWG (Sharp, Wild, & Gumley, 2005). The majority of research has focused on interventions devised by clinicians to decrease IDWG. This reflects a positivist view to health management and these approaches to research often fail to consider the experiences of people who undertake HD. Health professionals do not have exclusive ownership of ideas about health and disease (Seymour, 1989). In fact, interventions devised by clinicians to improve health outcomes may have limited impact because patients do not identify such measures to be related to their own perceptions of their experience (Casey, Johnson, & McClelland, 2002; Seymour, 1989).

In order to create a culture of collaborative care where the patient and health care team work in partnership to achieve mutually negotiated and agreed goals, it is vital for the health care team to engage effectively with service users. The health care team needs to appreciate patients' experiences, health beliefs, attitudes and expectations of both their illness and treatment. A change in attitude and thought processes is required to transfer the emphasis away from the goals of the health care provider. Rather, the patient's experiences and perspective needs to be considered by HCPs before they are able to work in partnership towards negotiated and agreed goals (Costantini, 2006). This will contribute to modifications to interventions that are developed by clinicians who may otherwise view patients as subjects of study (Chio & Fandt, 2007).

A number of qualitative studies have examined the experience of living with ESKD (For example: Faber, 2000; Hagren, Pettersen, Severinsson, et al. 2005; Lindqvist, Carlsson, & Sjoden, 2000; Rittman, Northsea, Hausauer, et al. 1993). The main focus of this thesis is the area of fluid restrictions and how people on HD experience them. It is prudent to review the extant qualitative literature to identify what has been reported about this phenomenon. Consequently, the following chapter will report the literature review that was used to inform the aim of this study.

1.3 Background to this research

I have worked with people suffering from CKD and ESKD for over ten years. As I developed my clinical expertise I started to become challenged by the language and attitude that 'dialysis' nurses often used and displayed in their everyday interactions with these patients. In my own clinical practice, I have been personally challenged when observing fellow clinicians translating their theoretical and conceptual understanding of an individual's experience into practical and relevant interventions. This was particularly evident when observing the way some nurses speak with people on HD about aspects of self-management, notably in the area of managing the intake of fluids. Comments from nurses like: "I know it's hard for you to follow the fluid restrictions but you have to do better with them; you are five litres over your dry weight, you have drunk too much! Is it any wonder you are so short of breath" have often been heard at the beginning of dialysis shifts. These statements reflect a paternalistic and authoritarian approach to nursing care, not one that is person centred.

My catalyst moment occurred one day in Scotland after a specific patient encounter with a patient I will call 'Jock'. Jock, a 28-year-old single, professional male continuously presented for his HD sessions with fluid overload. It was interesting to watch the interactions between this man and the dialysis nurses. Typically, the conversations went: "Jock, you're five kilograms over your dry weight, don't you know what you're doing to your heart!" Needless to say, this critical approach was ineffective and only served to alienate Jock. I spoke with him one day after we had stabilised him (after an episode of pulmonary oedema). I acknowledged the difficulty I could see he was having with managing his fluid between dialysis sessions. He instantly became defensive, "I know, I know, it's stuffing up my heart". 'Jock' had been on HD for six months, he had developed ESKD after a short illness and it was clear the long term damage to his heart was not a priority for him at this stage of his life. I asked him to give me some words to describe this life changing experience. He gave responded "Loss...I've lost my job, I've lost the function of my kidneys and the ability to eat and drink what I want and I'm stuck in this place three times a week and all you nurses do is nag me about my fluids when you have no idea what it is like to be me". He challenged me to try for one day, to drink no more than 1000mls of fluid and see

what it was like. This interaction proved integral to the future of my nursing career and impressed upon me the need to continuously ask myself: Do I make assumptions about understanding the life experiences of these people? I tried the '1000ml challenge' and failed miserably. Jock was right, I had no idea.

1.4 Structure of this thesis

This thesis is presented in five chapters. Chapter 1, the introduction, presented the background and motivations for this study being undertaken. The challenges confronting both people requiring dialysis and staff providing care were identified. Chapter 2 will review the qualitative literature relating to the experience of people with ESKD undertaking HD. The review will encompass issues related to loss, restriction, support and coping, adjustment and the process of redefining one's self in the face of being diagnosed with ESKD. Chapter 2 will conclude with making recommendations for future research and justify the purpose for this study.

Chapter 3 describes the research design and process chosen for this study. The constructs of credibility, dependability, confirmability and transferability are described and discussed in the context of establishing the rigour and trustworthiness of the data and findings of this study.

Chapter 4 reports the findings of the study and describes the three super-ordinate themes and eight sub-themes that emerged from the data. The final chapter of this thesis discusses the findings of this research in relationship to the extant literature. Areas of commonality and new knowledge will be discussed in addition to making recommendations in the areas of clinical practice and future research. This chapter concludes with some comments and challenges HCPs to consider the manner in which they engage with people on HD when discussing fluid restrictions and associated IDWG.

Chapter 2 Literature review

2.1 Background

Research that considers the experience of living with chronic illness assists health professionals in understanding the social and adaptive processes of participants (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010), and the meaning attached to their unique experience of illness. Previous studies that addressed fluid restrictions and associated IDWG in people who undertake HD, have reported the results of interventions devised by health care providers (Barnett, Li Yoong, Pinikahana, & Si-Yen, 2008; Bots, et al., 2005; Molaison & Yadrack, 2003; Sharp, Wild, Gumley, et al., 2005). These interventions have been conducted using quantitative research designs that have explored the relationships between IDWG and socio-demographic, behavioural, health belief and educational variables (Barnett, et al., 2008; Krespi, Bone, Ahmad, Worthington, & Salmon, 2004; Sharp, Wild, & Gumley, 2005). In these studies, the patient's perspective does not appear to have been reported which suggests that the individual meaning attached to the illness experienced by individual participants has not been considered. Quantitative studies are unable to describe the personal meaning of illness because they focus on measuring prevalence, incidence, compliance, outcomes and reporting rates, means, odds ratios and regression modeling of factors in specific populations.

The terminal phase of CKD's illness trajectory is ESKD. While some people will experience a gradual transition to ESKD, other presentations are characterised as 'late presenters'. Late presenters are people who are diagnosed in the later stages of the disease process and do not have the opportunity to adjust to either the meaning of illness or the impact that it will have on their lives. End Stage Kidney Disease is treated either through kidney transplant, renal replacement therapy (i.e. HD, PD), or the withdrawal of active treatment/conservative care. Patients receiving HD or PD are also required to take various pharmacological preparations, and adopt dietary and fluid restrictions to replace the natural functions of the kidney. While some studies have considered the transition from CKD to ESKD, the purpose of this literature review is to examine the extant literature that considers how people who undertake HD experience ESKD and associated fluid restrictions.

2.2 Search strategy

A literature search was conducted for the period 1990-2011 using Medline, CINAHL, Proquest 5000 including dissertation and thesis databases, PsycINFO and the Cochrane library using the following search terms: hemodialysis, haemodialysis, end stage kidney disease, end stage renal failure, fluid restriction, dietary restriction, interdialytic weight gain, experience and qualitative. Australian and American English spelling variations were included. The search was supplemented by manually reviewing reference lists of relevant papers.

Inclusion criteria were:

- Published English language research papers that reported studies focussing on fluid restrictions or IDWG in people undertaking HD.
- Papers that reported the experience of people with ESKD whereby the majority of participants undertook HD.
- Studies that reported receiving institutional (or equivalent) ethics approval.

Papers were excluded if:

- They reported the experience of living with the HD machine rather than ESKD.
- The cohort studied included paediatric cases, or people exclusively undertaking PD or who had received kidney transplants.
- They exclusively reported quantitative findings relating to fluid restriction or IDWG.
- The paper reported validation of survey instruments relating to research in the domain of fluid restriction/IDWG.

A total of 156 papers were identified in the initial search. These were then reviewed and assessed using the inclusion and exclusion criteria which resulted in 19 papers for this review. No additional papers were identified during a manual review of reference lists of included papers.

2.3 Summary statement

The studies identified in this review, with the exception of the papers from Krespi, et al. (2004) and Tijerina (2009), who used mixed methods⁴, used a qualitative approach. Papers were inconsistent in identifying the geographical location of the studies. Those that did identify the location of the study were predominantly from Canada and the United States of America, other countries included Australia, New Zealand, Sweden and Greece. The majority of participants undertook HD in hospital and community based facilities and were recruited using either snowball or purposive sampling methods. The predominant method of data collection was through the semi-structured interview of participants. Data analysis was guided, on the whole, using interpretive descriptive designs with some papers using phenomenology, content analysis, grounded theory and case study methods. The key features of the studies included in this review are summarised in Appendix 1.

2.4 Results

The overarching theme of most papers was the impact and significance of loss and restriction associated with ESKD. In addition, papers described the variation in how people with ESKD manage their illness experience to generate a new sense of self. People with ESKD have identified that despite this transformational experience they wish to be seen as normal by their family and HCPs. Throughout this experience participants have described their insights into the management of self; the illness experience; the 'system' and those who work in it, support and coping, and the impact of living with ESKD on support networks. The interconnectedness is particularly evident between the themes of loss and restriction associated with the treatment regimen and the resulting dependence on the HD machine and HCPs. Consequently these themes cannot be viewed as discrete categories.

2.4.1 Loss

People living with ESKD have described how the disease has encroached on what they could do prior to commencing HD. Consequently feelings associated with loss are

⁴ For the purposes of this literature review the quantitative findings of these studies were not reviewed.

commonly described within the qualitative renal literature. The overall experience of loss is multidimensional and is linked to all aspects of living with ESKD. The loss of freedom (Al-Arabi, 2006; Faber, 2000; Hagren, Pettersen, Severinsson, Lutzen, & Clyne, 2001; Tijerina, 2009) is described in several studies and is often associated with the restrictive nature of the treatment regimen.

Hagren et al. (2001), in a qualitative interpretive study from Sweden, contextualised loss in terms of the experience of 'suffering' with ESKD. Participants described how their dependence on HD, helped them to avoid death but at the expense of personal freedom. Loss has been further described in terms of loss of finance and occupation (Salvalaggio, Kelly, & Minore, 2003); physical appearance, health and autonomy (Al-Arabi, 2006; Faber, 2000; Rittman, Northsea, Hausauer, Green, & Swanson, 1993); independence (Salvalaggio, Kelly, & Minore, 2003; Tijerina, 2009); and identity and functional ability (Tijerina, 2009). Salvalaggio, Kelly, & Minore (2003) have further described how reduced financial capacity exacerbated the feelings of dislocation from home communities in Canadian first nation patients.

The study by Al-Arabi (2006) revealed the *meaningful losses* experienced by participants during their illness trajectory. These themes were consistent with the feelings of loss associated with physical appearance, and altered family and social dynamics. Tijerina (2009) identified that a cohort of Mexican American women associated loss with multiple constructs including personal freedom, identity, functional ability and independence. Tijerina (2009) also described how the treatment associated with ESKD adversely influenced participants ability to sustain societal functionality and relationships.

Loss of autonomy and independence creates dependence on others and in some cases, a health care system that is perceived to be foreign (Burnette & Kickett, 2009; Salvalaggio, Kelly, & Minore, 2003). The corollary of loss is a life that is dependent on the restrictive nature of the treatment regimen, the HD machine and personal relationships (Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Hagren, et al., 2001; Namiki, Rowe, & Cooke, 2010; Salvalaggio, et al., 2003; Tijerina, 2009).

2.4.2 Restriction

The predominance of themes associated with a life consumed by the restraints of ESKD resonates throughout the qualitative literature. Hagren, et al., (2005) described how treatment for ESKD encroached on patients' time and space. Participants' experiences of ESKD were described as an existential struggle particularly characterised by *not finding space for living* and *attempting to manage a restricted life*. The restriction on food and fluid is a commonly identified stressor for people on HD with dietary restrictions adversely impacting social routine (Clarkson & Robinson, 2010; Faber, 2000; Kaba, et al., 2007). Participants in a study by Kaba, et al., (2007) expressed how they avoided social situations as a dietary adherence management strategy.

Restrictions were not limited to those of a dietary form. The restrictive nature of the illness and its treatment regimen permeates to all areas of life including travel, occupation, and time and finances (Burnette & Kickett, 2009; Clarkson & Robinson, 2010; Curtin, et al., 2002). Al-Arabi, (2006) described three sub-themes that were consistent with the conceptual category of *life restricted*. *Tied down*, *left out* and *doing without* described the restrictive nature of a regimen that sustained life yet paradoxically, reduced its quality. Being *tied down* was also conceptualised as a relationship of dependence on both technology and the HD machine. This relationship has also been described by Hagren, et al. (2001), Faber (2000) and Rittman, et al., (1993) who collectively reported the loss of freedom in terms of dependence on both the HD machine and HCPs. Kaba, et al., (2007) reported a study exploring how 23 people on HD with Greek origins perceived their problems. Five themes were described with two of them, *dependence* and *limitations of life* specifically associated with the existential struggle connected with a life dependent upon care givers and an imposed medical regimen.

Rittman, et al., (1993) provided insight into the adaptive process of integrating technology into patients' ways of life using a Heideggarian phenomenological framework. The constitutive pattern *control: the meaning of technology* described how technology replaces kidney function and how its control impacted on patients' way of living and approach to life (Rittman, et al., 1993). Technology and the relationship of living with fluid restrictions are complicated by the patients' understanding that HD

removes fluid. This creates a juxtaposition. On one hand patients are told by health professionals to adhere to rigid fluid restrictions yet from their reported perspective they see HD as cleansing by nature and compensating for 'failures' in adherence (Rittman, et al., 1993). The compensatory nature of HD was also cited as a major facilitator of poor motivation to restrict fluid intake in the study by Smith et al., (2010). Smith et al., (2010) used content analysis and semi-structured focus groups to describe the facilitators and barriers of fluid management in a cohort of 19 people receiving HD from two different facilities in the United States of America. Several pre-determined domains guided the formulation of six themes, knowledge, self-assessment, social, physical, environmental psychological factors. Participants revealed the challenges people in HD face in terms of managing fluid restriction at a practical level but the findings and choice of data analysis method sought to quantify the percentile of each theme occurring as a facilitator or barrier rather than describing the experience of living with fluid restrictions.

The view of a restricted life identified the deleterious impact of ESKD and its treatment on people's lives. Al-Arabi (2006) described the use of coping strategies to manage imposed restrictions such as acceptance and social support that were part of the larger theme of *staying alive*. These imposed restrictions were inherent in the theme of *life restricted* however participants reported a conscious decision to redefine their normal self in order to stay alive and maintain an acceptable quality of life.

2.4.3 Redefining self: a new sense of normalcy

The process of integrating the experience of living with ESKD into the person's understanding of self is well described in the literature albeit with authors using different phrases or terms. The themes *taking on a new understanding of being* (Rittman, et al., 1993), *redefinition of self* (Gregory, et al., 1998), *reframing* (Walton, 2002), *psychological adjustment* (Salvalaggio, et al., 2003), and *adjusting to life with ESKD* (Ravenscroft, 2005), all describe transitional processes of individuals restructuring 'self' within the context that the extant self still existed.

The qualitative literature has reported conflicting perspectives on how participants come to understand their new sense of self within the context of their personal illness

experience. Curtin, et al., (2002) uses the term transformation to describe an endpoint in the process of adjustment in long term dialysis survivors, which sees the patient transition to comprehensive self-manager. Whereas Gregory, et al., (1998, p. 764) suggests that a “*new sense of self* is an emotional/psychological state that fluctuates with the evolving meanings of illness and treatment and perceived quality of supports”. Gregory, et al., (1998) suggested this process is characterised by the acknowledgement of uncertainty, dependence on technology, HCPs and support structures.

Ravenscroft (2005), using an interpretive descriptive design in a Canadian study, described adjustment as a process of finding a balance between illness and normalcy similar to that described by Walton (2002). Walton (2002) used the theme *reframing* to depict a coping mechanism that enabled a process of moving beyond negative perceptions of viewing their dependence on treatment as a burden, to more positive views such as dialysis being a life giving treatment. Walton (2002) suggested that reframing was used by participants as a technique to manage other challenges presented. The ability to effectively process information and modify perceptions was supported through the presence of HCPs and other patients. Where Walton (2002) used the term reframing, Ravenscroft (2005) and Gregory, et al., (1998) described a conscious decision making process whereby adjustment (Ravenscroft, 2005) or redefinition (Gregory, et al., 1998) was achieved through making conscious choices, evaluating the risk versus benefit of health behaviours, implementing control measures and trying to reframe the illness experience within as normal a context as possible. The adjustment process enabled participants to accept ESKD through self-regulating the extent to which they would allow the realities of the illness to intrude into their lifestyle.

Rittman, et al., (1993) described the longitudinal nature of *taking on a new understanding of being*. Participants revealed how time and numerous coping strategies enabled them to manage the early experience of illness intrusion and substitute it with a new understanding of self that was integrated into a ‘normal way of being’. The experience of ESKD and its treatment became contextualised into a new meaning and understanding of self. Curtin, et al., (2002) used the term transformational experience in their exploratory descriptive study to understand the coping strategies of eighteen

people who had been on dialysis for longer than fifteen years. The transition from 'normal' self to 'comprehensive self-manager' occurred through an adaptive process of reforming self through self-affirmation and restructuring the illness experience into their new understanding of self. Al-Arabi (2006) described a similar phenomenon and suggested that the realisation that participants had this control, facilitated adjustment to life with ESKD. Most authors have described an active process of adjusting to life with ESKD as a process of recontextualising the illness into their extant self which is characterised by autonomy, hope, support, self-determination and affirmation, selective attention, control, negotiating balance, acceptance and a focus on self-management (Curtin, et al., 2002; Gregory, et al., 1998; Namiki, et al., 2010; Ravenscroft, 2005; Walton, 2002).

Not all people with ESKD are able to, or have the inclination to 'come to terms' with their illness. Acceptance for some was derived from personal faith (Al-Arabi, 2006) or a pragmatic choice to 'get on with life' (Al-Arabi, 2006; Namiki, et al., 2010). Krespi, et al. (2004) conducted a mixed method study using the Health Belief Model (HBM) to guide their inquiry into patients beliefs about ESKD and its treatment. The qualitative phase (n=16) described fluid and dietary restrictions as externally imposed challenges that dominated life. Some viewed these restrictions with ambivalence while others adapted to, or tolerated them. Some participants perceived the restrictions not in terms of adherence but perversely as ways to circumvent the "frustrating and boring rules" associated with them (Krespi, et al., 2004, p193). This demonstrates an alternate view of illness acceptance when compared to other studies in this field. Participants in the study by Curtin, et al. (2002) described that despite the challenges to their sense of self they were able to separate themselves from their disease processes and in doing so, were able to redefine their new embodied sense of self; and the process of adapting and coming to terms with the restraints imposed by ESKD and its treatment. This new understanding of being, demonstrated a gradual transition from a disruption in daily living to reconstituting and integrating their illness experience as a 'normal' way of life. Consequently, the transformation to new self, embodied the successful adjustment to ESKD.

Walton (2002) reported a Glaserian grounded theory study of spirituality with eleven people on HD. The predominant theme was expressed as a “social process of *finding a balance* in life” (Walton, 2002, p. 448). This process was determined as being dynamic yet individualised in nature and consisted of four phases: Confronting mortality; reframing; adjusting to dialysis and facing the challenge. Walton used balance weight scales as a metaphor for *finding a balance*. The analogy between the category of finding a balance and participants ‘weighing’ the risks associated with health behaviours is consistent with the later findings of Ravenscroft (2005, p. 506) who revealed that adjusting to life with ESKD was reliant on “*learning to manage, finding a balance and accepting the illness*”. Personal control and hope were identified as influential factors supporting the adjustment process.

Gregory et al. (1998), using a grounded theory approach, revealed that patients’ *new sense of self* was largely dependent on the meaning of the illness and treatment experience in addition to their perception of support. The constructs of redefinition of self, support quality and illness meanings were associated with critical turning points in the adaptation process. The successful negotiation of these constructs could assist or encumber their acceptance of ESKD and its treatment and modify participants’ perceptions of support networks and health behaviours. Adjustment was akin to adaptation and was associated with a series of physical, emotional and psychosocial changes that assisted the transition from old self to new self. The new self evolved as participants experienced new aspects of the disease process and its treatment. The challenges associated with the transition to a new way of being led participants to describe the uncertainties associated with their future and their reliance on technology and HCPs.

The literature provides divergent perspectives in the domain of illness acceptance. It is unclear whether acceptance is some form of unconditional acquiescence or whether it is a form of reluctant imposed resignation. It is suggested that people with ESKD who undertake HD make individualised adjustments to a number of areas of their lives in order to be able to cope with the competing demands of treatment. These adjustments may be contrary to the advice given by health professionals and consequently provide the potential for tension between the patient and the system.

2.4.4 Adjustment: Impact of the health care system and health care professionals

Participants of studies in this review have expressed varying perspectives of their experience of the health care system and how interactions with HCPs influence their lived experience and adjustment to life with ESKD. These experiences are generally described in terms of clinical and interpersonal competence, both of which are able to elicit positive and negative experiences.

Curtin and Mapes' (2001, p.388) exploratory descriptive study of 18 long term dialysis patients concluded that self-management of their illness involved carefully constructed "relationships to and interactions with" the health care system and those who work in it. Curtin and Mapes (2001) reported the 'orchestration' of participants' interactions with HCPs. Despite the obvious benefits of therapeutic relationships with the health care team it was essential for these participants to manage the system and those who represent it, in order to survive in the long term and in a manner that suited their accepted way of living. The theme *impression management* described participants' intention to improve their chances of receiving optimal care rather than foster relationships with the HCPs. Participants revealed that they could never fully trust the HCPs' abilities. Consequently, in order to ensure that their treatment was incident free, *vigilant oversight of care* and *active self-advocacy* were required. Participants felt confident to intercede on their own behalf if they perceived an encounter or intervention was not in their best interests. This phenomenon was not universally described in the literature.

Hagren, et al. (2005) described the phenomena of emotional distance and vulnerability in the care situation. This provided further insight into staff-patient relationships with the theme *feelings evoked in the care situation*. The subtheme *sense of emotional distance* related to this cohort's relationship with HCPs. A feeling that nurses did not attempt to relate or try to understand their life situation contributed largely to this. One participant, a 29 year old male described his struggle with limiting his fluid intake and how the nurses would "... start nagging me. Well I know I've been bad, but it's impossible to stop yourself when you're thirsty. I've told them 'would you last on [500mls] a day?', then they'll tell me 'but we're healthy!' As if I didn't know" (Hagren, et al., 2005, p. 297).

Therefore a sense of emotional distance was created that contributed to their existential

struggle. Similarly, Faber (2000) described how poor communication and the lack of social interaction with HCPs adversely impacted the therapeutic relationship. Furthermore, participants in the study by Smith et al., (2010) identified that despite knowledge being an important facilitator of managing fluid restrictions, they often did not understand the foreign terminology used by HCPs and what they were being taught, particularly when they had not experienced the consequences of poor fluid management. Hagren, et al., (2005) expressed vulnerability in terms of the consequences of living with ESKD and dependence on care givers. This vulnerability related to dependence on HCPs has also been described by a cohort of Australian Aborigines (Burnette & Kickett, 2009). These participants described how poor communication with HCPs exacerbated feelings of disempowerment, which resulted in negative views of the health care system. Participants described a distinction between European nurses and those from other cultural backgrounds. They suggested non-European nurses were more sympathetic to their lived experience and were more likely to communicate and identify with them as patients.

Ravenscroft (2005) and Gregory, et al., (1998) identified that patients expressed greater satisfaction with the continuity of care provided by nurses compared to doctors. Several studies described how HCPs who demonstrate a willingness to appreciate the value of the patient's lived experience are regarded more positively than those who do not (Burnette & Kickett, 2009; Gregory, et al., 1998; Ravenscroft, 2005). Gregory, et al., (1998) described how nursing support facilitated adjustment to dialysis while reducing the anxiety and uncertainty associated with it. Participants voiced a longing for HCPs to treat them as individuals not as patients. Being viewed and treated as an individual facilitates trust and facilitates therapeutic relationships (Hagren, et al., 2001; Ravenscroft, 2005).

2.4.5 Adjustment: decision making and control (learning to manage)

ESKD causes considerable disruption to the lives of people who experience it. The disease impacts all facets of life and according to one participant in Ravenscroft's (2005, p. 505) study "there is no getting away from it". When patients leave the health care setting they are left to make their own health management decisions. ESKD requires

the patient to actively participate in treatment demands in addition to HD.

Consequently the successful management of ESKD is reliant on the self-management decisions made by patients when they leave the health care setting.

Faber's (2000) socio-cultural analysis of four peoples' lives with ESKD contributes to understanding how people on HD attempt to maintain a normal life. Consistent with the methodological design, Faber also interviewed the main social support person and HCPs from the renal department where care was delivered. Faber's participants described the work of living with ESKD and that this work included a life outside the dialysis setting. All participants reported that living with fluid restrictions was difficult. They also described a willingness to accept the corollary of ignoring fluid and dietary restrictions in order to maintain a sense of normality. However the consequence of this desire for normality may be that HCPs label these patients as 'non-compliant' and presume that they are not aware of the consequences of their actions rather than acknowledging conscious behaviours aimed at leading a normal life (Faber, 2000; Hagren, et al., 2005; Rittman, et al., 1993). Rittman, et al., (1993) identified the theme, *taking on a new understanding of being* which offered a similar perspective of the lived experience to that described by Faber (2000) when compared to the traditional models of compliance/adherence. Rather than accept externally imposed restrictions, Rittman and colleagues suggested this could be interpreted as a natural part of adapting to a new way of living rather than 'non-compliance' per se.

Ravenscroft (2005) identified participants' willingness to actively choose which elements of their illness they would 'attend to'. This construct of adaptive adherence or *selective attention* (Ravenscroft, 2005) is similarly described by Faber (2000), Curtin and Mapes (2001) Rittman (1993) and Polaschek (2003). Faber (2000) suggested that people with ESKD may rationalise non-adherence in an attempt to feel *normal*. In this way they are able to assert a semblance of control over the disease despite the risks associated with disregarding dietary advice. Making conscious choices in terms of illness management appears to facilitate the adjustment process by enabling the individual the opportunity to exercise control over the extent to which the illness intrudes in their life rather than submit to a 'mandatory' regimen and associated lifestyle (Ravenscroft, 2005).

Polaschek (2003) used a critical interpretive methodology to reveal the differences between professional assumptions and the patients' reality of living with ESKD. Polaschek identified that from the patient perspective, the need for treatment and hence 'compliance' was viewed as a process of negotiation. Rather than completely follow their prescribed regimen, this cohort of patients experimented with and modified their therapeutic prescriptions in order to integrate HD into their normal lifestyle (Polaschek, 2003). This form of rationalised self-modification to treatment regimens was based on the need to accommodate the 'treatment' into their lifestyle. Participants identified that they were unable to share these adjustments as they felt the HCPs would not understand their motivations.

Extensive support mechanisms have been described as integral to assisting patients and their family to cope with living with ESKD. Support mechanisms extend to spiritual dimensions including faith, church, prayer and God (Clarkson & Robinson, 2010; Walton, 2002). Al-Arabi (2006) described how *trust in God* afforded confidence in the ability to successfully manage their lives. Holding on to spirituality and love for others was another motivator to stay alive and further assist in adjusting to dialysis, developing insight and establishing a new sense of purpose in life (Walton, 2002).

2.4.6 Support and coping

Findings from the qualitative literature reinforced the notion that support is a crucial element in managing and adjusting to life with ESKD (Al-Arabi, 2006; Clarkson & Robinson, 2010; Gregory, et al., 1998; Namiki, et al., 2010). Gregory, et al., (1998) categorised support as being informal, (ie: partnership with family members and loved ones) or formal (ie: HCPs). A tension exists in that successful self-management of ESKD is reliant on strong foundational support structures (Al-Arabi, 2006; Clarkson & Robinson, 2010; Gregory, et al., 1998; Namiki, et al., 2010). However the rigours associated with treatment of the disease simultaneously have a pervasive effect on the same relationships (Gregory, et al., 1998; Salvalaggio, et al., 2003) and can potentially create family dysfunction (Tijerina, 2009).

Studies exploring the challenges associated with living with ESKD have portrayed a desire associated with *coping* (Clarkson & Robinson, 2010), *hope* (Namiki, et al., 2010)

and *staying alive* (Al-Arabi, 2006). Some participants have described their determination to meet the challenges associated with living with ESKD as driven by the hope for a cure or that a kidney transplant would soon become available (Al-Arabi, 2006).

Gregory, et al., (1998) described support roles within the context of people with ESKD continuously redefining their sense of self in response to the illness and the response of others to the new self. Participants' expressed how informal support persons observed the progression from an independent individual to a dependent person with a chronic illness. The tendency of others to maintain relationships and provide emotional support facilitated the process of accepting ESKD, its treatment and consequences. This phenomenon was consistent with Al-Arabi (2006) who revealed that participants' motivations to live were driven by *love from others; trust in God* and *accepting it as part of life*. *Love from others* described participants' perspectives on elements of support that motivated them to continue their treatment.

Despite the need for support from significant others to successfully integrate the illness into a new sense of being, people with ESKD described trepidation relating to the pressure that the demands of the disease places on others. In some cases the limitations experienced by people with ESKD have directly impacted the lives of support persons (Gregory, et al., 1998). In particular, travel associated with HD and the time intensive nature of treatment in general, intrudes on marital and familial relationships and places immense strain on such relationships (Hagren, et al., 2001).

2.5 Discussion of findings

The progression through the illness trajectory of CKD and the development of ESKD required individuals to make profound adjustments to their accepted way of living psychologically and in their daily routines (Curtin, et al., 2002). The qualitative literature identified in this review revealed the degree to which ESKD and its associated treatment impacted on people's lives. This body of literature supported the themes of loss and restriction in the experience of the disease. Despite the limitations imposed on life, participants from these studies described the importance of cultivating strategies to maintain their quality of life and limit the impact of the disease on their

lives. These strategies in part, assist people with ESKD to negotiate a pathway of adjustment which culminates in the development of a new identity that is grounded in their illness experience. How the successful adjustment to life with ESKD occurs remains unclear. The transition to a new sense of normalcy is not linear and is distinguished by uncertainty (Kaba, et al., 2007; Namiki, et al., 2010) and suffering (Polaschek, 2003). Curtin, et al., (2002) suggested that the transition from normal self to a 'transformed' comprehensive self-manager occurs through an adaptive process of reforming self through self-affirmation and the restructuring of the illness experience. Gregory, et al., (1998) described a process whereby participants considered risks, identified and prioritised control measures and then contextualised the illness and its treatment into the new sense of self. Despite this transformative process, people on HD want the health care team and others to see them as normal people and to appreciate their experiences, health beliefs, attitudes and expectations of both their illness and treatment (Gregory, et al., 1998; Hagren, et al., 2001; Ravenscroft, 2005; Rittman, et al., 1993).

The literature revealed numerous strategies that assisted people to come to terms with a life that is restricted by ESKD and its treatment. Of these strategies, support structures resonate as the major factor which sustains patients in the adjustment process. Unfortunately the disease creates a tension whereby support is needed to cope and manage, yet the burden of the disease fractures support systems and is linked with the concept of loss (Gregory, et al., 1998; Hagren, et al., 2001; Namiki, et al., 2010; Salvalaggio, et al., 2003; Tijerina, 2009).

The literature reviewed described a disconnection between the assumption of HCPs and patients' realities, (Polaschek, 2003) with participants in some studies expressing that nurses did not appreciate or respect their personal experiences which adversely affected the adjustment process (Burnette & Kickett, 2009; Gregory, et al., 1998; Hagren, et al., 2005; Ravenscroft, 2005). Faber (2000) suggested that HCP's aims to improve patient's health are in direct contrast to the patients' aim of living a normal life. Patients who do not meet HCPs defined goals may be categorised as 'non-compliant' or in denial (Faber, 2000), and these terms alienate patients because they are not meaningful in the context of maintaining a normal life (Paterson, 2001). People

undertaking HD, report undertaking a conscious process of selective attention to symptoms and treatment regimens in order to feel normal (Ravenscroft, 2005). This phenomenon has also been described in people undertaking other renal replacement modalities (Lindqvist, Carlsson, & Sjoden, 2000). Patients' have additionally described the orchestration of interactions with HCPs (Curtin & Mapes, 2001) and in some instances, making conscious decisions to disregard medical advice and exceed their fluid restrictions (Faber, 2000). These strategies assist them to integrate their illness experience into their extant self while maintaining a sense of control. However, HCPs may not understand this.

2.5.1 Future research

The management of ESKD is complex and multifaceted. Treatment is not limited to dialysis alone and patients must endure numerous food and fluid restrictions in addition to various pharmacological interventions. Given this, it is plausible to suggest that a patient's illness experience is dependent on how they comprehend and manage these elements of RRT into their way of being. Consequently further research is required to reveal the effect specific elements of the treatment regimen have on the global experience of living with ESKD.

Several studies examined the general experience of living with ESKD (Curtin, et al., 2002; Faber, 2000; Hagren, et al., 2005; Kaba, et al., 2007; Rittman, et al., 1993). While others have more specifically considered the challenges (Al-Arabi, 2006), management strategies (Curtin & Mapes, 2001) and beliefs (Krespi, et al., 2004) associated with living with ESKD. There is a paucity of qualitative research in the domain of IDWG that considers the individual experience of managing fluid restriction and therapeutic interactions in this domain. This may be attributed in part to its relationship to the larger experience of living with ESKD. Given that patients themselves report fluid restriction as one of the biggest challenges they face (Johnstone & Halshaw, 2003; Sharp, Wild, & Gumley, 2005) further research in this domain is warranted.

Fisher et al. (2006) suggested that repeated episodes of fluid overload secondary to non-adherence behaviours may negatively impact on staff-patient relationships and perceptions of patient care. The potential labelling of patients by staff as 'non-

compliant' can create a confrontational and tense clinical environment (Casey, et al., 2002). Patients' are well informed of the consequences of fluid non-adherence as part of their pre-dialysis care yet this knowledge does not translate into adherence (Molaison & Yadrack, 2003). This chapter has reviewed the literature that has considered the experience of people living with ESKD who undertake HD. While these studies have widely described the overall illness experience of these people, it is necessary to further examine elements of how they experience ESKD, specifically areas such as dietary and fluid restrictions.

2.6 Justification and purpose for this study

There is a need to further explore and describe specific elements of the experiences of the treatment and management of ESKD for people on HD. This will provide clinicians with some insight into the difficulties encountered in their daily lives and may assist in overcoming the tendency of clinicians to assume that they 'know' what the patient needs.

To support people living with ESKD it is important to understand the personal meaning of disruption and the nature of their experience of living and managing these self-care aspects of their treatment. We can gain a deeper understanding of this disruption by examining their experiences, attitudes, beliefs and how they interpret and make sense of these phenomena in their lives.

If the health care community is to provide appropriate interventions and effectively engage with the people they provide care for, it is important to understand the impact that aspects of the disease process and its management have on them. In particular, the aspects of self-management that are conducted away from the dialysis unit. Exploring the experience and meaning of living with fluid restrictions and associated IDWG for people on HD is the focus of this present study.

This study seeks to understand and describe the meaning of fluid restriction and the perspectives involved in managing IDWG for people undergoing HD in a regional dialysis unit. The motivation for this research was to provide a voice for those who undertake HD, so that clinicians caring for them will be able to comprehend the effect of managing IDWG on these peoples' lives. This enhanced understanding of the

experience of the patient can be used to inform support and intervention strategies that will augment clinical practice and therapeutic relationships.

2.6.1 Research question

This study was conducted to address the question: What is the experience of fluid restriction for people receiving haemodialysis in a community based setting?

The following chapter will describe the study design and research methods that were used to answer the research question.

Chapter 3 Research design

3.1 Introduction

This chapter will describe the design, methods, and data analysis of this study exploring the experience of fluid restriction for people on HD.

3.1.1 Research question

This study was conducted to address the question: What is the experience of fluid restriction for people receiving haemodialysis in a community based setting?

3.2 Research design

The experience of illness is unique to each individual, it is socially constructed (Williamson, 2006) and deeply personal in nature. The experience of living with fluid restrictions for people on HD is no different. In order to understand and describe this experience it was essential to go to the source of the experience to understand it; the individual on HD. Due to the subjective nature of these experiences a qualitative descriptive design was chosen to develop new understandings in this area. Sandelowski (2000) and later Neergaard, Olesen, Andersen, & Sondergaard (2009) suggested that a qualitative descriptive design is an appropriate approach when a straight description of a phenomenon is desired. Qualitative description is a pragmatic form of naturalistic inquiry that serves to interpret and describe the experience through the eyes of the participant not the researcher (Sandelowski, 2000, 2010; Sullivan-Bolyai, Bova, & Harper, 2005). The qualitative descriptive design involves a comprehensive summary of the phenomenon from the participants' perspective which is written in a language that is similar to that of the participants' own language (Neergaard, et al., 2009).

The epistemological underpinning of this research acknowledges that:

1. Multiple realities exist which are constructed in relation to the context and social experiences of each participant. Consequently, human experience is unique, deeply personal, and subjective in nature.

2. Due to the uniqueness of this human experience no existing theory could account for the phenomenon being studied. Consequently the description of the phenomenon must emerge from and be grounded in the data.
3. It is impossible to separate the researcher and the participant. The researcher is an instrument by which the research process is mediated. Therefore complete objectivity is not able to be realised.

(Morse & Field, 1996; Thorne, Kirkham, & O'Flynn-Magee, 2008)

This study used a qualitative descriptive design. An outline of the study design is provided in Figure 3-1. Data were collected using semi-structured interviews and artefacts brought to interviews by participants. A semi-structured qualitative interview affords the researcher the opportunity to investigate the phenomenon experienced by the participant (Babbie, 2007). Boyd (2001) describes this as exploring subjectivity which enables the researcher to gather rich, in depth data to make sense of, and explore the meaning attached to the experience of the participants.

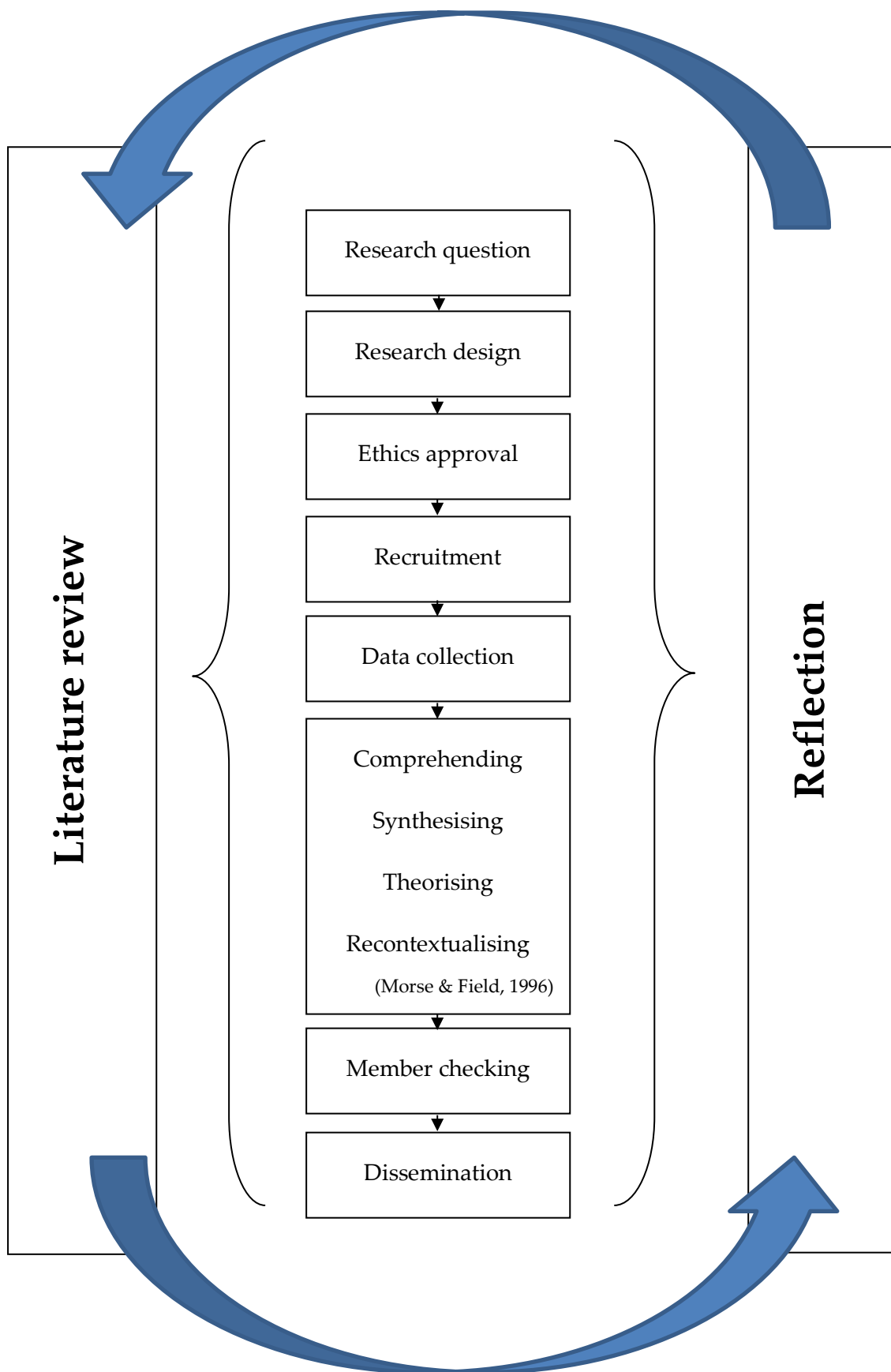


Figure 3-1: Study process

3.3 The research setting

Participants were invited to participate in this research from a community based dialysis unit that is geographically separate to the central dialysis unit of a tertiary referral hospital in regional NSW. The unit has a self-management focus and consists of two separate dialysis treatment rooms, one of which is used for HD and the training of people in preparation for home HD. The unit dialyses approximately 80 people per week and has a total clinical staffing full time equivalent of 11.4 to work Monday-Saturday from 0700-2230.

The participant group was sampled purposefully, due to the specific nature of their condition and experience associated with managing fluid restriction. While any individual who undertakes HD would have been appropriate for this study the decision was made to recruit participants from the community setting. People attending community units are often more haemodynamically stable than people undertaking HD in a centre or hospital based unit. Consequently the opportunity to identify participants who were in good health and able to freely share their experiences of fluid restriction and associated IDWG⁵ was maximised.

3.4 Ethical considerations

Ethics approval was granted for this research by the Hunter New England Area Health Service Human Research Ethics Committee (HREC) (07/12/12/5.05) and the University of Newcastle HREC (H-2009-0077). Data collection commenced in January, 2008 and concluded in March, 2008. The ethics approval letters are provided in Appendix 2 and 3.

All individuals who were invited to participate in the research project were informed that their participation was voluntary and entirely their choice. Full disclosure of the study's aims was provided. Potential participants were advised they could withdraw from the study at any time without providing a reason. Further, they were advised that if they decided not to participate, or to withdraw from the study, their decision would not disadvantage them in any way or affect their access to health care and services. No participants withdrew from the study.

⁵ The amount of fluid weight accumulated between HD sessions

All data were de-identified during transcription to protect anonymity. After the participants had reviewed and approved the interview transcript, the recordings were erased. In addition, the patients' privacy was protected by using pseudonyms during the interview and in transcripts.

There were no anticipated risks involved with this research. If participants were to become distressed or unduly upset as a result of talking about their experiences during the interview a referral to counselling services was available (ie: the renal social worker or other counselling service acceptable to the participant). No referrals were required.

Data were securely stored and password protected for a period of seven years as required by the HREC. They will be destroyed according to guidelines for disposing confidential data within the University of Newcastle. Access to the data was restricted to the research team.

3.5 Research processes

3.5.1 Preparing for recruitment

The Nurse Manager of the community dialysis unit was provided with information by the researcher about the study protocol. A staff member (who would have legitimate access to medical records and to the patients' personal dialysis boxes⁶ data) was nominated to initially screen the patient list at the unit using the inclusion and exclusion criteria to identify eligible participants for the study.

3.5.2 Inclusion criteria

Participants were eligible to be recruited to the study if they:

- Had undertaken HD in a community based satellite unit on a permanent basis for more than four weeks.
- Spoke English as a first language.
- Were at least 18 years of age.

⁶ A box that people undertaking haemodialysis use to store personal non-valuable items personally utilised during their dialysis session such as a blanket. The box is also used as a 'letter box' for patient correspondence.

3.5.3 Exclusion criteria

Participants who had impaired mental capacity, identified by concurrent diagnoses were excluded from the study.

Out of a total of 70 people receiving HD in the facility, 11 potential participants were excluded. Five because they did not speak fluent English; two due to diagnosed cognitive impairment; a further four participants were excluded because they had been on HD for less than four weeks. Consequently a total of 59 people met the inclusion criteria at the time of recruitment.

3.5.4 Participant recruitment

Participants were recruited using a purposive sampling technique. Purposive sampling enables the researcher to intentionally recruit participants to study the phenomenon in question (Creswell, 2009). This method was appropriate as the study required participants to experience the phenomenon of fluid restriction, associated IDWG and HD in order to be able to describe its meaning for them. This sampling strategy assured the recruitment of participants who were able to articulate their experience in order for the researcher to develop themes, interpretations and meanings of the phenomenon of fluid restriction (Liamputtong & Ezzy, 2005).

A sequential recruitment strategy was utilised to purposively recruit participants. After the initial screen, an envelope containing an information letter (Appendix 4), consent form (Appendix 5) and a reply paid envelope was placed randomly into five patients' personal dialysis boxes by the nominated staff member (as per section 3.5.1). The information letter outlined the research project; asked patients to take the letter home, read it again and consider their interest in participating. It stated that if they were not interested in participating they should disregard it and that this would not adversely affect their treatment regimen in any way. Those who were interested were asked to sign the consent form and return it in the enclosed reply paid envelope. Once the signed consent form was received the researcher contacted the participant to arrange an interview at a time and place of their own choosing. Three participants consented within two weeks of the first 'round' of invitations to participate. The remaining two declined the opportunity to take part in the research. At this time the researcher

requested that the nominated staff member randomly distribute a second round of five envelopes into the eligible participant's dialysis boxes. Interviews commenced the following week, with four out of the five second round participants consenting to participate within four weeks.

Recruiting in small groups of five ensured controlled recruitment and avoided the ethical dilemma of recruiting more participants than required. Morse (2000) warned against using sample size calculators in qualitative research at face value. Instead she recommended that several criteria be considered including the nature of the subject matter, the study's scope and design and the quality of the data. Given that the study cohort was homogenous and that the research question, and hence the scope, of this study was very specific, an open estimation of five to ten participants was initially proposed in the ethics application. As suggested by Miles & Huberman (1994) and Creswell (2009), data collection and analysis occurred in tandem. Consequently the researcher was immersed in the data being generated and was able to identify when no new themes or information were forthcoming from the data. This concept, referred to as data saturation (Guest, Bunce, & Johnson, 2006), was identified after the seventh interview and consequently no further recruitment occurred. It should be noted that some, for example: (Morse, 1989, p. 44) argue that "new data may always be revealed" and consequently, the concept of data saturation is not plausible. This argument is acknowledged by the researcher, however the time constraints associated with the Master's program also influenced the decision to cease recruitment.

The quality of the data elicited from the interviews was rich and afforded an in-depth understanding of participants' experiences which supported Morse's (2000) assertion that fewer participants would be required if rich data were easily obtained from the interviews. Accordingly, the total number of participants was considered adequate given that the purpose of this study was to describe the experience of the participants rather than generalise the findings to a larger population (Babbie, 2007).

3.5.5 Data collection

Participants consented to participate in a semi-structured in- depth interview at a time and place of their choosing. This varied between participants. One participant chose to

be interviewed in her own home, another requested to be interviewed during dialysis treatment in a private room. The remaining participants chose to be interviewed in a private room at the community dialysis unit prior to commencing dialysis. The interviews (See Appendix 6 for interview schedule) of approximately one hour in duration were conducted by the researcher. Using a single interviewer maintained interview style and consistency over the duration of the interviews (Babbie, 2007). After each interview the student researcher met with his supervisors to debrief. The following demographic data were also collected: age, gender, years on RRT, previous home HD, education level attained, employment status, number of dependants and marital status. Each participant's monthly average IDWG was collected as well. This provided the researcher with data to determine how well participants managed their IDWG. Interviews were recorded and transcribed verbatim with the participants' consent. After transcription was complete, each participant was given a copy to review to verify the transcripts were a true and accurate record of the interview prior to commencing data analysis. The transcription was also verified by the researcher. All transcripts were confirmed as consistent with the interviews by participants and the researcher.

Questioning style consisted of a series of broad, open ended, exploratory questions as well as probing questions to further explore or clarify potential themes that emerged throughout the interview. Each interview commenced with the question *Please tell me what it is like to deal with fluid restrictions as part of your day to day life?* Participants were also invited to bring an artefact (eg: photograph, montage, or statue) to the interview that they felt would further assist them in describing their experience. If the participant brought an artefact to the interview, they were asked at an appropriate time during the interview *Please explain the meaning behind the item that you brought along today in terms of your experience with managing fluid gain?*

The decision to include the use of artefacts as a data collection method added meaning and depth to the process of understanding the participants' experience of living with fluid restriction. The use of artefacts enabled participants to discuss their experiences and to identify through the artefact what had meaning to them. Consequently, the artefact alone did not tell the story; the context was provided by the participants' story

of their experience. The use of artefacts afforded a descriptive medium for participants to provide retrospective reflection of their experience. This approach encouraged a more intuitive and creative method of describing and understanding experience, and reduced the reliance on the limited expression available through spoken language.

The use of artefacts as a data collection method enabled analysis to progress from the corporeal story to an abstract and more personal sense of the participants' experiences. The choice to use artefacts in this study was influenced by the participatory action research methodology, photovoice. Photovoice, grounded in critical education and feminist theory, uses photography to enhance the recording and reflection of a community's strength and concerns to enable critical dialogue and knowledge generation (Wang & Burris, 1997). Photovoice enables participants to photograph elements of their experience to define in picture what has meaning to them. These pictures are then used to provide a voice for the participants to enact social change. Participants in photovoice studies often come from marginalised and disaffected communities (Poudrier & Maclean, 2009). While this present study did not seek to enact social change, the use of images was thought appropriate in order to assist capturing an essence or fundamental characteristic of human experience that is not easily expressed in words. Additionally, any artefacts brought by participants could be used to help in sharing their story and consequently, enabling a more intuitive way of describing their personal experience of fluid restriction to HCPs.

People receiving HD are not marginalised per se, however the notion of power imbalances between patients and HCPs is well documented (Henderson, 2003). People receiving HD do not always follow 'prescribed' dietary and fluid restrictions. This perceived 'non-adherence' is often a source of stress for nurses (Dermody & Bennett, 2008). This stress contributes to conflict in therapeutic relationships and HCPs do not necessarily consider the social context (Russell, Daly, Hughes, & Hoog, 2003) or experience of patients who must endure the rigours of following complex therapeutic regimens. This experience is not generally understood nor viewed empathetically by HCPs due to their expectations of adherence with the therapeutic regimen (Polaschek, 2007).

Artefacts were also used in this study so that the findings could be presented in a manner that would assist health professionals to consider the meaning and experience of managing IDWG and how they interact with their patients. One of the underlying theoretical tenets of photography is that it 'documents what it shows' (Galasinska, 2003). Using artefacts to illustrate a participant's experience of fluid restriction did not merely index a location or object; it illustrated the existentials of lived time and space. Visual images are remembered, they have immense power to impart a narrative that informs, educates and persuades others (Lester, 2006).

3.5.6 Data analysis

Interviews were analysed using the four stage process described by Morse and Field (1996) namely, comprehending, synthesising, theorising and recontextualisation. The initial stage of analysis, comprehending, involved the preparation of data for analysis. This stage required the researcher to be immersed in the data through an iterative process of transcribing, reading, rereading, listening to the audio recordings, reflecting and categorising to familiarise himself with the stories of the participants. During the initial readings of the transcripts, remarks or notations were made in the margin of the transcripts. These notations highlighted recurring patterns of key descriptive words, phrases or ideas, in addition to emerging themes and connections with other transcripts. Excerpts from all participants' transcripts were then combined and assigned descriptive categories as they emerged from the data (Sandelowski, 2000). Morse and Field (1996) described comprehension as making sense of the data. Thorne (2008) further suggested that comprehension involves the researcher familiarising themselves with the research setting in addition to the participants' experience. Comprehension is achieved once sufficient data exists to develop a "complete, detailed, coherent and rich description" of the participants' experience (Morse & Field, 1996, p. 104). This preliminary stage was conducted independently by the researcher in conjunction with advice from the research supervisors who then met to discuss their findings before embarking on the second stage of data analysis.

The initial notations and marginal remarks within the transcripts supported the synthesising stage where both the researcher and supervisors sifted through the data to

reveal patterns in addition to shared and divergent experiences, management strategies and behaviours that characterised participants' experiences of fluid restriction. This process was undertaken manually using a large white board to review the findings and discuss variations in data interpretation. As patterns and relationships were extracted and conceptualised, themes began to emerge from the data.

The theorising stage occurred seamlessly from the synthesising stage and resulted in movements in abstraction, and themes and sub-themes from the data. The inter-relationships between themes and sub-themes were subjected to alternate explanations for their occurrence to either confirm or disconfirm their existence (Morse & Field, 1996). The emergent themes were then tested by identifying examples across interviews to ensure that they were well grounded and representative of all stories (Miles & Huberman, 1994; Thorne, 2008).

The emergent themes were then taken back to the participants in the form of a figure (see figure 4.1) along with a preliminary manuscript for verification of the results. This process of *member checking* assisted in maintaining the credibility (Lincoln & Guba, 1985) of the data analysis. Member checking enabled participants to confirm that the themes developed by the researcher conveyed the meaning of fluid restriction as experienced by the participants rather than from the perspective of the researcher (Creswell, 2009).

Recontextualisation, the final stage of analysis brought the preceding three analytical stages together to present the extant findings in Chapter 4 of this thesis. The process of recontextualisation affords the possibility for the emergent themes or theory to be generalised or recontextualised into other settings (Morse & Field, 1996). Consequently, the newly generated knowledge is able to be positioned in relationship to the extant literature with a resultant appreciation of the implications and application of the research findings to real world practice (Thorne, 2008).

3.6 Ensuring the rigour and trustworthiness of the data

In the preceding three decades the quality of qualitative research and the concept of methodological rigour has been the subject of determined debate (Milne & Oberle, 2005). Rigour is a "way of demonstrating the legitimacy of the research process,

ultimately ensuring the empirical evidence is representative of reality” (McBrien, 2008, p. 1286). Establishing the trustworthiness of a qualitative study is integral to the notion of rigour (Lincoln & Guba, 1985; Shenton, 2004). Rolfe (2006) suggested that after years of debate the qualitative research community has yet to reach consensus or indeed determine whether it is necessary to agree on how quality in qualitative research should be measured. Adding to the complexity of this debate is the lack of clear guidelines as to what constitutes rigour in qualitative research (McBrien, 2008; Rolfe, 2006) with at least 26 separate strategies for verifying rigour in qualitative research discussed in the literature (Miles & Huberman, 1994). Three positions are dominant in the literature, 1) qualitative research should be evaluated according to quantitative criteria; 2) alternative evaluation frameworks should be developed for qualitative research and; 3) that each qualitative study should be assessed individually (Long & Johnson, 2000; Rolfe, 2006). In addition to the variety of evaluation frameworks argued by methodological experts are the myriad of terms, and their associated definitions, to describe what constitutes rigour in qualitative research. The lack of consensus stems from the origins of rigour in quantitative research methods which is classically illustrated using the concepts of validity and reliability (Seale, 1999).

Some qualitative researchers have distanced themselves from positivist terminology and pursued alternative terminology and methods to establish the trustworthiness of a study (Miles & Huberman, 1994). Consequently, authors have created alternative criteria that have been described as analogues of validity and reliability (Ryan-Nicholls & Will, 2009). Confusion occurs when positivist variants of validity and reliability are used in qualitative research. Notions of validity and reliability criteria in quantitative research are incongruent when applied to naturalistic inquiry (Shenton, 2004). Qualitative researchers, therefore, are beginning to use terms that are more congruent with naturalistic inquiry.

The criteria for rigour for the purpose of this thesis was the trustworthiness criterion espoused by Lincoln and Guba (1985) and later Letts, et al., (2007). Due to the myriad of orientations towards validity and reliability and the resulting complexity of the debate surrounding rigour this thesis adopts a realist position (Porter, 2007). This position assumes that truth is a socially constructed concept and reconciles that while

multiple descriptions of reality exist, multiple paradoxical or conflicting descriptions cannot (Sandelowski & Barroso, 2007). For the purpose of this thesis, the trustworthiness of the research is demonstrated through reference to credibility, confirmability, dependability and transferability (Letts, et al., 2007; Lincoln & Guba, 1985; Miles & Huberman, 1994; Shenton, 2004). Consequently, while the researcher still chose what to describe in this qualitative descriptive study, the description must also meet the criteria of credibility, dependability and confirmability.

3.6.1 Credibility

Establishing credibility is an essential step towards demonstrating the trustworthiness of any qualitative study (Letts, et al., 2007; Lincoln & Guba, 1985). Due to the epistemological view that multiple realities exist in human experience, it is vital that the researcher comprehensively demonstrates that they have provided an accurate portrayal of the phenomenon being examined (Morse & Field, 1996). The questions posed here are: Do the findings accurately report the phenomenon being studied? Are they authentic? Are they credible to the participants and to the reader? (Miles & Huberman, 1994)

The reporting and consequent credibility of the phenomenon being studied extends to the experience of the researcher (Angen, 2000; Patton, 1999). This includes the degree of expertise in data collection methods (Patton, 1999; Tuckett, 2005). The student researcher in this study has:

- Fifteen years' experience in interviewing and assessing patients in acute, chronic and rehabilitation hospital and community settings.
- Facilitated tutorial groups at both undergraduate and postgraduate levels.
- Read extensively on qualitative interview methods and undertaken courses in mentorship and clinical supervision which included training in questioning and interviewing techniques.

In addition, the student researcher debriefed after each interview with his research supervisors who were experienced in the area of qualitative interviewing.

The authenticity and hence credibility of the data was further supported during the process of transcribing the interviews. All interviews were recorded and transcribed verbatim by a qualified transcriber. The credibility and dependability of the data was supported through the researcher auditing the transcripts against the recordings (Tuckett, 2005). The transcripts were then reviewed prior to the commencement of data analysis by each participant to validate that they were a true and accurate representation of the interview that had taken place.

Further steps taken in this present study to ensure credibility and establish its trustworthiness were:

- The participants were purposively recruited by a person who was independent to the research study.
- The interview process was consistent for all participants and represented best practice with interview technique (Roulston, deMarrais, & Lewis, 2003). This afforded all participants the opportunity to share their experiences equally.
- The data analysis was independently confirmed by experienced qualitative researchers.
- Member checking was used to verify the credibility of the findings with the participants of the study (Lincoln & Guba, 1985; Sandelowski & Barroso, 2007).
- The study design was presented and defended in front of a panel of three qualitative research experts through the confirmation process required by the student's tertiary institution (Long & Johnson, 2000).
- Various elements of the research process and findings have been presented at national and international conferences. In addition the findings of this research have been published in a peer reviewed publication, see Sinclair and Parker (2009).

3.6.2 Dependability

The criterion of dependability relates to the stability (Lincoln & Guba, 1985) or consistency (Miles & Huberman, 1994) of the data over the period of the study (Ryan-Nicholls & Will, 2009). In order for this to occur, the design of the study needs to be

consistent throughout the project with a clear decision trail articulated to enable auditing of the process (Letts, et al., 2007). According to Morse and Field (2006), the consistency, or dependability, of a study questions whether the findings could be replicated using similar participants or context. Dependability is established with the comprehensive reporting of the research process whereby a clear audit trail is available for the reader and/or other researchers to follow if they choose to replicate the study. For these reasons dependability is sometimes used interchangeably with the term auditability (Ryan-Nicholls & Will, 2009). Dependability is similar to the concept of replicability in quantitative research (Lincoln & Guba, 1985). However, experience is a subjective and dynamic concept whereby any given phenomenon being studied constantly evolves and develops new meaning by those who experience it. Consequently the positivist assumption which suggests that if a study was replicated under the same conditions similar results would be generated is untenable in the qualitative context (Shenton, 2004). This study met the criteria of dependability by employing the following strategies:

- The research design and processes of this study were clearly outlined in sections 3.5 of this chapter, including a comprehensive explanation of the data collection process in section 3.5.5.
- The research design and methods are clearly outlined providing a clear audit trail of the research processes undertaken (Sandelowski & Barroso, 2007).

3.6.3 Confirmability

Confirmability relates to the factual accuracy of the researcher's account and consequent freedom from bias in the research process and subsequent findings (Morse & Field, 1996). The criterion of confirmability considers the comparative neutrality of the researcher and the processes that are established to ensure the findings of the study emerge from participants' experience rather than the bias and influence of the researcher (Miles & Huberman, 1994; Shenton, 2004). Where credibility relates to the legitimate description of the phenomenon, confirmability questions if the researcher has accurately translated or interpreted what the words or themes *mean* to the participants involved in the research. More specifically, has the researcher

described/interpreted the expressed phenomenon from the participants' perspective rather than being biased by their own ideology or assumptions (Maxwell, 1992)?

In order to establish confirmability the researcher must provide sufficient detail to illustrate that the findings of the research are grounded in the data through the use of excerpts from interviews. Steps taken to ensure confirmability in the present study were:

- Figure 4-1 was provided to participants to verify accuracy in emergent themes and consistency with participant experiences.
- The findings are grounded in the data with multiple examples provided to demonstrate thematic origins. The additional use of artefacts brought by participants further support the legitimate description of the phenomenon.
- A comprehensive account of the study methods and procedures, including data analysis are provided in this chapter thus providing an audit trail (Koch, 2006; Lincoln & Guba, 1985; Ryan-Nicholls & Will, 2009).

3.6.4 Transferability

Shenton (2004, p. 63) defines transferability as the ability of the researcher to

...provide sufficient detail of the context of the fieldwork for a reader to be able to decide whether the prevailing environment is similar to another situation with which he or she is familiar and whether the findings can justifiably be applied to the other setting.

The notion of transferability, the application of a study's findings, beyond the context of the cohorts studied, has been the subject of vigorous debate between authors in qualitative research (Lewis & Ritchie, 2003). Guba and Lincoln (1989, p. 241) suggest that the "burden of proof for claimed transferability" is on the reader not the researcher. If the reader is able to identify that the context of the study is congruent to that of their own setting then the findings may be transferable (Lincoln & Guba, 1985). However, the researcher must present a detailed description of the cohort studied, the setting and the research processes involved to afford the reader the opportunity to determine if this is the case (Letts, et al., 2007; Shenton, 2004).

Factors within this study that would assist the reader in determining the criteria of transferability include:

- The provision of a rich description of the context and process in which the study was undertaken (Lincoln & Guba, 1985; Miles & Huberman, 1994).
- A comprehensive account of the recruitment setting and cohort is discussed in addition to the data collection methods outlined and the time period in which the data were collected (Shenton, 2004).
- The findings are grounded and supported by the extant literature and discussed in Chapter 5 of this thesis.

3.7 Conclusion

This chapter has described the research setting in which this study was conducted, the sampling frame and inclusion and exclusion criteria for participants. A detailed description of the research design was presented in addition to a number of verification strategies that were undertaken to ensure the trustworthiness of the findings of this study. This comprehensive description provides an audit trail that will enable the reader to determine the integrity and authenticity of the study's findings.

According to Sandelowski (2000, p. 338), "The outcome of qualitative descriptive studies is a straight descriptive summary of the informational contents of data organised in a way that best fits the data". The following chapter will introduce the participants from this study and present the findings through the description of their experience of living with fluid restrictions.

Chapter 4 Findings

[It] was a struggle in the beginning. I felt that I was losing something else. I have experienced dialysis as a time of letting go and having to cope with the feeling of loss. One of those losses was that my normal function was decreasing and I wasn't sure how I'd be when it went all together.

- Grace

4.1 Introducing the participants

Seven participants, six women and one man, consented to participate in the study. Their age ranged from 39-82 years. Their average length of time on HD was 2 ½ years (range: ten months to six years). Two patients had previously received kidney transplants which had failed. All participants and family members have been assigned pseudonyms.

Irene was a seventy two year old woman who had been on HD for a total of two years and nine months at the time of the interview. Her average IDWG for the preceding month was 2.1kg. She was a widow with no dependants and lived with her son and granddaughter. Irene appeared shy and reserved and had a very flat affect throughout the interview. She found it difficult to express her experience of living with fluid restrictions. The interview was characterised by long pauses after questions and despite asking open ended questions and using probing questions, Irene responded with short one sentence answers. The interview lasted for fifteen minutes and was the shortest of all interviews after it was apparent that Irene was finding it difficult to share her experiences.

Tom was a vibrant and energetic eighty two year old widower who had been on HD for three years at the time of the interview. Tom's average IDWG for the preceding month was 2.0kg. He was a retired tradesman who lived on his own. He was meticulous with his appearance and very methodical in the way he went about things in his day to day life.

Lee was a sixty nine year old retired widow who chose to be interviewed while she was undertaking HD. Her average IDWG for the preceding month was 0.8kg. The interview took place in a single room away from the other patients in the unit. She had no dependants and lived on her own. Lee had been on HD for eighteen months and had a self-reported 'addictive personality'. She was seeing a psychologist as part of treatment for depression and a history of suicidal ideation. Lee had recently become a grandmother again and found this to be a joyous time of life despite the contradictions of the issues she personally struggled with, particularly with her physical and mental health.

Grace was an eighty year old spinster and had been on HD for twenty seven months and self-identified that she had come to terms with living with fluid restrictions. This was very much evident with her average IDWG for the preceding month being the smallest of all participants at 0.15kg. Her background was in education and she had once been heavily involved in her local church. Her strong faith was evident throughout the interview and she found much of her strength in her local community. Grace lived alone and lamented the changes that her kidney disease had inflicted on her life. However she saw her situation as a challenge from her God to strengthen her character.

Becky at the age of thirty nine was the youngest of all the participants in this study. Despite this she was the longest dialysis survivor of all the participants. Her average IDWG for the preceding month was 0.5kg. Becky was quiet and reserved and had been on RRT since she was eighteen years old. She initially commenced on HD then received a kidney transplant which she had for nineteen years. After the failure of the graft she recommenced HD and had been maintained on HD for six years at the time of the interview. Becky's interview was held in her home at her request. The interview was interrupted several times, twice by a tradesman, and three times by her mother who sat in on the interview at Becky's request. Becky was also very flat in affect and had a history of depression.

Tracy was a fifty seven year old woman who had been on HD for two and a half years after living with a kidney transplant for twenty eight years. Tracy's average IDWG for

the preceding month was 1.2kg. She was a retired teacher and was quite at ease with sharing her experiences. The interview occurred before her HD session at her request in a private office in the dialysis unit in which she was a patient. She specifically asked to do the interview 'pre-run' because she felt it was important that she was wide awake so she could clearly articulate her feelings. Living with chronic xerostomia⁷ she was particularly passionate about sharing her experience.

Leonie was a fifty five year old woman who was currently unemployed as a direct result of her illness. Leonie's average IDWG for the preceding month was 1.8kg. She had been on HD for ten months at the time of interview and was waiting to commence PD as this was her preferred method of RRT⁸. Leonie had been on RRT for the shortest amount of time out of all participants and was considered a 'late presenter'. Due to the largely silent nature of CKD it is not uncommon for a person to present to a general practitioner complaining of feeling increasingly unwell only to find themselves undertaking HD by the end of the week. This sudden upheaval does not give the person sufficient time to psychologically prepare for the rigours of treatment for ESKD. The fact that Leonie was a late presenter reflected in some of her comments during her interview and more interestingly some of what was not said in her interview. Of particular note was that she did not talk about struggling with fluid restriction per se. This may have been related to the fact she still retained a degree of residual renal function. However, early in the interview Leonie identified that she had never drunk huge quantities of fluids before she developed ESKD. Despite this she still had times that she found "exceptionally difficult".

4.2 Introduction: The nature of living with fluid restrictions, a summary of themes

The development of ESKD and the need to restrict fluid intake marked the beginning of a journey that required participants to confront losing the ability to drink freely, something once taken for granted. Participants in this study described the immense difficulty associated with being thirsty and never being able to truly quench their

⁷ Chronic dry mouth due to lack of saliva

⁸ Treatment to replace the functions of the kidney (i.e: peritoneal dialysis, haemodialysis and kidney transplant)

thirst. Living with fluid restrictions disrupted their core identity and permeated throughout their lives, particularly in the areas of socialisation and losing the freedom to drink freely.

Data analysis revealed that the essential elements of living with fluid restrictions for people undertaking HD in the community setting were *magnitude of loss, constant struggle and accepting*. Participants experienced each of these elements in varying degrees and at varying stages of their illness trajectory. Eight associated sub-themes (see Figure 4-1) were also identified which were found to be inextricably linked to each other.

A sense of loss was a consistent feature of participants' stories, particularly in their reflections comparing their current life with life before commencing HD. The experience of loss was pervasive and impacted participants normal way of living. Facing the magnitude of this reality was experienced as a constant and torturous struggle regardless of whether participants, from a medical perspective, successfully managed their fluid restrictions or not. Despite the gravity and magnitude associated with this loss, participants revealed that the *consequences* of ignoring fluid restrictions were, in some cases, too great to risk. Participants identified that they needed to assume responsibility for their own health. Consequently they talked about the *surveillance* and *maintenance* strategies they used to manage living with fluid restrictions. Not all participants were able to comprehensively self-manage or adhere to their prescribed fluid restrictions. On occasions when participants did not adhere to restrictions they described feelings of guilt. Social networks played a dual role in assisting participants to cope or manage as they provided a reason for them to continue to live, while simultaneously providing the *support* for them to be able to continue living.

In time, participants described progressing to a point where they no longer resented their situation but were able to adjust and accept it to some extent. The transition to this point facilitated an awareness of the physical *consequences* of excessive IDWG in addition to various *support* mechanisms including those provided by family, friends and HCPs. Over time each participant came to the realisation that life, in their new and

changed circumstance, was still worth living. Participants who reported stringently and consistently managing their IDWG expressed that they had much to live for in spite of their loss.

One participant's description captured the story of participants as a whole. Grace described her experience with fluid restriction using the analogy of being tied up and consequently losing her freedom to be able to do whatever she wanted. However over time, through the *constant struggle*, the relationship with what was once considered normal was slowly integrated and accepted into a new sense of self, whereby the ropes were loosened. This process was mediated through various strategies and goals which Grace and other participants used as they struggled towards adapting to and accepting a new way of living.

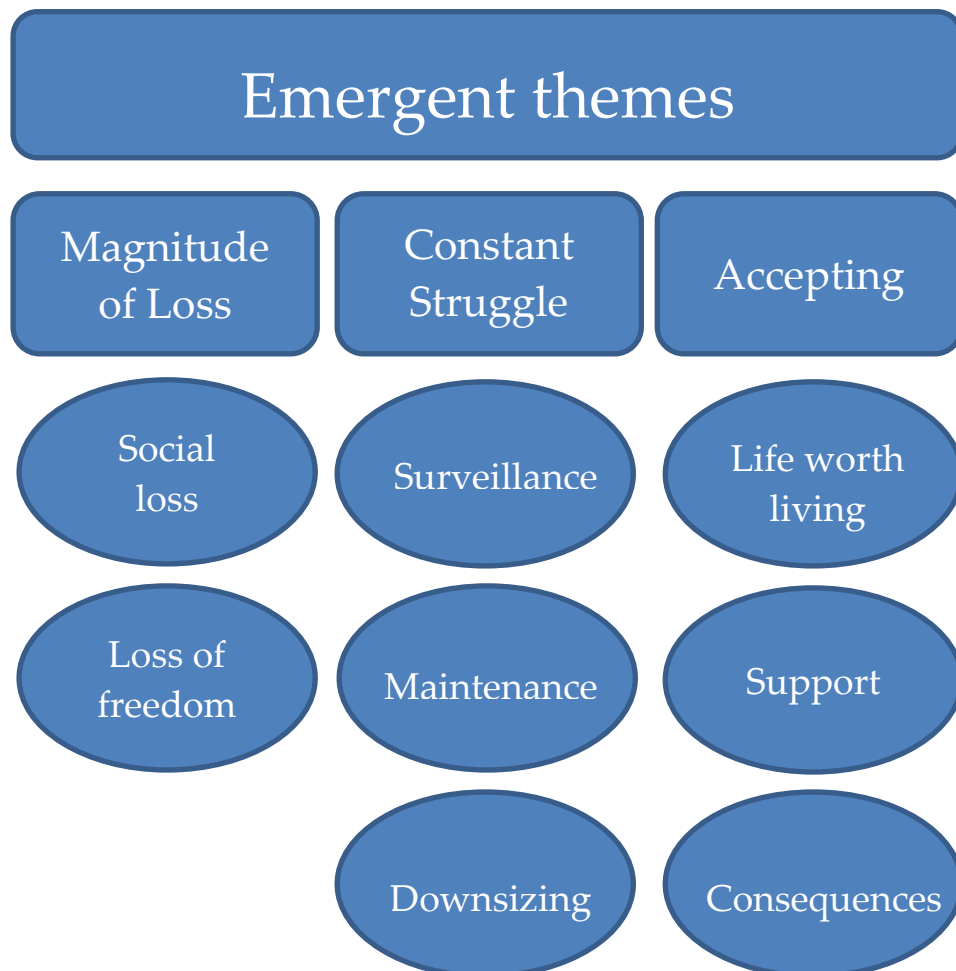


Figure 4-1: Summary of results with three superordinate themes and eight sub-themes

4.3 Magnitude of loss

...that defines it more than anything, the things that you can't do...

- Lee

Loss was a central and significant theme for all the participants in this study. Whilst the specific nature of loss varied across participants, all were overwhelmed by the scale of the loss and the enduring impact fluid restrictions had on their lives. The theme *magnitude of loss* describes the enormous impact of losing the ability to drink freely. The impact was inescapable and infiltrated many aspects of their lives. Of particular significance to participants were their loss of the freedom to drink as they once could and the influence of this during social occasions.

Participants consistently described an overall experience of loss of kidney function. The impact of the treatment for this functional loss, including fluid restriction, amplified the extent to which participants experienced loss. *Social loss* and the *loss of freedom* were essential components that emerged from participants' stories that described the magnitude of their loss. Reminders and the influence of fluid restrictions were omnipresent and contributed to the magnitude and significance of their loss.

Participants were constantly reminded of what had been taken from them. These reminders came in various forms including beverage advertisements on television or in magazines or having to decline the offer of a drink in social situations. These reminders challenged their will power to adhere to fluid restriction targets set by physicians. This was made all the more difficult given that the consumption of fluid was once taken for granted; touted as being 'good for you' and a natural inclusion at social events or activities and generally associated with pleasure.

Such reminders also reinforced the challenges that fluid restrictions posed to participants' sense of self. Leonie said: *I hate being sick and you know, there's lots of days that I don't feel well, I'm just not my normal self. My fluid restriction is making me feel different to everybody else.* Irene viewed this similarly saying, *well I'd like to be like everyone else and have [drink] what I wanted, but you can't.*

Grace too, identified that in the early days of her dialysis treatment she did not feel *normal*. She attributed this, in part, to *not going to the toilet very much*. In time she was

able to reframe her view of losing urine output to recognise inherently that she retained her identity but was no longer *a well lady*.

Before participants developed ESKD, fluid could be consumed without any thought of *consequences*; it was considered normal, and an activity that relieved their thirst which was required to remain healthy and functional. The ability to drink was also associated with freedom, pleasure and social occasions.

When you're in the company of people, like if we go out socially, everybody around you is drinking wine or whatever, it doesn't really make much difference but they're all sitting there and you unfortunately can't do that.

- Leonie

Tracy described the sense of frustration she experienced with no longer being able to drink freely and its impact on her social life.

I suppose frustration more than anything because, because I want to drink and I know I can't. So it's frustrating. Socially limiting ... I had dinner last night and I've got lunch tomorrow and I had morning tea on Monday. I thought this is going to be a hard week ... If I have a week where I don't have anything like that I think well its gunna [sic] be a good week. Not good because I'm not going out. But, good because my fluid will be easier to control. Because social things are difficult.

- Tracy

Tracy used an analogy of going shopping to describe what having to restrict fluid intake was like for her, and how ESKD had removed her choice to drink just because she wanted to. Being restricted in what she could drink had reduced a task associated with free choice to one that must be considered with caution at all times:

I like to be able to do the things that I like to do. Like go shopping. I want to feel that I can do it physically. Not that I like shopping but, if I want to I can do it. If I want to go out for the day I can do it. And if you're unwell it makes things very difficult. And I think that's normal, normal healthy people do that. You know they think I might go shopping so they just go they don't stop to think can I cope with this? You know am I gunna [sic] be able to manage it?

- Tracy

While drinking from a physical perspective is still possible, participants described how ESKD took away their ability to freely drink without first having to think “can I cope with this?”

The experience of loss elicited a range of emotions from participants. In time, some expressed a conscious choice to accept the loss. Others expressed emotions such as anger, fear, and resentment particularly in the early stages of their illness.

I think I was little bit angry that I had gone into this state and when I say a little bit angry I'm modifying it I know, but it wasn't a real unmanageable anger or, but I suppose it was more a why is this happening? Why do I have to walk this path in my latter years?

- Grace

Grace described how she associated consuming fluids with specific daily routines and as a consequence identified that she did not experience excessive thirst outside these times as did other participants like Tracy. However, when faced with events or activities that she used to associate with fluid consumption the magnitude of Grace's loss emerged: *I miss those ones [drinks] that I'm having usually at those times, I miss it very much, you know, that's a big deprivation.* Quite often these moments' related to social occasions and it was at these times that participants described their biggest temptation and consequently, their biggest challenge.

The participants' experience of loss moved beyond that of physical function to encroach on the domains of socialisation and the freedom to do what was once considered normal. Together, the *loss of freedom* and the inability to engage in social activities required lifestyle changes. This was particularly difficult for Leonie: *I suppose all of that [adjusting to life on dialysis] was hard to deal with, but then the diet and the fluid intake was also very difficult to deal with too, so yeah it was a whole change of lifestyle.*

Participants described the difficulties associated with adjusting their lifestyle habits to living with fluid restrictions. Social occasions proved most difficult to endure, the loss of which will be discussed in the next section.

4.3.1 Social loss

Participants reported that while loss was a consequence of the management of ESKD, they were constantly reminded of this loss which had to be managed or ‘dealt with’ lest they suffer the short and long term *consequences* of not implementing effective fluid maintenance strategies. These included, but were not restricted to intradialytic⁹ complications such as cramping, hypotension, vomiting, unconsciousness or long term *consequences* such as heart failure. Social occasions proved most challenging due to the association of consuming fluids within social contexts. The sub-theme of *social loss* demonstrated the extent to which living with fluid restrictions affected participants’ lives. It highlighted the inescapable nature of not being able to drink as they were once able to, and how fluid consumption was reflexively embodied in the context of social interaction. Participants described social occasions as being the most difficult times to endure and some expressed the preference to avoid them all together in order to avoid the difficulty associated with them. This further compounded the sense of loss, as loss was no longer the loss of the ability to consume fluids but the loss of shared social connections that come with these occasions.

Due to the difficulty associated with managing their fluid restrictions, participants often chose to avoid situations where they would be tempted to drink beyond their allocated fluid allowances. Grace, for example, was once heavily involved in church activities and had a very active social life. The idea of sitting through community meetings and social functions, watching others pouring cup after cup of tea became too difficult for her and resulted in her choosing a self-imposed restriction to forgo these events. In this case, fluid was a conduit which connected Grace with her community.

I really felt I couldn't sit there for an hour, an hour and a half, two hours and go through all this. It was too much for me but what was I depriving myself of? I was depriving myself of the social aspect of those meetings and being with my community. I miss that very much. I felt that that was the big thing that was out of my life and it put me outside the sort of the normal running of the community and what was going

⁹ Complications during haemodialysis from the Latin *intra* meaning within or during

on. I used to get papers to tell me what the meeting was about but that's not the same. The social aspect was very important to me.

- Grace

The deliberate choice of self-deprivation arose because of the struggle associated with the challenges of maintaining prescribed fluid restrictions during social events. These challenges far outweighed any pleasure derived from being there. The sense of loss was further compounded as Grace became disconnected from the social relationships that she valued. It was apparent that participants on the whole, were able to judge their ability to successfully self-manage their restrictions and in some cases would rather choose to avoid social situations rather than succumb to temptation. The avoidance of social occasions contributed to the *magnitude of loss* experienced by participants.

Social occasions were no longer seen by participants as just about catching up and spending time with friends. Watching others take orders for 'the next round', going to the bar to get drinks and watching them being consumed prompted reactions not normally associated with these occasions. Participants recalled feeling upset and angry and overwhelmingly identified that, in the context of fluids, social occasions were 'hard' to face because they were continually reminded of what they had lost. Consequently, these occasions posed a *constant struggle* and provoked a continuous battle with self between the feeling of wanting another drink and knowing that they shouldn't. Becky, who at 39 years of age was the youngest of all participants, spoke of an active social life despite the challenges and emotions it posed:

I get upset because like, we go out a lot and have drinks and stuff like that and everybody would be going to get drinks and all that and you think 'oh gee, I'd love a drink' and you just sit back and you sit on this one drink for however long you're there, yeah. I find that hard.

- Becky

Leonie similarly described the impact of *social loss*.

It's like when we go out with our friends on their boat sometimes and everybody is just socially drinking and I sit there and I can't do that and it's warm and it's lovely, and you feel like doing it, but you can't.

-Leonie

Lee described her experience of loss using a magazine picture (Artefact 4-1) and two old Polaroids, one, a distinctly Australian landmark (Artefact 4-2), the other of her sitting in front of the family caravan enjoying her 'happy hour' prior to her developing ESKD (Artefact 4-3). While Artefact 4-1 demonstrated 'happy times' associated with social occasions this was not the case for Lee. It represented times that were now lost in the face of having to manage fluid restrictions.



Artefact 4-1: Happy times

Lee was a self-confessed 'tea drinker' and much like Grace made a conscious decision to avoid social situations where she would be tempted to drink. Lee also spoke of her *addictive personality* and *weak will* and how important it was for her to implement strategies to overcome these internal challenges. It was Lee's addiction to Bex powders that led to the Analgesic Nephropathy that caused her ESKD. She battled with the consequences she described as having brought upon herself. *I'm here [on dialysis] because I was addicted to Bex powders and that's why I'm on dialysis, it's all self-inflicted* - Lee

The impact of fluid restrictions made it particularly difficult for participants to engage in social occasions. For some, avoiding social events was an acceptable alternative because the temptation to drink and the difficulty associated with the constant reminders of what they could no longer have far exceeded the joys associated with these occasions. As a result, participants described how they lost a degree of freedom in their lives as a consequence of having to manage their fluid restrictions. This loss of freedom will be discussed in the following section.

4.3.2 Loss of freedom

All participants identified a relationship between the loss of their kidney function and its impact on their ability to do what was once taken for granted. Consequently fluid restrictions encroached on participants' sense of freedom. The loss of freedom was described from two perspectives. Firstly, that the freedom to drink whenever they wanted to, was taken away from them through the necessity to adhere to fluid restrictions. Secondly, that in order to cope with fluid restrictions, some participants made a conscious choice to avoid events or activities where they would be tempted to drink beyond their allocated amount. This decision impacted participants' lifestyle choices and again infringed on a freedom of choice that was once taken for granted.

Lee's description of Ayers rock and the story of her annual family holiday to the Northern Territory (see Artefacts 4-2 and 4-3) revealed her meaning of loss and highlighted the magnitude to which fluid restrictions had impacted her life. While ultimately it was the dialysis regimen which prevented Lee from going on family holidays with friends, it was the loss of the ability to do things that were once taken for granted that constituted the significance of her loss.

Ayres Rock it's nine kilometres around, we walked and I remember how thirsty we were...what you'd done socially before fluid restriction you can't do now... you know and our happy hour, well we really looked forward to our happy hour when we pulled into a caravan park and that defines it more than anything, the things that you can't do, those days are over, those social days have gone.



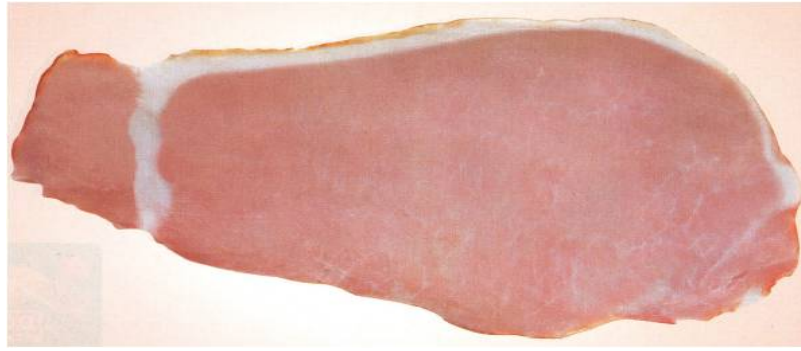
Artefact 4-2: *'I remember how thirsty we were'*



Artefact 4-3: *'Happy hour'*

Lee described how she often read magazines to help pass the time while undertaking HD. For Lee, images within these magazines served as a constant reminder of her disease and represented certain activities or pleasures that she had to curtail or avoid. Lee brought a variety of pictures to the interview that she had cut out of a magazine while she was on dialysis. Lee's use of images and narrative described her loss of things she could not do anymore. They described her loss of freedom. Fluid restriction meant not only curtailing fluid consumption but also foregoing certain types of food with high sodium content that would make her thirsty. So for Lee, images such as Artefacts 4-4, 4-5, and 4-6 represented as a constant reminder of what she had lost:

[They represent] the things I can't do anymore. These were just little ones you know, the salt (See Artefact 4-4), I can't have salt and chips and juice. Yeah and of course these were just out of a magazine of the things that we shouldn't have to make us thirsty.



Artefact 4-4: *The salt*



Artefact 4-5: *These were 'just' out of a magazine*



Artefact 4-6: *The things I can't do anymore*

The notion that these images were '*just out of a magazine*' highlighted that the images alone were not representative of the extent of what the reality was for Lee or indeed, other participants. Participants expressed how they were faced with constant reminders, all day, every day; pouring a cup of tea, tinkling ice, a glass of water to take medication, feeling thirsty, summer, having a shower, having a drink with friends, or

going to a shop and seeing a wall of refrigerators containing assorted beverages. While they had not lost the capacity to drink physically, they had lost the ability to drink freely. The mere physical act of drinking triggered thought processes to consider how much they were drinking and the potential consequences associated with excess fluid consumption. Fluid restrictions were seen to have taken away a freedom that was once considered normal. Social situations compounded this feeling for Leonie. Leonie's experience highlighted the interrelatedness of *social loss* and the *loss of freedom*:

I feel cross being where I am at, because I can't live my normal life like I used to. I can't just drink whatever I want to drink whenever I want to drink it ... we weren't massively social, but we did sort of go out quite a bit and that sort of thing... you just know that you can't do that like you used to...It's not only how much, it's what you can have. I really loved soups and casseroles and wet food, what I would call wet food... I enjoy wet food and I can't have wet food.

- Leonie

The act of drinking was not a simple decision anymore. This was difficult and left participants feeling depressed and disheartened. Anecdotally, participants described how they were not alone in feeling this way and that there were *a lot of people* on HD who felt similarly. Leonie described why fluid restrictions had impacted her ability to undertake things freely and how the loss of this left her feeling *a bit down*.

Sometimes you feel a bit down and I'm sure there are a lot of people [on dialysis] that feel like that. Because of the effect it's had on my lifestyle. Because I can't do what I used to do. I can't, I don't feel like I can plan all the things that I used to think that we would do.

- Leonie

The previously natural phenomenon of drinking freely was now restricted in order to extend life, supplement treatment and minimise treatment associated complications. Fluid restrictions were a burden that participants did not want to endure but knew they would eventually have to choose between fighting or accepting them. Throughout the interview Grace frequently used words such as tied up, bound, restricted, and tied

with a rope to illustrate her experience of living with fluid restriction. All of these words represented the lack of freedom fluid restrictions now imposed and the irony that the very word 'restriction' was an antonym of freedom. Grace used artefact 4-7 to describe the curtailing of her freedom as a result of living with fluid restrictions.

I felt as if I was tied up. You know I wasn't as free and I was being brought in and tied up with the restrictions that I had to undergo. I think it was sort of the loss of freedom and I think during that early stage of my dialysis I would have been what you might classify as 'tense'. I lost some of my buoyancy and I tie all that up with freedom and perhaps in the early stages I didn't want to talk about it very much and as far as the 'tied up' business goes it was sort of, it goes with the word 'restricted'. I was restricted and symbolically that would have been I was tied with a rope.

- Grace



Artefact 4-7: 'Restricted'

For Grace, artefact 4-7 invoked a powerful sense of being tied up or bound against her will. The image represented her *loss of freedom* and the *constant struggle* she faced as she came to terms with managing her fluid consumption behaviours.

Participants were once able to drink for pleasure, enjoyment or because they were thirsty. ESKD and its associated fluid restrictions now required participants to enact a conscious decision making process to determine whether their fluid consumption

behaviours to that point in time permitted them to consume further fluid. The freedom to drink freely, as and when they wished, was no longer a possibility.

Participants described how their experience of loss was most intense in the early days of starting HD. A heightened sense of apprehension existed in knowing that in time, the loss of urine output would be complete, they would no longer have any residual renal function and they would need to further restrict their fluid consumption which would further compound the *constant struggle* they experienced.

4.4 Constant struggle

I can't get away from it, I'm thinking about it all the time... It's a constant battle...

Tom

Regardless of participants description of thirst, they all identified that their experience with managing fluid restrictions, whether they successfully managed it or not, was a *constant struggle*. The theme *constant struggle* emerged from participants' description of the unnaturalness of restricting fluid consumption and how it contradicted the very nature of being. Human experience is unique and the theme of *constant struggle* was expressed in varying ways. Some participants highlighted the unnaturalness of their struggle and described how the very concept of fluid restrictions went against the natural drive to drink.

I enjoy the garden, so I often find myself out in the garden particularly on a nice day, nice being warm and sunny and if I'm out there for any length of time and you've been weeding and all that sort of thing, you'd tend to build up a perspiration and you feel really thirsty and you go back inside and you know that you can only have a small drink. You can't have a big drink which you feel like. You feel like a glass of water or whatever, but you can only have a little bit and that's when I think 'oh you know, this is really very hard', because yeah, you really, your body feels like it needs more than that and I don't know whether that's because it's used to over the 50 odd years it's used to drinking whatever it needs to drink at the time, or, and I'm sure that's what it is, it's just part of habit, but I also think that the body feels like it needs it too when

you've been out in the heat, you feel like you need to drink and I don't know how to eliminate that feeling.

- Leonie

The unnaturalness of having to deprive one's self of fluid was further compounded by the historical influence of numerous primary health messages throughout participants' lives which taught them the importance of drinking 'plenty' of water in order to promote health and support normal body function. Leonie similarly described this juxtaposition.

I suppose it's a feeling that you've done that always in your life. Everyone told you that drinking lots of water was really good for you and suddenly everybody's telling you you're not allowed to do that.

- Leonie

As a consequence, participants described having to fight nature and fighting nature was akin to fighting against oneself which took significant strength and energy. *It's really hard because you spend all of your time being dehydrated, your bodies trying to tell you to drink* (Tracy). For Tracy there was an added irony between the time when she was required to drink increased amounts of water to maintain her renal graft (transplant) to now, being on HD, where fluid is promoted as a harbinger of serious consequences.

It's a bit ironic that you know three years ago I was having to drink three litres of fluid a day and now I have to try to keep it to a minimum. I think to myself I really prefer the three litres, I managed that much better than I managed the restriction.

- Tracy

In the face of experiencing such a *constant struggle*, participants were faced with the reality of having to manage their fluid restrictions. Participants spoke of multiple occasions throughout the day where they were faced with making a decision on whether they should drink or not. During these times, participants identified coping strategies that enabled them to manage, with varying degrees of success, their fluid intake behaviours. The subthemes of *surveillance*, *maintenance* and *downsizing* emerged from the primary theme of *constant struggle*. The sub-themes were all inter-related and

served as approaches to combat the *constant struggle* they faced each day with fluid restrictions. *Surveillance* represented the monitoring behaviours of fluid consumption and body weight, whereas *maintenance* embodied strategies used to maintain fluid restriction targets. *Downsizing* was closely associated with *maintenance* but was clearly a separate strategy used by some participants to manage fluid intake.

Despite the implementation of strategies to reduce thirst and monitor fluid intake, the decision on whether to implement them and 'do the right thing' or ignore them and suffer the *consequences* during their next HD treatment was a *constant struggle* and became a continuous battle of will. *It's like fighting nature all the time because you want to drink all the time. You have to have a really strong will to do that* (Becky).

Metaphors using 'battle' terminology were used consistently by the majority of participants when explaining what it was like to go through each day living with fluid restrictions. The 'battle' was not physical; rather it was an existential struggle with the desires of self and the realities of living with fluid restriction. The 'battle' metaphor was reflected by a wide range of expressions including: *occasional win, it beats me, it's a constant battle, fighting nature* and *I was really fighting it*.

Tom highlighted the challenges he experienced using both past and present tense and often used battle metaphors to describe his experience. The nature of explaining his experience in this way highlighted how his personal journey was torn between times of coping and times when the struggle became too much.

I'm struggling and sometimes it's very disappointing as I said before ... [I ask myself] could I have tried harder, and I don't think I can, I think I'm at my maximum. I'm getting used to it and as I say, I have the occasional win, but it beats me more than I'd like it to.

- Tom

Each interview began with the question: "What is it like to deal with fluid restrictions as part of your day to day life?" "The majority of participants' immediate response was that living with fluid restrictions was *hard, very hard* (Irene); *Very trying, very trying* (Tom); *very hard* (Becky); *very, very hard when you've got to stick to 500mls* [fluid

restriction] *a day* (Lee); *It's really hard* (Tracy). For participants and particularly Tracy this amounted to frustration.

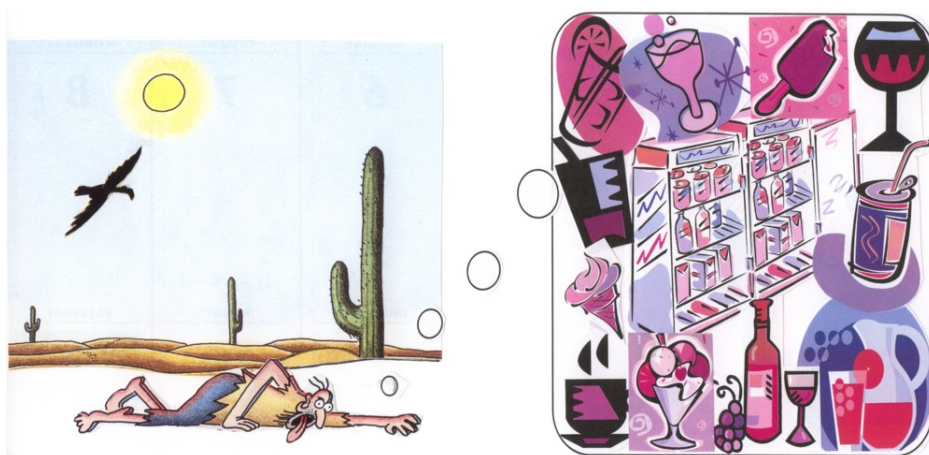
I spend all my life wanting to drink. I wake up in the morning and I'm dry and the first thing that you want to do is have a drink and um and that basically goes on until I go to bed at night. So it's like that. Frustrating! Um, for me frustration is having bottles of drink in the fridge and not be able to touch them it's like little kids seeing an ice cream, wanting it and not being able to have it. That kind of frustration.

- Tracy

Tracy designed a montage (see Artefact 4-8) to describe the paradox she experiences 'almost all the time':

I was thinking this guy, a man in the desert crawling along with his tongue hanging out. That's how I feel, almost all of the time... You know not only do I feel like that but I'm doing this fantasising about drinks. And if I go into a shop and see those big walls of fridges with drinks in it. It's really embarrassing I just sit there waiting to be served and I just look at it all and I think, you know, to me that's just like heaven. And um, that's the story of my obsession about fluids.

- Tracy



Artefact 4-8: *The man in the desert*

The narrative informing artefact 4-8 illustrates the struggle Tracy endured. The paradox of being continuously thirsty, yet even though she could physically drink she knew she should not. For Tracy, there was a struggle between wanting to drink to the point of obsession and knowing that *surveillance* and *maintenance* behaviours were required in order to maintain her wellbeing and minimise the consequences of excessive drinking during her HD sessions including hypotensive episodes, vomiting, cramping, and blackouts.

The notion of being preoccupied with wanting to drink was not unique to Tracy. Grace described the struggle she faced as she continuously monitored her fluid intake.

It's something that is continually on my mind about how much I'm having and some days I find it difficult not to have that extra glass. I find it difficult when I go out and I'm with company and they're drinking, well we usually have soft drinks or something and I will just have one and I'm inclined to want more.

- Grace

This struggle was reinforced each time a participant was reminded of the either fluid consumption (ie: drinking) or output (ie: urinating). Lee recalled a recent weekend away with her daughter to highlight the constant reminders of her loss and struggle. In particular, the impact of witnessing her daughter come back from the toilet.

I'm that conscious of fluid all the time and Melanie went to the toilet and when she came out I said, Oh God I wish that was me, that would have been two cups of tea, so it's there on my mind all the time, you know, I was only joking with her but you're conscious of it.

- Lee

This manifested itself as an inner battle with self, balancing fluid consumed for that day and bargaining for *just one teeny, weeny drink* (Tracy). On occasions the struggle was easy to overcome but on other occasions it became too great. Coping strategies, in these instances, in addition to the thoughts of potential physical consequences were put aside for the quenching of thirst and the gratification of one drink. Tracy

highlighted that for her, conceding to the *constant struggle* was almost an act of rebellion saying *bugger [sic] my dry weight*¹⁰.

Participants described feelings of culpability when the struggle became too much and they exceeded their fluid restriction target. The juxtaposition of the naturalness of drinking when hot and/or thirsty compared to the challenges of the 'new self' who had to consider fluid intake continuously, sometimes became too much. Lee described:

Some days like yesterday was very hard, I really felt the heat yesterday something shocking, I was drenched, the whole of my hair was like I'd had a shower with the heat... it's there [thirst] constantly...and the day[s] like yesterday, I thought I'd gone over and I couldn't help it. I feel really guilty, really guilty.

- Lee

With the feeling of guilt, some participants described their expected interactions with dialysis staff, if they arrived for dialysis having drunk more than their prescribed fluid restriction. On these occasions participants' resigned themselves to nursing staff speaking to them about exceeding the target. Lee was fully aware when she was in excess of her prescribed fluid restriction, yet still felt the need to apologise to the nursing staff.

I said I know I shouldn't have two but I'm going to have the second one, and I was ready to apologise to whoever was on [nurses on the shift] that I was naughty but it was a hot day too, it was a stinking hot day at the cemetery.

- Lee

Tom simultaneously described his struggle and his expectations that if he exceeded his target he deserved to be rebuked by staff.

I can't get away from it, I'm thinking about it all the time... It's a constant battle. I know that I've got to do it and I do my best but quite often my best is not good enough. When I get in here I sometimes hang my hand out for a whack.

- Tom

¹⁰ Dry weight: The body weight determined as if one's kidney were functioning normally. Dry weight is the target weight that people on dialysis should be at the completion of their 'dialysis session'

Participants described constant *longings* for fluid and the associated struggle with trying to curtail a natural desire to drink, a desire that was 'hardwired' into their body via a thirst mechanism that is as natural as the fight or flight response. Consequently, participants described fluid restrictions for what they were, *restricting*. The desire to drink controlled their lives, dominated their thoughts and confined their social activities. Grace described her early experiences with managing IDWG and the emergent symbolic theme of her struggle with unwanted restraint. '*I felt as if I was tied up. You know I wasn't as free and I was being brought in and tied up with the restrictions that I had to undergo.*'

Despite the *constant struggle* participants described, they all identified that regardless of the personal challenges fluid restrictions imposed on them, they were required to implement a range of strategies to ameliorate the struggle and attempt to engage in healthy fluid management behaviours, albeit sometimes unsuccessfully. Consequently the subthemes of *surveillance*, *maintenance* and *downsizing* emerged from the data. The first of these, *surveillance* will be discussed in the following section.

4.4.1 Surveillance

Participants described the use of strategies to monitor or measure fluid intake and output and their resultant IDWG. These *surveillance* practices were described by some as a necessity to be able to manage fluid restriction and by others as unthinkable as they would only further remind them of the *constant struggle* they had to face daily. *Surveillance* was described in varying degrees by all participants, however each participant had developed their own techniques that they were comfortable with, and suited the personal meaning of their illness and its treatment. Consequently, *surveillance* practices took several forms. They were simple and specific and included measuring the amount of fluid consumed and calculating the volume of fluid output through the use of scales or measuring jugs. *Surveillance* was not undertaken in a surreptitious manner; rather it was used as a strategy to monitor fluid restrictions and consequent fluctuations in dry weight.

Tracy, despite being on dialysis for two and a half years, described how her daily routine still included daily weights in order to manage her fluid intake for the day.

I weigh myself every morning and then that gives me an idea of what I have to do during the day. So I weigh myself with my dialysis clothes on so if I know that I'm gunna [sic] go over the 1.5litres [target IDWG] I cut back during that day where I can. If I think that I'm gunna [sic] be fine I can have my full cup of tea in the morning.

- Tracy

For Leonie, who at the time of interview had only been on HD for ten months, the physical measurement of fluid intake was not an option.

I can usually monitor what I drink and I don't measure at all. Some people always say, you know, 'you should measure what you drink', I don't do that, I think if I had to weigh and measure everything it would make it even more traumatic. That's why I don't do that, I find if I just try and control my own drinking habits, and I get quite used to that and by coming in here I know how much I'm putting on and so consequently I don't feel I need to measure, it balances itself out. I don't deny myself being able to drink. I think that doing that it's even more difficult so I try and just restrict rather than deny.

- Leonie

Leonie's experience of *surveillance* was a conscious thought rather than a physical action of measurement. Due to Leonie's short dialysis tenure she still experienced significant residual renal function which meant, when compared to other participants, her fluid restrictions were far less stringent. This may explain the difference in her experience. However it was evident that she was still coming to terms with the upheaval in her life as a result of being recently diagnosed with ESKD.

Time appeared to afford some participants the opportunity to modify *surveillance* behaviours as they became more familiar with their fluid input and output. Lee described:

I've got a little cup about 150mls at home, I'll use that little cup and I know how much I've had as I said, it's only here [the dialysis unit] that I have the full cup and then I used to measure all my output, I've still got the measuring jug in the toilet, but I've been doing it so long now that you know what you're putting out you know,

and I can say to myself, 'Oh that's a little cup of tea', but for eighteen months I measured everything I put out. I was pretty obsessive about it. But I'm not now, a nurse said to me once, because I grizzled about measuring everything, and she said 'you will eventually be able to guess it yourself', well I do now.

- Lee

Grace described a similar experience:

I'm going back to the early part of dialysis, I think it worried me because I'm fairly particular by nature. If I'm asked to do something I like to do it, I was measuring my fluid output at that stage and I was trying to keep to that. I found it very restrictive I was pretty particular about measuring the urine for the 24 hours and then trying to just drink according to that... but I haven't done that for a while.

- Grace

The implementation of *surveillance* strategies did not always enable participants to meet their prescribed fluid restrictions. As with other participants Tom described monitoring his weight continuously, however *surveillance* alone could not guarantee success.

I keep an eye on my weight all the time, in fact I get a bit paranoid about it. I've got new scales; the other ones weren't good enough. I think I'm doing okay, and then I come in here and I hadn't done as well as I wanted to do.

- Tom

Irene had been on HD for two years and nine months at the time of interview. Her average IDWG for the preceding month was 2.1kg. Irene's story was very different in comparison to other participants. Irene described her experience with fluid restrictions as being *trying, very trying* and acknowledged that she was continuously over her prescribed fluid intake.

Irene's description of managing her fluid restrictions highlighted the ambiguity of human experience. At the commencement of the interview, Irene stated *I'm always over my fluid* and her pre-dialysis records demonstrated that this was the case. Yet throughout the remainder of the interview Irene described multiple occasions where

she had been offered fluid but restricted herself by only having a mouthful. The internal struggle was evident.

Well I just know I can't have it so I don't have it...I've got a friend who likes a beer she'll open a bottle of beer and she'll say want a mouthful? And I'll say yes I'll have a mouthful, so I'll have a mouthful with her and I'll want more but I can't have it.

- Irene

Irene's inner battle was apparent. Where other participants clearly articulated their struggle with managing fluid, Irene was unable to describe her experience in any detail. Her responses were often closed and short. Her response to the meaning of fluid restrictions was that '*you just gotta [sic] deal with it, that's all about it, you got it, you gotta [sic] live with it and you gotta [sic] deal with it.*' Consequently, Irene was managing her fluid restrictions in her own unique way.

Each participant had a unique experience of their own personal struggle and approached *surveillance* practices as they applied to their own personal experiences and life circumstances. *Surveillance* strategies served two purposes for participants; to guide *maintenance* behaviours while acting as a quality control mechanism relating to the success of *maintenance* behaviours. *Maintenance*, the second subtheme of *constant struggle* will be discussed in the following section.

4.4.2 Maintenance

Surveillance strategies informed *maintenance* behaviours. Where *surveillance* focused on the measurement of fluid intake and output, *maintenance* related to practical approaches that assisted participants in relieving their *constant struggle* with thirst and fluid restrictions and achieving their recommended fluid restriction target. As participants struggled to abide by fluid restrictions they identified how they developed multiple strategies at both cognitive and practical levels. These strategies went some way to mitigating the challenges associated with fluid restrictions.

Thirst was cited as the major symptom attributed to fluid restrictions. Consequently, the alleviation of the sensation of thirst was a major priority for all participants.

Maintenance strategies were varied and ranged from restricting dietary sodium intake to keeping a supply of grapes, hard boiled lollies and/or ice cubes to stave off thirst and

minimise the desire to drink beyond their allocated fluid allowance. Each participant had a preferred method by which to do this. For Tom, ice cubes and periodic sips of water helped, *'quite often what I'll do is to ice some water and have a glass of water and just take sips maybe every half an hour or I have a bit of ice, I keep a good supply of ice (Tom).* Tracy was prescribed eighteen medications and as such had to further ration her fluid intake to account for the times she needed to take her medications. Ice was a preferred thirst quencher for her as well.

So I am controlled and I am careful but because of the tablets and because of the dry mouth I just have to have some degree of fluids right through the day not just with meals, like I'm constantly in the freezer just grabbing a bit of ice to keep my mouth moist.

- Tracy

Lee alluded to artefact 4-1, to describe both *social loss* and a *maintenance* strategy she used to make socialising more rewarding:

Because we're not supposed to drink beer or wine and we go out for dinner at a Club for birthdays or any of those sort of things, so if I know I'm going to the Club for dinner I cut down on my tea [in the day] and I have a half scotch and dry in a 7 ounce, so if I know I'm going I do cut down to allow myself one alcohol drink at the Club.

- Lee

Maintenance strategies staved off thirst to a point however, despite having them in place they were not always enough. Thirst and the associated desire to drink at times became too much for participants and the *maintenance* strategies were set aside to satisfy their insatiable thirst

I keep grapes in the fridge and rather than go and have a drink, I'll go and eat a couple of cold grapes to try and moisten the mouth or suck an ice cube but at times I've just got to have a half cup of tea.

- Lee

Participants described that while practical strategies went some way to alleviate thirst they also needed to use the resolution of their mind to support them. Consequently, psychological strategies were also developed to alleviate thirst. These included distraction techniques or attempting to use the resolution of mind. Tom described how he refrained from drinking sometimes to the point that he became '*quite uncomfortable*'. While the majority of participants described practical strategies to manage their IDWG, Tom felt that while these were important, his main battle was with his own will.

Well it's I believe, the challenge is in the mind. That one has to realise that that's it and that's part of it you know. You've got to realise that you've got this and be practical about it but, first of all you've got to have it sorted out in your mind and [then] try to impose that onto your physical state.

- Tom

Maintenance was not restricted to the physical realm in the form of practical or measurable strategies. Participants also described a journey whereby they moved from what was normal before they needed to restrict their fluid intake to reconstructing a new way of thinking which required adaptations to be made in order to manage the requirements of their treatment regimen. Tom suggested that the journey to effective self-manager required more than physical or behavioural strategies.

Something that I feel that you know, you can come in here and do nothing else but talk about it, that's something that I don't want to do...it's a mental challenge, oh yes, and of course the physical's got to come in because you've got to put that into practice to the best of your ability...I realise that I've got to do something about it and I just can't run away with my wishes, that's why I keep you know the ice water, taking sips. I don't drink and take a gollop, just to keep my mouth from getting dry.'

- Tom

Participants also described how being busy or distracted assisted them in forgetting that they were thirsty. '*I still get very thirsty; I try to do something else to make myself forget about it and [laughs] things like that* (Irene). Similarly, Leonie also described the added benefit of being busy. '*If I'm busy that helps because you're not thinking about drinking at the time* (Leonie).

For Tracy, her distraction techniques were more subtle and not a conscious process. The idea of thinking about not drinking only compounded her struggle and she found it easier to be pragmatic about her situation and accept what was reality.

It's probably better not to think about it. Because I think if you kind of focused on it all the time you'd be even more obsessed so you don't think about what's in the past and you know you can't keep looking back to what it was 'cause that's not what it is now. So I'm actually kind of pretty good at doing that I think. Saying well you know that was a previous life this is what I'm living now so you know there's no point in longing for something that was.

- Tracy

Maintenance strategies were primarily aimed at alleviating thirst in ways other than directly drinking fluid or distracting the mind from the presence of thirst and the desire to drink. Participants also described a strategy that assisted them in rationalising their fluid intake in a manner that allowed them to replace 'normal' volumes of fluids with 'smaller portions'. This was not specifically a *maintenance* strategy to alleviate the *constant struggle* of thirst but a strategy that allowed them to rationalise fluid consumption through the use of physically smaller fluid receptacles or halving the fluid 'portion' in the absence of smaller cups or glasses. This subtheme of *downsizing* will be discussed in the next section.

4.4.3 Downsizing

Downsizing enabled participants to restrict or rationalise their fluid intake rather than overtly deny themselves fluid consumption. Leonie alluded to this in her statement, '*I don't deny myself being able to drink. I think that doing that, it's even more difficult so I try and just restrict rather than deny.*'

The practice of *downsizing* is best illustrated by a photo taken during the interview at the request of Becky. Becky's interview was conducted in her home and while she did not have a photo to describe her experience she brought out the cup and glass she used every day and asked me to photograph them for her (see Artefact 4-9) next to a 'normal' sized cup and glass.



Artefact 4-9: *'I've got a 120ml cup, that's my tea cup and I've got a 70ml glass*

I've got a 120ml cup, that's my tea cup and I've got a 70ml glass, yeah that I use and I have a cup of tea in the morning that's, that I have my tablets with and then pretty much during the day I'll have like, sometimes, I'll have you know a couple of cups or something like that and then I'll have the soft drinks or something like that in the little tiny 70ml cup and yeah and then have another cup of tea at night.

- Becky

The images demonstrate that *downsizing* was a conscious decision to replace 'normally sized' portions, in this case cups and glasses with equivalents that carried a lesser fluid volume. This practice was universally used by all participants and if a smaller glass, for example, was not available then participants adapted accordingly.

Last night I was out to dinner and at the end of dinner I ask for a cup of tea in an espresso cup and the poor waiter came and didn't know what was going on, the tea bag didn't quite fit in the cup. But it was perfect size for me it was 50 mls it was great but you know they just kind of look at you as if you're crazy why would you want a cup of tea this big.

- Tracy

Tom said *I use a very small cup of 100mls and I try to stick to that or if I'm a bit lighter, I'll go to half of another cup which held 150 [mls].* Whereas Lee used the strategy of only ever

half filling a cup: *I only half fill it. I never fill it up. The only time I have a full one is here on the machine, I have a full cup. Other than that I only have a half cup.*

Leonie, who approached her fluid management very differently to other participants, due to her residual renal function still implemented a *downsizing* strategy.

I was very used to having lots of cups of tea and I can't do that anymore, [laughs] so I have a small cup instead of a mug ... So that restricts you as to how much you drink I suppose and I try not to ever finish a cup, like I always leave something in the bottom of a cup and throw it out, but only a small quantity.

- Leonie

Participants used a variety of techniques to lessen the burden of the *constant struggle* they faced each day as they battled the unnaturalness of limiting fluid consumption. These strategies were implemented at varying times within participants' illness experience. For some, the notion of *surveillance* was no longer required as they became more comfortable with knowing the limits of what they could drink and measurement was no longer required. For others the process continued as it reassured and guided them as to how well they were managing their fluid restrictions. In contrast for Leonie, the idea of measuring input and output would have served as an unwelcome reinforcement of the *constant struggle* she already faced. Participants all described that, in time, they were able to adjust to the rigours of fluid restrictions and came to accept, in varying degrees, that fluid restrictions were now a reality, regardless of how hard it was to manage them. This journey to acceptance will be described in the next section and is the final theme revealed from this study.

4.5 Accepting

I think I was able to accept it, I won't say easily, but I did come to a point of accepting the things that I had to let go of.

- Grace

Participants described multiple strategies they used to manage their *constant struggle* of living with fluid restrictions. The underlying motivations for this was very clear; to

stay alive and live longer. Consequently each participant identified their own unique incentive for accepting the fluid management element of their kidney disease, regardless of whether they successfully managed it or not. Consequently the theme, *accepting* was not identified as a linear progression to understanding and adherence but a multifaceted, torturous struggle unique to each participant. It consisted of three sub-themes: *life worth living*, *support*, and *consequences*. The *constant struggle* of living with fluid restrictions and the journey to accepting was partially mitigated through support structures and knowing that life was worth living. These two factors along with knowing the *consequences* of not adhering to fluid restrictions assisted the majority of participants to accept the challenges as a necessary hurdle to manage in order to live longer.

Participants voiced that fluid restriction was only one of the issues that they had to manage with ESKD. While most reported it as one of the most difficult aspects of treatment, participants did not view specific elements of their treatment in isolation. Rather, the management of their ESKD was viewed in its entirety. Grace appeared to have spent a lot of time reflecting on how she had faced the prospect of life on dialysis.

Not only in that area of fluid, you know in so many other areas where you have to let go and it's no good fighting and saying 'I don't want this'. I said to myself, 'It's either accept it and go along with it or accept the result of not co-operating with the dialysis business' and I came to an acceptance and I think it was that was how I coped with the fluid business.

- Grace

Once participants had moved beyond knowing that their kidneys would no longer function, a process of adjustment began which commenced with an acceptance that their kidney disease was not a temporary acute type illness.

I never gave up hope that the kidneys might start functioning again, but unfortunately they haven't [laughs] and I suppose at the start I just thought they would and this was going to be a temporary situation and I would deal with it and that was fine. But of course as you get further down the track and you realise that's not going to happen, you have then got to deal with the fact that you know, you're

on dialysis

- Leonie

A period of transition then ensued whereby participants described the enormity of a life reliant on RRT. During this time many personal and clinical challenges were faced, including managing fluid and dietary restrictions and this process was described by participants as a *constant struggle*. Participants described a period of reflecting upon the pros and cons of fluid restrictions and concluding that healthy fluid management behaviours were desirable because they would live longer. Grace alluded to artefact 4-7 as she described the difficulties of coming to accept living with fluid restrictions.

I was really fighting it, but I couldn't release myself from what was binding me. I couldn't say, well I'll just get rid of those ropes or whatever, no this is going to be how it is, but you're going to have to release yourself from that, otherwise you're going to go down a negative path, and so I did release myself from that and become more free and I don't think about that now very much.

- Grace

Grace concluded with reference to the symbolism of artefact 4-7 that her acceptance had released the bonds of fluid restriction.

There's less, the rope is down there much more...Now that I've released myself from some of those shackles, the word is acceptance of the reality of what my life is now. It's changed from what it was and I say in the journey situation, I'm walking a different road but I still have some of these things from the other life there too to help me.

- Grace

Tom, who admitted continuing to struggle in managing his fluid restrictions, acknowledged that he was on the right track but that the psychological challenge was difficult as he attempted to manage his day to day fluid *maintenance* activities. Tom rationalised the need to accept fluid restrictions as part of living longer.

I accept it as part of the deal...it is part of living longer and if I don't, if I don't do it, well obviously it's going to be detrimental to myself and my family.

- Tom

A personal belief that life was worth living was evident in participants' stories. This provided sufficient motivation to assist them in facing the *constant struggle* and, in time, accept fluid restrictions as part of their life. This sub-theme of a *life worth living* is described in the following section.

4.5.1 Life worth living

The sub-theme of *life worth living* describes participant motivations to accept the rigours of fluid restrictions in order to fulfil dreams and aspirations that they had yet to achieve in life. This could only be done by living longer. All participants described the motivation to live longer, including Becky who asserted her reason for maintaining healthy fluid gain behaviours was because;

I want to live longer, yeah. I'm too young, like I'm too young to go now. I don't want to go now. Like yeah, there are still things I want to see.

Tom described how he was realistic about his personal circumstances and acknowledged that accepting his situation would help him live longer.

[I am] pretty realistic about things and you know I accept that this is the way it is and it's up to me, I realise that I've got to do something about it... because I want to live longer.

Each participant maintained unique reasons for wanting live longer, for some of the older participants the motivation to live often derived from family sources.

My motivation is to stay alive so I can see my grandchildren...My daughter keeps telling me it's maybe a couple of years away [laughs]. So yeah, but I've got so much more to do and to live for.

- Leonie

Coming to the realisation that they had a *life worth living* was not immediate, rather it took time and various *support* mechanisms including HCPs, friends and family. The process of accepting grew from the knowledge that failing to accept or adhere to fluid

restrictions would adversely affect their ability to live life to its full potential. Lee, who had struggled with all aspects of her treatment regimen, identified that despite the struggles and continued pressure that fluid management had placed on her life she had come to accept it. Her rationale for acceptance was multifaceted including doing the right thing and having goals that made *life worth living*. The notion of accepting the responsibility of her self-management was part of doing the right thing. Lee understood that other people also invested time into her and her treatment; consequently she needed to do her part to maintain her wellness and from her perspective, not waste peoples' time. Lee also described her ambition to live to see her great grandchildren. At the time of the interview she had just become a grandmother for the first time.

I have accepted this as part and parcel of my life so the fluid is yeah, I think about it a lot but it's, I accept it. It was a big deal, but it's not a big deal now. I'm handling it...I want to be there a bit longer for my girls, my grandkids, my great grandkids...with the fluid restriction I think if I'm going to come here four hours, three times a week and go home and drink what I want, eat what I want then it's a complete waste of time. I'm wasting the nurses' time, I'm wasting the doctors' time and I'm wasting my time, so while I'm on dialysis I try to do the right thing.

- Lee

The recognition that life was worth living in conjunction with the desire to live longer was not sufficient to assist participants in their journey to accepting. *Support* was crucial to help maintain their focus and drive in addition to providing strength in difficult times. *Support* was derived from several areas and will be discussed in the following section.

4.5.2 Support

The ability to effectively self-manage their fluid intake required participants to call on a range of strategies to minimise the potential for adverse sequelae as a direct result of poor fluid management behaviours. Support networks were described by participants as key enablers in the process of accepting living with and managing fluid restrictions on HD. Participants described how support networks enabled coping, the development

of strength and resolution and in most cases, the acceptance of living life with fluid restrictions. Participants identified that the most support was derived from HCPs, friends and family.

Support from health care professionals

The support from HCPs emerged as a key facilitator in developing practical strategies to augment the process of participants accepting their changed life circumstances. Their descriptions were not specifically about adherence, rather participants described a process of understanding and accepting changed circumstances and the discovery of practical (ie: *surveillance* and *maintenance* behaviours) and psychological strategies to manage fluid restrictions.

[My Psychologist] has helped me a terrible lot and in different ways, you know, he's given me a different outlook on life. Moving into the units, I'm more friendly there which I wasn't, I'm going to Church now, yeah everything has changed... you know over two years I've had contact, he's been wonderful, he rings me you know ... I went through that period where I thought, Oh I can't do this, I can't do it, but I was determined to it, yeah I found it very, very hard. I have just accepted it now.

- Lee

Participants described how nurses, on the whole, provided additional comfort and educational support. The nurses were able to clarify goal expectations with participants as to what they could and should do to manage fluid restrictions. Goals were supported through practical advice on ways to reduce the desire to drink including chewing gum, sucking on boiled lollies or ice chips rather than gulping water.

Well I had very good instruction from [identified two nurses]; they were very helpful in outlining what the best practice would be in dealing with this ...they point out to me that you know, it's in my own interest.

- Tom

The support from nurses also came in the form of taking the time to listen to participants own individual cares and concerns. Participants described how this

enabled them to feel as though they mattered in a health care system that was touted as being too busy and under pressure to provide individualised service. Consequently, this gave participants a sense of identity within the system and encouraged them to continue to do their part in self-managing their fluid restrictions. This support also assisted some to overcome the anxieties initially faced at the beginning of their dialysis journey.

When I first started I was a mess and [identified a nurse in particular] was here then and she'd give me a cuddle and you know, she was absolutely wonderful. She made me feel like I mattered you know and the nurses who have been doing it longer [ie: practicing nursing] they, you're not a number with them.

- Lee

Grace highlighted how her fear and uncertainty when she first started dialysis was lessened by the power of her faith and the understanding, that for her, God would guide those HCPs entrusted with her care.

I was afraid of what was going to happen to me. I still get a little bit fearful but then I, as I said in the beginning of the interview, I believe I'm in God's hands and not only God's hands but the doctors hands etcetera, who'll make that passage easy for me I hope.

- Grace

Support from friends

Participants alluded to their friends and family being supportive of them in relation to their illness. Tracy, who was also a cancer survivor, explained how her cancer support group's understanding of her unique situation provided her with strength.

They're [cancer support group] wonderful. I got to dinner late last night and they had a glass of ice on the table waiting for me. They know. Yeah, they don't offer me drinks and um, they've always got a glass of ice there waiting for me. And if I've been up at the hospital all day, like yesterday, when I hadn't had anything to drink since lunch time, and I was a dry as chips. And so I actually got a lemonade and I had a few sips out of it and then I just said can I put that down the other end of the

table. And they didn't comment, they just put it down the other end of the table. 'cause they knew exactly what I was doing. If it was sitting in front of me I would drink more than I should so I just pass it down the other end of the table and said someone finish it off and they did. And they don't need to say why do you want us to do that, 'cause they know.

- Tracy

However, the support from friends was not always beneficial and sometimes contributed to additional struggles in managing their fluid restriction. While friends were described as being supportive, participants also described a conflict whereby occasions arose that demonstrated how their friends' genuine best intentions were not always aligned with participants' medical needs. This was attributed to support persons' (friends or family) lack of understanding of the importance and *consequences* of living with fluid restrictions. Tracy described the battle she faced with friends (excluding her cancer support group) *'every time I have a cup of tea.'*

Most of my friends make a cup of tea for me and I say just a small one and they look at it and say that's too stingy and we just can't give you a cup of tea that small so they give me that much and I have to go and tip most of it out 'cause if I just had it in front of me I would drink the whole lot. They are doing it out of kindness, they don't want to be mean with the fluids but they don't understand how important it is.

- Tracy

Tom also described a similar experience whereby friends' lack of understanding or perception of his situation contributed to the further perpetuation of his struggle:

Well I've talked of this about to one particular friend, she's been very good, she and her husband are very good to me and if I go to her place we get a full cup of tea, 'come on, you've got to', obviously she doesn't understand the implications of, you know she says, 'well you've got to drink', that sort of business which doesn't help me.

- Tom

Friends were initially described as supportive but as participants described their experience it emerged that that was not always necessarily the case. Friends best

intentions often contributed to the struggle with their insistence on tempting participants with further fluid consumption. By contrast, participants described support from family quite differently.

Support from family

Participants described varying experiences relating to support and family. For some participants, kidney disease and its management was openly discussed and created a source of strength. Alternatively, Tom and Tracy described a reluctance to discuss their disease, or seek support from their family. This reluctance appeared to be a mechanism that maintained independence and protected loved ones from their own personal struggles.

You tend to keep the worst parts of your problem from your family to protect them because if you told them, you know, or you kind of, the things that you were worried about it would just worry them more.

- Tracy

As I say, they don't, we don't talk about it very much. It comes back to, they can't do anything about it and I wouldn't want to put any, I mean they've got their problems without, they're very good to me and I wouldn't want them to feel that they're falling down because they're not all the time discussing it with me. No, I like my independence and I want to stay independent.

- Tom

The other participants described family support as an enabler which assisted them in facing the management of their disease with purpose and strength. For Lee, her will to live longer was driven because of the support she received from her family.

To start with I thought, 'Oh I can't do this anymore', but now it's, it's I've accepted this is the way I've got to live. You want to live a bit longer; you try and do the right thing to live a bit longer. Because it is the support that's, because if it had of been left to me I would never have gone on it, no. It is the support that's got me to this stage. I can't, that is the only reason. If those girls had just let me do what I wanted to do and never said anything, I wouldn't be here. I wouldn't have done it and I think they know

but that I wouldn't have done it and it meant everything to me that they were interested enough for their Mum to give me the support they've given me.

- Lee

For some participants openly discussing the challenges faced brought their families closer together. This was particularly relevant for Leonie who had also recently experienced an interstate relocation.

I suppose my family's been positive and my husband has been a great support, so those things have been very good and I think it's brought us a bit closer together because when you deal with these sort of problems you either I think, get a bit closer or you don't deal at all sort of thing and I think that we both have dealt with it reasonably well.

- Leonie

Support networks and the realisation that life was worth living were key components in the process of accepting changed life circumstances and fluid restrictions. However, participants still experienced HD and fluid restrictions by themselves. The *consequences* of not maintaining fluid restrictions were experienced by themselves and no-one else. These *consequences* were severe and avoiding them proved to be the main motivation behind accepting and adhering to fluid restrictions in their lives. If they experience the most serious of all *consequences*, death, the motivations of having a *life worth living* would be for nought.

4.5.3 Consequences

Accepting fluid restrictions was inherently influenced by the *consequences* participants would experience if they failed to adhere to fluid restrictions and not maintain adequate IDWG. These *consequences* were described from both short and long term perspectives. Intradialytic or short term *consequences* related to symptoms experienced while on dialysis while long term *consequences* related to the effect of poor fluid control on their heart. It was evident that a period of transition was required before participants were able to adequately adjust and accept life with fluid restrictions.

During this time participants were able to process and implement specific strategies that would enable them to manage fluid gain behaviours successfully.

I've gradually started to feel half way human again and I've got a different attitude now than what I had when I first went on it. I'm pleased now because I do feel better and I know I won't if I overload myself with fluid.

- Lee

Tracy identified how her motivations to maintain healthy fluid gain behaviours were influenced by both short and long term *consequences*.

Long term the heart thing, short term if I'm over my dry weight when I come to dialysis and I have to take off a lot [of fluid¹¹] I cramp really badly and it makes it very unpleasant and its easier just to keep your [fluid] weight down a bit and have a reasonable dialysis where you don't cramp.

- Tracy

In time, participants described coming to understand what their bodies could and could not cope with in terms of fluid removal during dialysis. Poor intradialytic experiences created a motivation to improve fluid gain behaviours in order to avoid similar experiences again.

I'm very aware of how much I can take off at one time. I used to have a hypo [Hypovolaemic episode] or go 'flat' on numerous occasions and I found out if I tried to take off more than two litres or 0.5 rate [Litres per hour] I was very likely to go flat... The worst experience I had was when I was sick [from a hypovolaemic episode], I was actually sick and I passed out. That was not very nice and I never want to do that again.

- Leonie

Participants also highlighted that the *consequences* of poor fluid gain behaviours during dialysis far outweighed the difficulties associated with instituting *surveillance* and *maintenance* strategies. Grace identified this as a strong motivator for her as she had learned that good fluid management strategies equaled minimal fluid related symptoms during HD.

¹¹ Fluid is removed during haemodialysis through a process of ultrafiltration. Patients refer to this as 'taking off' fluid

Well the good thing was that it was going to add to my wellbeing I think. That's what I thought of when I came up here for dialysis, there's not much, not overly a lot to take off [i.e. fluid] because I used to get sick during haemodialysis. I think that was the predominant thought that if I don't do this I'm going to be in trouble.

- Grace

Leonie described the juxtaposition that she faced in her mind in trying to make sense of her struggles with maintaining health fluid gain behaviours. The struggles related to the immediate physical response to fluid consumption. Initially there is gratification, the quenching of thirst, there is no obvious, real time, immediate consequence to having something to drink.

You don't feel sick, you don't, it doesn't do anything to you, you know what it does in the long run, but in that particular period of time, if you have a drink, it doesn't make you feel bad or anything.

- Leonie

Leonie identified this as a key reason as to why the struggle existed.

If those things [ie: Fluid, foods containing high potassium and phosphate content] that I was told not to have were going to make me sick or feel bad, then it would be easy not to have them but they don't make me feel sick or feel bad. I know that they've told me I'm not allowed to have these, but I don't feel bad by having them [laughs].

- Leonie

However Leonie was very much aware of the long term consequences of poor fluid management.

It pressures the heart, they explained all that to me, how the heart will become flabby and it won't work properly and all that sort of thing and so I'm very aware of that too, that's why I don't try to over drink or have too much to drink because I don't want to put any, I've got enough problems, I don't want my heart to give out on me as well [laughs].

- Leonie

While intradialytic symptoms were described as immediate concerns, participants were well aware of the long term consequences of excessive IDWG on their heart.

It's really mainly to protect my heart, yeah. That's what it really comes down to. I've got to look after my heart, yeah and the best thing was to just stop drinking, just take that load off, yeah, stop drinking.

- Becky

Some participants also described witnessing other patients' experiencing both short and long term fluid related symptoms while they were on dialysis. This was quite confronting and unavoidable due to the open plan of the dialysis unit whereby all patients could see each other and no privacy curtains were installed. Seeing other patients in distress provided further motivation to persist with healthy fluid gain strategies so that they did not find themselves in similar situations.

I've seen patients here who are overloaded to a fairly big degree dying of heart failure and I don't want to do that. I'm too young. So I don't want to get in that position. And that's basically what drives, I suppose the surveillance. Because I think not long after I started out here several patients died. And I'd been on dialysis with them enough to hear them talking about it and drinking schooners and coming in three or four kilos over [their dry weight] and I just thought oh that's not a good thing to do. So I think that's probably what's driving me. I don't really want to get in that position.

- Tracy

The perceived short and long term *consequences* of poor fluid gain behaviours assisted participants in accepting the importance of fluid restrictions. The personal experience of previous episodes of uncomfortable fluid related intradialytic symptoms motivated participants to maintain healthy fluid gain behaviours.

Time, coupled with support enabled participants to come to a point in their illness where they made a conscious decision that because life was worth living, acceptance was necessary. For some participants, the process of accepting culminated in the

conscious decision to implement strategies that would enable them not only to live longer but accept the influence ESKD, and its treatment would have on their lives.

4.6 Summary

The experience of intradialytic symptoms proved a strong motivator for participants to adopt healthy fluid gain behaviours, as did witnessing fellow patients experience both short and long term *consequences* of excess IDWG. These experiences reminded participants of the need to remain vigilant with their *surveillance* and *maintenance* behaviours. For some participants, the experience also provoked the recognition that they were too young to experience the long terms consequences of poor fluid gain behaviours because they still had goals they wanted to achieve; and that regardless of the struggle they experienced, life was still worth living. In time participants came to accept this in varying degrees. For some participants, this process was relatively easy, for others it was a process they were still working on.

The journey to accepting was supported through family, friends and HCPs. Health Care Professionals provided practical advice and support, but on occasions would remind participants of their indiscretions relating to not adhering to their fluid restrictions. To some extent this contributed to the feelings of guilt that participants had already described feeling when they knew they had exceeded their fluid restriction for whatever reason. Family members provided a source of support as well as a purpose to continue living. Some participants described the decision not to share their personal difficulties with family members as they did not want to burden them with their suffering. On the whole, participants described how their friends did not understand the severity or implications of excessive IDWG as a result of not following their fluid restrictions. This was particularly difficult during social situations and avoiding social engagement and community was sometimes easier than facing the *constant struggle* to restrict fluid consumption while those around them drank fluid freely and without the fear of *consequences*.

The need to restrict fluid consumption in order to minimise intradialytic symptoms and live longer deepened the sense of loss that permeated throughout participants' lives. The enormity of this loss and the extent of its impact on participants' lives were

central to their stories. Loss was consistently described in terms of the *loss of freedom* and aspects of social interaction all of which were seen as *consequences* of having to manage IDWG through fluid restrictions.

This chapter has described the experience of living with fluid restrictions of seven people on HD in a community dialysis unit in Australia. The following chapter will discuss the findings of this chapter in relationship to what is already known about the experience of living with ESKD and consider the new areas of knowledge this study has generated. The implications of this study on practice, education and future research will be discussed.

Chapter 5 Discussion and conclusion

This study set out to understand what it was like for people with ESKD, who were undergoing HD, to live with the restriction of fluids and to answer the research question: What is the experience of fluid restriction for people receiving haemodialysis in a community based setting? The qualitative descriptive research design utilised for this study was a suitable approach for answering this question, and identified specific themes and sub-themes that were all profound expressions of the experience of living with fluid restrictions. Chapter 4 described the experience of living with fluid restrictions in a group of seven people who accessed HD in a community setting. Overall, participants described that not being able to drink spontaneously and adhering to strict limitations of fluid intake was *“hard, very hard.”*

This final chapter will position this study within the literature reviewed in Chapter 2. It will discuss areas in which this study confirms or contradicts the findings of these studies and identify new knowledge that it has generated. In addition, it will describe the implications of the findings and provide recommendations for clinical practice and future research and some concluding remarks.

The experience of living with fluid restriction was described in rich detail. All participants identified that living with fluid restriction was *“hard”* and as the interviews progressed they were able to reflect upon, process and describe the enormous impact that this aspect of treatment had on their lives. Although each participant was required to restrict their fluid intake in varying amounts, each story provided a unique insight about what it was like to live with fluid restrictions every day for this group of people with ESKD undertaking HD.

Despite this unique experience, common themes emerged from each story. These themes can be utilised as epistemological pointers with the richness and diversity of participants’ experiences providing impetus for future research to further describe, understand, reflect upon and test new theories and interventions across a range of similar experiences. Although no story contradicted the stories of others, it was evident that each participant’s experience of adjusting to, and *accepting* the need to restrict their

daily fluid intake, was unique to their personal situation and illness journey. The commonalities of these stories were consistent with the findings of several studies identified in the literature review of this thesis. It should be noted that the literature reviewed in Chapter 2 considered the findings of research that studied the *overall* experience of living with ESKD and being on HD not the experience of living with fluid restrictions, although some of these studies briefly alluded to the difficulties patients experience in this area. The emergent themes from this present study contributed several new areas of understanding about the complex and inter-related experiences of living with ESKD and specifically fluid restriction.

For this group of people undertaking HD, living with fluid restrictions proved to be a *constant struggle* to deal with a loss that presented in various forms. In time, most participants were able to implement successful strategies which enabled them to accept their changed circumstances. During this period, participants were also able to affirm themselves and their reasons for living in addition to identifying clear motivations that gave them the strength to face the constant reminder that they could no longer drink freely as they had once previously. This process of *accepting* the nature of fluid restriction was identified as a unique, complex and multifaceted journey for each participant.

Previous studies have explored the prevalence of fluid non-adherence (Kara, Caglar, & Kilic, 2007; Kugler, Vlaminc, Haverich, & Maes, 2005; Port, et al., 2004), physiological (Bots, et al., 2004; Sung et al., 2006) and socio-demographic (Kugler, et al., 2005; Molaison & Yadrick, 2003; O'Connor, Jardine, & Millar, 2008) factors influencing IDWG, the facilitators and barriers relating to the self-management of fluid restriction (Smith, et al., 2010), the consequences of high IDWG (Movilli et al., 2007) and interventions to decrease IDWG (Barnett, et al., 2008; Bots, et al., 2005; Sharp, Wild, Gumley, et al., 2005). While other studies have explored the overall experience of living with ESKD, no study in the published literature has specifically explored what it is like to endure fluid restrictions for people with ESKD. Consequently, this study addresses a specific domain of the ESKD illness experience that has not been previously reported in the literature and provides new insight into a facet of treatment that is considered to be

one of the most difficult aspects of the management of ESKD (Johnston & Halshaw, 2003; Sharp, Wild, Gumley, et al., 2005).

The disruptive, restrictive, and limiting nature of ESKD and its treatment has been well described in the literature (Al-Arabi, 2006; Hagren, et al., 2001; Hagren, et al., 2005; Kaba, et al., 2007; Polaschek, 2003). While previous research has identified the effect of ESKD on peoples' lives, this study has contributed to a deeper understanding of the inescapable and omnipresent nature and influence of fluid restrictions on these peoples' lives. The identification of the theme *constant struggle* highlighted the extent to which participants' lives were affected by fluid restriction. Whereas the theme *magnitude of loss*, highlighted the degree to which loss was experienced and impacted their lives. Finally, *accepting* described the motivators that assisted participants in overcoming their experience of loss and managing to cope with the constant struggle that daily fluid restriction imposed. Considering these themes in isolation would discount the complexity and inter-relatedness of these human experiences. This was particularly evident with the connection between loss and struggle. The consequence and magnitude of the *loss of freedom* to drink spontaneously was a constant struggle. Participants managed an internal conflict between what was once considered normal and a process (i.e. to restrict fluid) that was necessary to integrate a new and foreign reality into their sense of self.

5.1 The nature of living with fluid restrictions: Physiological and psychological loss

The theme of loss was central to participants' experience of managing fluid restrictions in this study, further reinforcing the findings of previous research (Faber, 2000; Hagren et al., 2001; Tijerina, 2009). The literature has described the experience of loss in people with ESKD mainly in terms of physical, cognitive and psychosocial function (Faber, 2000 and the loss of choice, freedom and decision making abilities (Al-Arabi, 2006). These were predominantly described in relation to what people with ESKD could no longer do. Loss has many connotations, not least the notion of losing something that potentially could be found again. In ESKD, loss is permanent; there is no cure, even if

people receive a kidney transplant¹². In contrast to these studies, which described loss within the context of the overall experience of living with ESKD, this present study identified a deeper and more comprehensive understanding of the pervasive nature of loss and continuous struggle with which participants endured fluid restrictions. The connection between participants' loss and struggle penetrated their lives with the reality of having to face and relive the loss repeatedly throughout every day.

Participants described in detail how the influence of fluid restrictions infiltrated throughout all aspects of their daily routines in addition to being reminded of it when they took their medication, when they were thirsty, when they were hot, or when they went out socially with others. Furthermore, fluid restrictions took away the simple pleasure and relief of thirst associated with drinking, again something once taken for granted. The loss was constantly being perpetuated by continuing with life and dealing with fluid related stimuli and again, this was revealed by participants to be a constant struggle.

One of the most significant features of living with fluid restrictions revealed by people in this study was that it is unnatural. Fluid restrictions disrupted how they had previously functioned and how they had come to know themselves in the world. Over the period of their lives, prior to developing ESKD, participants described how they were socialised to believe that drinking plenty of fluid/water was good for their body. The experience of being thirsty and feeling the need to drink was a natural phenomenon that could easily be overcome with a spontaneous response, without thought, but the advent of ESKD now required drinking to be curtailed.

Participants described the enormity of this experience of loss but the depth and significance of it is unfathomable without having experienced it. While participants particularly spoke of *social loss* and the *loss of freedom*, these were seen as direct *consequences* of their loss of kidney function. One of the functions of the kidneys is to regulate fluid balance. This was no longer possible and, as a consequence, they relied on a machine to replace this function in addition to having to engage in the self-regulation of fluid intake every day. Participants described their struggle of having to

¹² A kidney transplant is still a form of treatment and people who undergo transplantation may need to recommence dialysis if the transplant is unsuccessful or fails over time.

limit an instinctive action that as human beings, they were physiologically programmed to do. The experience of thirst, or being thirsty, is universal, the experience of denying the very impulse or desire to drink is not.

The experience of living with fluid restrictions evolved from a combination of social and objective experiences. Participants described a grievous loss relating to personal and social freedom. The loss combined with the need to manage fluid intake created a struggle that was grounded in the innate reality that, physiologically, humans are 'hardwired' to drink. People drink for one of two reasons, they are either thirsty or they are in a social situation where having a drink may be the norm and constitute a form of gratification or pleasure. Consequently participants not only struggled with their objective body and its loss of function but their phenomenal body. Their life experiences had encultured drinking as part of every aspect of life and they needed to develop a new understanding of their corporeal reality, that fluid (ie: excessive) is not necessarily good for them anymore. Furthermore, this understanding needed to be combined with management strategies to adapt to this new way of living. This process of adaptation or *accepting*, required participants to consider the embodied nature of their experience and consider the *consequences* of failing to adapt. They then balanced that by determining the extent to which they valued their life, realising that failing to adapt meant a decrease in both the quality and duration of their life.

The onset of ESKD and the need to restrict fluids went against the very nature of the innate human impulse to drink when one is thirsty. Leonie best illustrated this with her statement: "*Fighting nature is like fighting against yourself and it takes strength.*" The very need to fight the natural urge to drink when one is thirsty or in a social situation created a psychological struggle for all participants. Participants described how they were constantly reminded of their previous freedom to choose to drink. Whether this was through simply feeling thirsty, going out for dinner, seeing pictures of drinks or sodium containing foods in magazines, or seeing walls of drinks in shop refrigerators; and the constant reminder of what they could no longer do was impenetrable and omnipresent. A significant feature of living with fluid restrictions was that the experience of loss and struggle are ubiquitous in nature. One of the participants questioned "*can I cope with this?*" The essence of this question highlighted the

association between the two major themes of loss and struggle. Participants acknowledged the gravity of their *loss of freedom* (see Artefact 4-3) and questioned whether they were capable of conquering the struggle that they faced in order to adapt to their disease and its treatment. The montage (see Artefact 4-8) developed by Tracy and the pictures (Artefact 4-4 - Artefact 4-6) cut out from a magazine by Lee, further supported this finding.

What made this all the more difficult to comprehend was that the action of drinking when thirsty still provided instantaneous gratification and there were no *immediate* consequences. However in time, participants learned that *consequences* would manifest, either before their next HD session, during it or, in the long term, in some form of cardiac condition. Short term consequences appeared to be a more prominent motivator, but participants were very cognisant of the long term effects of poor fluid management and the relationship with increased risk of mortality.

Drinking is encultured in society. Over time, from a very young age we adopt patterns of behavior relating to drinking that are not necessarily associated with thirst. Whether it is at a children's birthday party, celebratory raising of glasses at functions, a family picnic or barbeque, catching up with friends at a local café or watching sport at the local hotel, the experience of consuming some type of drink during these occasions is universal. Consequently, the diagnosis of ESKD and the need to commence fluid restrictions does not limit the individual to a set of physical consequences alone. This study revealed that the combination of an inborn physiological stimulus to drink, and the psychological battle to resist it, compounded the experience of fluid restrictions for all participants.

It may appear easy to differentiate between the physiological and psychological impact of loss (for example losing a limb or one's eyesight). This was not the case for participants as both features were embodied in their experience of fluids, what it meant to them and how restrictive the impact was on their lives. This was particularly highlighted by Artefact 4-7 used by Grace. The imagery of being tied up and bound provokes many strong feelings including being forced against one's will, being restricted, a lack of freedom and in Grace's case, and indeed for all participants, being

restricted from something you want to do, but know you can't. This study revealed that the physiological impact of fluid restrictions (i.e. thirst) not only meant going without, but created a psychological desire for fluid consumption as well (see Artefact 4-8). Participants described knowing that they shouldn't drink beyond their restrictions but the trio of imposed fluid restrictions, being thirsty and the sense of unnaturalness of going against the very nature to drink further exacerbated the struggle to maintain healthy fluid consumption behaviours.

This study demonstrated that fluid restrictions also significantly disrupted established associations with personal relationships, the understanding of participants' place in life and consequently, their ability to interact with the world as they knew it. While this is consistent with previous studies exploring the experience of living with ESKD (Hagren, et al., 2001; Kaba, et al., 2007; Salvalaggio, et al., 2003; Tijerina, 2009), it has extended our understanding of the magnitude and seriousness with which this affects peoples' lives.

The theme of *social loss* is well recognised in the literature with the studies of Al-Arabi (2006) and Clarkson and Robinson (2010) revealing the contribution ESKD and HD play in affecting peoples' lifestyles most notably in social domains. A cohort of 23 people on HD in Greece described how fluid and dietary restrictions created limitations in their lives (Kaba, et al., 2007). In particular they revealed how these restrictions prevented them from participating in social events like going out with family. However this is the extent to which the impact of fluid restrictions is described and there is no differentiation between the impact of fluid and dietary restrictions. Tijerina (2009) also described the limitations of ESKD particularly in terms of loss of the independence and the ability to maintain social roles but this study described this experience in the larger context of living and making sense of the entire treatment regimen for ESKD and not the specific meaning of living with fluid restrictions. Participants in this present study also described their sense of loss in terms of the *loss of freedom* and the loss of social interaction in their lives. What was remarkable was that they were all still able to make the individual choice to drink freely and not adhere to fluid restrictions, but their personal motivations and experiences assisted them to make conscious choices to adhere despite the enormity of the challenge.

Polaschek (2003) and Salvalaggio, et al., (2003) both described the notable impact of HD treatment time on participants lifestyles particularly in terms of independence and the ability to travel and have holidays. The description and links to these themes in many studies (see also Rittman, et al., (1993)) are grounded in stories about the demands of undergoing HD not explicitly living with and managing fluid restrictions which is an additional stressor to the overall treatment of ESKD. Consequently, studies to date have lacked depth and richness in the description and meaning of what it is like to restrict fluids in one's life.

5.2 Attempting to ameliorate the struggle: Management and coping strategies.

In order to overcome the innate and constant struggle, participants adopted strategies to ameliorate the persistent sensation of thirst and wanting to drink, but not always successfully. In some cases participants chose to forego activities once central to their identity and their lives like socialising with friends. For some, missing out on this integral aspect of social contact was more palatable than having to confront the struggle that existed during those times. This is consistent with Kaba, et al., (2007) who also described the avoidance of social interaction as a means of managing fluid and dietary restrictions. While Kaba, et al., (2007) study superficially categorised this as a strategy, this present study provided a deeper understanding of the immense difficulty and disruption this caused to participants lives and their very identity. This was best illustrated by Grace as she spoke about how the need to avoid social occasions and meetings took her away from her community, a part of her life that held great meaning and provided her with identity. Yet despite her community being such an integral part to her being, and something that gave her identity, the immense struggle associated with managing fluid restrictions was greater than the loss of identity that she experienced from no longer socialising with her friends.

Participants described that despite continually struggling with fluid restrictions and its impact on their lives, in time they came to identify and consolidate strategies to lessen the burden of the struggle. Participants did not reveal any new strategies that are not already commonly taught in pre-dialysis programs. In this study they were thematically described as *maintenance* strategies to alleviate thirst and minimise fluid

intake, and *surveillance* strategies, to monitor dry weight and fluid intake and output. Regardless of the degree of loss identified by participants, *surveillance* and *maintenance* behaviours supported the process of *accepting* and adopting healthy fluid management behaviours. What participants did reveal that has not previously been identified was that no matter how successful these strategies were, the inherent struggle to deny a natural instinct still remained.

Participants described an active engagement with the struggle which in part, assisted them to implement coping strategies to alleviate thirst and to manage their fluid intake. The adoption of healthy fluid management behaviours (for example using smaller glasses and teacups, see Artefact 4-9) appeared to assist in decreasing the burden of the struggle over time but never erased it totally. Thirst could be eased by sucking on an ice cube or chewing on a grape but not quenched as it might be, by drinking a large glass of water. The strategies may have provided temporary relief but were wholly inadequate to satisfy the sensation of being thirsty. Consequently the struggle remained to balance the knowledge that satisfying one's thirst may provide immediate gratification, but have serious short and long term *consequences* for overall health and wellbeing.

Knowing the *consequences* in part, afforded some participants the strength to engage in the struggle associated with restricting fluids but this was not an easy task. In the study by Al-Arabi (2006), the theme 'staying alive' described the motivators (love from others and God) participants used to encourage them to continue with treatment until either a cure or transplant became available. Participants in this study did not conceptualise their motivations in this manner, they were aware that a cure was not a reality. Instead, their motivations were far more internalised. None of the participants rationalised the need to manage fluid restrictions in terms of waiting for a kidney transplant, indeed this was not described by any participants in this study. Motivators were inherently central to where their priorities were in life, they identified that they had to assume control of this aspect of treatment and merely *accepting* fluid restrictions as some point of conditional acquiescence would not drive them to achieve their goals. This significantly differs to the findings in the study by Rittman, et al., (1993) where participants did not allude to personal consequences of non-adherence but

alternatively described that poor adherence practices could be compensated through HD, rather than identifying an individual responsibility to self-manage fluid intake between HD treatments.

This chapter has so far argued that both the loss and struggle associated with fluid restrictions are inextricably linked. What became evident in participants' stories was that no matter what strategies they employed to relieve thirst they were not enough to ameliorate the struggle to achieve healthy fluid management behaviours and that more were required. Participants began to describe the need for support as an additional mechanism to assist with the inherent struggle they faced and help them come to terms with, or accept fluid restrictions in their lives. From the broader perspective of living with and managing ESKD, this is consistent with other studies that have reported support from various parties including family, friends and HCPs (Gregory, et al., 1998; Namiki, et al., 2010; Ravenscroft, 2005; Smith, et al., 2010) as key facilitators in coping with the rigours of ESKD and its treatment. However in the context of this present study it affirmed the inextricable links between the three overarching themes revealed in this study. Support could not be isolated as a construct that solely facilitates the process of *accepting* fluid restrictions. It also played a crucial role in helping participants find balance between the loss they experienced, the constant struggle they faced and the need to incorporate fluid restrictions into their lives.

The notion of support and coping in negotiating life with ESKD is not new (Burnette & Kickett, 2009; Gregory, et al., 1998; Ravenscroft, 2005), particularly the benefits of support from family and friends in negotiating the management of ESKD (Clarkson & Robinson, 2010; Gregory, et al., 1998; Hagren, et al., 2001; Salvalaggio, et al., 2003; Smith, et al., 2010). Support from HCP's was also identified by participants in this present study as a key facilitator of effective self-management of fluid intake in this study. Participants drew strength from the support inherent in their relationships with HCPs. This support manifested in the form of giving advice and practical strategies to manage fluid restriction but more significantly as taking the time to listen and understand individual stories of challenges, concerns and changed circumstances. This further reinforces the findings of Smith et al., (2010) who identified knowledge from HCPS as the most common facilitator of fluid adherence. Ravenscroft (2005) has

similarly described the positive experience provided by HCPs when patients perceive that they have taken a genuine interest and concern in their own lived experience. This care in conjunction with the support from family and friends enabled participants in this present study to negotiate the health care system and more importantly, resolve their place in the world and identify that life was worth living.

Curtin and Mapes (2001) identified how some people undertaking HD deliberately managed HCPs in order to retain a sense of control over their disrupted lives.

Similarly, Faber (2000) described a dichotomy between some of the nurses and patients views where partnership was not central to the ethos of care, rather an 'us versus them' dynamic. In this present study this was not the case. Previous studies have reported conflicting perspectives regarding participants' description of HCPs' support. Faber, (2000) described relationships based on the biomedical view of compliance, and Burnette & Kickett, (2009) reported the impact of negative interactions associated with episodes of care. Gregory, et al., (1998) revealed polarising perceptions of nurses as being either supportive and caring or inattentive and devoid of a caring manner. The variation in these findings could be attributed to myriad factors including ward/unit culture (Flynn, Thomas-Hawkins, & Clarke, 2009; Meterko, Mohr, & Young, 2004), nurse stressors including burnout (Argentero, Dell'Olive, & Ferretti, 2008; Ross, Jones, Callaghan, Eales, & Ashman, 2009) and models of care like the presence of primary nursing in dialysis units (Flynn, et al., 2009; Thomas-Hawkins, Flynn, & Clarke, 2008).

Hagren, et al. (2001) described how patient centred care facilitates trust. In turn, it assists in the overall adjustment to living with ESKD. Gregory, et al. (1998) has also described how the successful negotiation of key constructs including quality of support either facilitated or reduced the likelihood of participant acceptance of ESKD and its management. This present study confirmed these findings and further revealed participants' appreciation of various avenues of *support* and reliance on both support and practical strategies to assist them with managing fluid restrictions. Of particular note were the participants' description of how nurses acknowledged and validated the challenges and changed circumstances they faced and the need to negotiate them. Participants did not describe nurses approaching the topic of fluid restrictions from the dominant biomedical position of compliance or adherence. Rather, the focus was

described in terms of successfully negotiating changed circumstances through the combination of *surveillance* and *maintenance* behaviours. This support from HCPs assisted participants to enter and develop therapeutic relationships as individuals, each with their own unique experiences and challenges rather than 'patients' who should be subservient to HCP's demands.

These findings were in contrast to those of Curtin and Mapes (2001) and to a lesser degree, Polaschek (2003) who identified that for some people on HD, self-management may be more about managing the health care system and those working within it in order to achieve better health outcomes. Again, it should be noted that these studies reported the overall experience of living with and managing ESKD. The differences between the findings of this present study (along with those of Hagren, et al., (2001) and Ravenscroft (2005)) and those of Curtin and Mapes (2001), Gregory (1998) and Polaschek (2003) should prompt HCPs to question whether enough is being done to teach HCPs about the significance of their interactions in supporting people with ESKD to successfully manage fluid restrictions. The implications of these findings will be explored later in this chapter.

5.3 Reframing, *accepting* and managing a modified life

The diagnosis of ESKD and the resultant loss of residual renal function required participants to undertake a personal journey to reframe socially entrenched thoughts and fluid consumption behaviours once considered normal, into a new sense of self that had to restrict fluid consumption along with many other self-management requirements. For participants, living with ESKD meant a radical change from a 'normal' understanding of the role of fluid in their lives to a new understanding that unrestricted fluid intake was no longer a healthy behaviour but detrimental to both their short and long term health status. Participants described a process of *accepting* that life had changed for them and that if they were to achieve their goals then fluid management was their responsibility and no-one else's. The consumption of fluid was a reflexive and embodied way of being. The need to now restrict its consumption extended beyond a cognitive process of reasoning and required the control of a natural

physiological stimulus which was an unnatural, difficult and uncomfortable experience.

Merleau-Ponty (1962) described how changes to the phenomenal body influenced one's experiences of the lived world. Consequently illness is experienced as a disturbance not just to the objective body but, more significantly, as a disruption to one's place in their lived world (Toombs, 1992). This was not dissimilar for participants in this study. The failure of the kidneys to function and the need to integrate fluid restrictions into their lives significantly disrupted their established associations with social and familial relationships in addition to their understanding of their place in the world. Participants described a process of reconstructing what they had previously considered as normal, in order to manage and accept a new way of incorporating the meaning of fluids into their lives. In 1807, Hegel (2009)¹³ described a process of reconstructing the experience of regulating the demands of the ill body. The experience of living with fluid restrictions, for these participants provided an alternate view, one that was grounded in the understanding that consumption of fluids posed no immediate threat to their ill body; hence the body did not demand regulation initially. However, if one was to consume excess fluid the body would respond accordingly and this experience assisted participants to reframe thoughts about poor fluid management behaviours. Eventually participants were able to conclude that the short and long term *consequences* of excess consumption did not align with their own personal goals in life or for their health.

Participants recognised the risks of not adopting healthy fluid management behaviours and weighed the *consequences* of poor fluid management versus the benefits of good fluid management and concluded that healthy fluid management behaviours were vital if they were to achieve their personal goal of living longer. Participants identified that they did not want to die early because they had determined that their life was worth living. They described how they still had things they wanted to achieve and therefore had to make the conscious decision to effectively self-manage their fluid intake. ESKD required them to do more than just receive HD. For example, Lee wanted

¹³ Translated text from 1807, translator J.B. Baillie

to see her grandchildren grow up and maybe even meet her great grandchildren, Becky felt simply that she was just too young to die and there were still things she wanted to see in life.

As participants described their personal journeys, it became apparent that their feelings, along with the ability to cope with or manage fluid restrictions changed over time. The ability to actively self-manage fluid intake was evident in the majority of participants' stories. Listening to them discuss their journey and experiences, it would be easy to associate the process of accepting and integrating the need for fluid restrictions in their lives with time alone. While it did take time to successfully integrate fluid restrictions into a new sense of self it was not time per se that facilitated this. It was the experience that time afforded, like identifying and developing *surveillance* and *maintenance* strategies that suited their lifestyle and personal circumstances. It was the opportunity time afforded to reflect on where they saw themselves in life, to confirm their families love and support, to develop therapeutic relationships with HCPs and finally, to experience the short term consequences of exceeding their fluid restrictions in the form of suffering the ignominy and discomfort of intradialytic symptoms. These factors assisted them to come to the realisation that diverting from medical advice was inconsistent with their motivations to prolong life because it was worth living.

The theme of *accepting* did not present as a linear progression to acceptance and understanding but rather as a multidimensional and tortuous process. For some, it led to the expression of an 'eventual' acceptance and understanding of changed circumstances. Consequently, they could either choose to fight it and remain angry, or accept it and enjoy the worthwhile elements of life. Accepting was associated with *support*, belief in a *life worth living* and a concern about the *consequences* of not adhering to fluid restrictions. The essential essence of this theme was that it was a transformative process that participants were undertaking to become successful self-managers and identifying the key facilitators that would assist them to achieve their goals.

The notion of a transformational experience has been described in the literature most notably by Curtin, et al., (2002). In exploring the processes involved with the successful

management of being on dialysis long term, Curtin, et al., (2002) revealed a series of affirmations that were integral in the adaptive course of self-management. From a healthy state characterised by a normal self with normal circumstances, ESKD required participants to come to terms with a changed self with changed circumstances eventually becoming a transformed self who retained the essential essence of the 'old' self. The transformational process of restructuring self, moved from the normal self to the changed self as participants reinforced their self-worth, self-identity and affirmed their will to live, along with the notion of self-efficacious behaviour and their need to remain in control of their situation. This present study's findings are consistent with the findings of Curtin, et al., (2002). Participants identified that despite their changed circumstances they retained their self-identity and despite having to integrate fluid restrictions into their lives, they were still normal. Additionally, they acknowledged that life was worth living and consequently they needed to assume control over their fluid *maintenance* behaviours to minimise long term cardiovascular complications and maximise their time left alive. While the concept of self-efficacy was evident, participants' ability to manage fluid restrictions was enhanced by support mechanisms as described previously. The ability to affirm their own self-worth and that life was worth living was derived from goals that were invariably family orientated and afforded them the determination to work through the challenges they faced to adopt and persist with strategies that could extend their life expectancy. As Lee stated *"I want to be there a bit longer for my girls, my grandkids, my great grandkids"*.

The process of transformation as described by various authors including Curtin, et al. (2002) and Gregory, et al. (1998), was also evident in the present study. It was noted that participants experienced a transformative process of accepting a life that required fluid restrictions. The term transformation reflects a process where people move from focussing their attention on the burden of living with a chronic illness to reframing their sense of self as an individual who is able to manage the disease (Dubouloz et al., 2010). Consequently, the notion of transformation embodies a successful adjustment to chronic illness (Curtin, et al., 2002; Dubouloz, et al., 2010; Paterson, Thorne, Crawford, & Tarko, 1999). This study's focus was to describe what it is like to live with fluid restrictions. While participants' stories identified the burden they faced, it was clear

that the majority of them had undertaken a journey that enabled them to reposition the drinking of fluid in their lives and focus on their responsibilities and motivations for the continuing need to self-manage this aspect of their care.

Curtin, et al. (2002) surmised that participants in their study restructured their illness experience by coming to terms with elements such as the intrusiveness of dialysis and the restrictive nature of ESKD along with the uncertainty associated with the future. In this present study, participants described alternate motivators namely the short and long term *consequences* of not adopting and accepting healthy fluid management behaviours. This has not previously been clearly described in the literature. If fluid *surveillance* and *maintenance* strategies were not adopted then the struggle would not be overcome, and their life which was worth living, would potentially be cut short. This offers a divergent view to participants in the study undertaken by Krespi, et al., (2004).

Krespi, et al., (2004) described in their study, how a group of sixteen people on HD perceived no tangible or immediate effect from adhering to fluid restrictions. This cohort also revealed that the relationship between the time from achievement of fluid adherence and long term benefits (e.g. living longer) did not act as a motivator for adherence. It should be highlighted that Krespi, et al. identified that this cohort appeared to lack insight into why dietary control was required as part of their management; consequently participants were sceptical and ambivalent about the topic of fluid restrictions. The participants in this present study described an alternate perspective in this regard. Krespi, et al., (2004, p. 194) posited that two different patient positions towards fluid and dietary restrictions existed. One, accepting restrictions, reflected a biomedical obligation to adhere and suggested that this was akin to “responsibility without ownership”. The contrasting position was that people owned the need for restrictions rather than seeing them as externally imposed sanctions on their lifestyle. The findings of this present study suggest the latter position was true for its participants. While they revealed the magnitude of the loss they had experienced and the continuous struggle they endured, their experiences over time enabled them to conclude, that for various personal motivations, the onus to adopt healthy fluid management behaviours was their responsibility and no-one else’s. These strategies were necessary to enable them to live a longer healthier life. This present study

described this phenomenon using the theme *Accepting* and is in direct contrast to the passive biomedical obligation of accepting restrictions described by Krespi, et al., (2004).

For participants, accepting restrictions was identified as a process, not the relinquishing of responsibility to manage fluid restrictions, in stark contrast to Krespi, et al., (2004) notion that accepting restrictions demonstrated 'responsibility without ownership'. The final divergence from Krespi, et al., (2004, p. 193) findings was that participants did not describe fluid restrictions as externally imposed "frustrating and boring rules", they recognised them as vital to their well being. They described the more explicit relationship between fluid restrictions and their pervasive impact on their families and friends and their lives while framing their stories with the need to effectively manage fluid restrictions to achieve their life goals. Despite their best intentions, all participants conceded that maintaining fluid restrictions was so very hard and that there were times when they succumbed to the internal struggle to satisfy their thirst and enjoy an extra drink, but even then this was a guilty pleasure which for some, meant they would be apologising to the dialysis nurses before their next treatment. Regardless, the need to quench one's thirst and find temporary solace from the constant struggle appeared to be an acceptable trade-off for the temporary gratification and relief from thirst on occasions.

Loss and the process of reconstructing one's sense of self are central themes for people who experience chronic illness (Charmaz, 1991; Jacobi & MacLeod, 2011; Paterson, et al., 1999). The development of a new sense of identity which incorporates new found meaning associated with the illness experience within the context of changed circumstances is also consistent with other research about living with ESKD (Curtin, et al. 2002; Gregory, 1998; Ravenscroft, 2005; Walton, 2002). Over time, reframing (Walton, 2002) a new understanding of self (Rittman, et al., 1993) is necessary in order to create balance (Ravenscroft, 2005) in life and maintain one's self-identity (Curtin, et al., 2002). In the context of this present study, this was a complex and multidimensional process and did not mean that the individual was no longer engaged in the struggle associated with fluid restrictions. This was similarly described by the emergent theory of Gregory, et al. (1998) who suggested that the new sense of self was

a fluctuating and evolutionary emotional and psychological position derived from the meaning of their illness experience, its treatment and the quality of support mechanisms. The struggle was omnipresent; the ability to eventually 'accept' and manage fluid restrictions successfully was not.

5.4 Implications and recommendations

The findings of this study, in conjunction with those of other studies, identified the polarisation between HCPs' and patients' views and experiences (Burnette & Kickett, 2009; Curtin & Mapes, 2001; Faber, 2000; Gregory, et al., 1998). This highlights the need to focus on HCPs' education to address potential mismatches between the reality of patients' experiences and HCPs' assumptions. Studies that have designed interventions aimed at improving adherence in this population have shown modest improvements in fluid adherence behaviours but are aimed solely at people receiving dialysis therapy (Barnett, et al., 2008; Sharp, Wild, Gumley, et al., 2005).

The findings of this present study suggest that it may be timely to develop education based interventions for HCPs in this area so that all patients may benefit from improved HCPs' patient dialogue. Participants in this study described HCPs as demonstrating empathy, understanding and taking the time to listen to them as they shared their experiences and challenges with fluid restriction. With the foundation of effective therapeutic relationships, HCPs were able to provide practical advice and emotional support about all aspects of fluid management behaviours. In time, this assisted participants as they grew to accept the impact of fluid restrictions in their lives. Of central importance to this finding was the sense of self efficacy, independence and identity these positive interactions gave participants as they negotiated a health care system that is often criticised for failing to provide adequate and individualised care (Cowie, 2012; Nolan, Davies, Brown, Keady, & Nolan, 2004). This finding has substantial credence in terms of considering how HCPs and particularly dialysis nurses should approach the topic of fluid restrictions with people on HD.

HCPs can improve their dialogue with patients about interdialytic fluid management by appreciating both the patients' experience and their stage in the process of accepting fluid restrictions in their lives. Avoiding the use of negative and paternalistic language

within this dialogue will enhance partnership in health management and the attainment of negotiated and agreed fluid maintenance goals (between HCPs and people receiving HD) (White, 2004). But first HCPs need to recognise and validate what people enduring fluid restrictions are experiencing. Individualised strategies can then be identified to support patients and assist them to engage successfully in healthy fluid management behaviours that suit their lifestyle. Our role as clinicians is to assist people living with the complexities of dealing with fluid restrictions to understand themselves in the context of their own reality and experiences.

The development of an education program that addresses the individual experience of managing restrictive treatment regimens would be beneficial not just for people on dialysis but any chronic illness that requires individuals to make dramatic life changes. This should be developed and instituted from an undergraduate through to a clinical level and delivered from an interprofessional perspective. The focus of any education program would be to increase the HCPs' understanding of the unique meaning and experience of illness and its associated management. This will support HCPs to develop the requisite skills to deliver care that is truly person centred (Cowie, 2012). A complementary patient and family education program could co-exist that focuses on resilience, self-management and empowering patients to challenge HCPs' assumptions and to work together in partnership.

Artefacts such as those collected during this research could be used as part of an education program (after the requisite consent has been gained from participants). The use of artefacts in this study was partly motivated by the opportunity to provide a more intuitive way of describing the meaning attached to participants' stories. Their use afforded a descriptive mechanism for participants to reflect on their experiences with managing fluid restriction and describe the reality of their lives. The addition of this data collection method was chosen to augment participants' stories and enhances the often ineffable nature of understanding individuals' illness experiences. These artefacts could serve as a powerful medium to assist clinicians in better appreciating the impact that managing fluid restriction has on patients' lives. Furthermore, the images and stories generated could also be used to inform education and support strategies directed at people with ESKD in an effort to assist them with negotiating

fluid restriction into their lives and with the intention to assist them to adopt healthy fluid management behaviours.

To successfully support people to negotiate fluid restrictions and deliver patient centred care, dialysis units need to make concerted efforts to engender a partnership between patients and HCPs. Unit cultures that promote strict 'compliance' and/or reward dependence and passivity in care (Kammerer, Garry, Hartigan, Carter, & Erlich, 2007) may be complicit in preventing the successful adaptation and acceptance of fluid restrictions. HCPs and patients should work in partnership to achieve mutually negotiated and agreed goals. HCPs need to appreciate patient experiences, health beliefs, attitudes and expectations of both their illness and treatment for partnerships to work successfully (Costantini, 2006). To achieve this, the health care team must engage with their patients, validate their experiences, adopt non critical attitudes and be willing to work with patients at any stage as they come to accept the role of fluid restrictions in their lives. Cowie (2012, p. 1037) suggested that HCPs can begin to achieve this by not only asking "what is the matter? But what matters?" Nurses are uniquely positioned to support people on HD in this way. However the partnership with other members of the multi-professional team, particularly social workers and psychologists should not be ignored. These health professionals have specific skills that can further support people who struggle with managing fluid restrictions in their lives.

Social Workers in particular, can advocate for the psychosocial needs of people on HD. They can achieve this by supporting nurses and other HCPs to understand how one's environment and social experiences contribute to the development of meaning, and how these experiences influence behaviour (Tijerina, 2009). Consequently, HCPs should then be able to identify that displays of fluid management behaviour outside the accepted norms of HCPs are not necessarily demonstrations of flagrant disregard of their advice. Rather, they may be viewed as a rationalised reasoning process (Donovan & Blake, 1992) grounded in the patient's lived experience which occurs as part of negotiating changed circumstances into a new way of living (Rittman, et al., 1993) in the hope of improving the quality of their lives (Polaschek, 2003).

People are continually growing and shaping meaning from their experiences, meanings that are associated with what is important to them at any given moment or stage in their lives, not the meaning of what is important to HCPs. Consequently HCPs must move from a biomedical perspective and first identify and understand the meaning of fluid restrictions for people on HD. With this foundation, partnerships can be forged with patients to identify and achieve goals through the development of negotiated and agreed fluid management strategies aligned with what patients' identify as being important in their lives.

5.5 Recommendations for future research

This is the first study that has focused on describing the experience of living with fluid restrictions for people on HD. Further qualitative studies are required to confirm these findings and identify additional relationships between themes. Furthermore, mixed method research designs should be utilised in future studies as we further investigate the phenomenon of fluid restrictions and the best ways to support people with ESKD. Mixed method designs would afford a better understanding of relationships between metrics that are considered important by health professionals while also considering the crucial patient perspective of their embodied and lived experience.

During the course of this study future directions for research became evident. Firstly, a study should be undertaken that examines the divergent experiences between people who manage fluid restriction successfully and those who do not. A hypothesis could be formulated that the theme of *accepting* and its constructs would be substantially different between people who consistently achieve acceptable IDWG (through good fluid management behaviours) compared to those who do not. Follow up studies could then be devised to test interventions that are specifically designed to support people who struggle to manage fluid restrictions and achieve 'acceptable' IDWG. These interventions would be based on patients' perspectives and experiences not clinicians' assumptions. Such interventions may prove to be more successful than clinician-devised interventions to improve health outcomes. Clinician-devised interventions may have less impact because patients do not consider such measures to be related to their own perceptions of their experience (Casey, et al. 2002; Seymour, 1989). Any such

intervention should be developed with the understanding that clinicians must respect peoples' fluid management choices, what is important for them, and what fits into their own personal goals.

When people commence on the pre-dialysis pathway¹⁴ a number of education sessions are provided to assist people to manage their disease. One of the sessions relates to dietary and fluid restrictions. While regional variation in practice exists, this education is delivered by a dietitian or a nurse after consultation with the patient's treating physician. Typically patients are taught about foods that have high fluid and sodium content and strategies to decrease sodium intake are discussed in addition to methods to alleviate thirst distress symptoms. In this study some participants may not have been equipped with sufficient strategies to self-manage their fluid restrictions. The retention of pre-dialysis education undertaken may be diminished if patients were uraemic or overwhelmed during the training program. Consequently, they may not retain information provided about strategies to support fluid restriction. Further interventional research could explore the benefits of subsequent education programs and/or facilitated support groups upon the commencement of HD to consolidate this information.

Additional research is required to identify other facilitators of the pathway to acceptance. This transformative process is part of a growing body of research (Dubouloz, et al., 2010; Paterson, 2001; Paterson, et al., 1999) that requires clearer conceptualisation and the development of a framework to further understand its context and process. The theme and process of *accepting* should be also explored in relation to theories of behaviour change, notably the trans-theoretical model. The trans-theoretical model of behaviour change suggests that the adaptation of behaviours requires an individual to progress through various non-linear stages (Prochaska & Velicer, 1997) and may be an appropriate theory to use as a foundation to explore the phenomenon of fluid restriction. Further research in this area would have practical benefits to people on HD as health professionals seek to develop successful strategies to support healthy fluid management behaviours.

¹⁴ A care plan to prepare them for undertaking renal replacement therapy

Given that the motivations for undertaking this study were associated with the need to understand and incorporate participants' voices and experiences, further research is also required that will build upon our understanding of this phenomenon and incorporate patients' views and participation. The inspiration to use artefacts as a data collection method for this study stemmed from the participatory action research methodology, photovoice which is grounded in health promotion principles and the feminist theory of voice (Wang, Cash, & Powers, 2000). The photovoice methodology uses photography to catalyse personal change (Wang, Yi, Tao, & Carovano, 1998) and could be used to promote an open dialogue between HCPs and patients in this area. Future researchers could adopt the photovoice methodology and use it to assist both HCPs and people who consider they are struggling with fluid restrictions to develop better coping strategies and therapeutic relationships.

5.6 Expected outcomes

This research has provided a voice for participants to describe their experiences of living with fluid restrictions which will provide an opportunity for HCPs to respond by providing more patient centred and empathetic care. The participants' experiences extend the body of knowledge that will enhance HCPs understanding of the difficulties patients face in the area of fluid management. This will subsequently assist HCPs to improve their dialogue with patients and develop management strategies relating to fluid gain between dialysis sessions that are relevant to patients.

5.7 Study limitations

The present study effectively revealed new information about the experience of living with fluid restriction, however it is prudent to acknowledge the limitations of this research and offer suggestions for future research in this area.

The sample for this study was recruited from a cohort of community dialysis patients who are not representative of the total HD population. Consequently, the results may not be transferable beyond this group of participants' experiences. The findings of this study may be transferable for the cohort studied and for theoretical purposes be applied across cohorts in similar settings. The purpose of this research was to explore and describe a phenomenon that is grounded in the experience of participants. The

reader may determine whether the findings of this study are transferable to other settings or are comparable to similar populations of interest (Letts, et al., 2007; Neergaard, et al., 2009).

Age and gender (Kugler, Maeding, & Russell, 2011; Kugler, et al., 2005; Molaison & Yadrick, 2003; O'Connor, et al., 2008; Saran et al., 2003) have consistently been demonstrated as key predictors of (poor) adherence to fluid restrictions. This present research design could have been strengthened by adopting a longitudinal design that interviewed participants at several points along the dialysis pathway (for example at first treatment, six months, year one, year two and year five) to understand the process of acceptance and the differences across age, gender and culture. Given that this research has been conducted within scholarly time restraints for the purposes of a Masters of Philosophy qualification, a longitudinal design was not deemed appropriate.

The findings in this present study could be affected by selection bias because the people who volunteered to participate in the study wanted to share their experience of living with fluid restrictions. People, who did not manage their fluid restriction well, may not have wanted to participate in the study for fear of being reprimanded for their inability to maintain fluid restriction. Consequently, the characteristics and experience of the people who consented to this study may be different to people who did not consent who experience high IDWG.

The purposive recruitment strategy employed for this present study relied on the concept of data saturation to determine when no new themes or information were forthcoming from the data (Guest, et al., 2006). Data saturation was identified after the seventh interview and recruitment was discontinued. More specific targeting of known people, who struggled with fluid restrictions, may have proven to be ethically challenging and was not considered justifiable within the time frame allowed for this study.

5.8 Conclusion

The purpose of this study was to describe what it is like to live with the phenomenon of fluid restriction for people on HD in a community setting in order to extend health

professionals understanding of this experience. Previous studies have contributed to our understanding of the overall experience of living with ESKD. Few of these studies have reported specific facets of management, and studies that have reported the experience of living with ESKD and have only cursorily described the understanding of what it is like to live with fluid restrictions.

One of the central tenets underpinning this research is that experience is unique and that the meaning derived from experience is socially constructed. People's illness experience can be explored by examining how they interpret and make sense of their own bodily disturbances. This study revealed that living with fluid restrictions is complex and multifaceted. The central themes of loss, struggle and accepting emerged from the participants' stories, while the complexity of participants' experiences enabled the identification of the inter-relatedness between the core themes identified.

The literature review in Chapter 2 identified commonalities associated with features of living with ESKD. The findings are consistent with those of other studies considering chronic illnesses that share physiological and treatment similarities with ESKD including diabetes (Furler et al., 2008; Gazmararian, Ziemer, & Barnes, 2009; Hill-Briggs & Gemmell, 2007; Paterson, et al., 1999), respiratory disease (Chen, Chen, Lee, Cho, & Weng, 2008; Cicutto, Brooks, & Henderson, 2004; Koch, Jenkin, & Kralik, 2004), and cardiovascular disease (Falk, Wahn, & Lidell, 2007; Freydborg, Strain, Tsuyuki, McAlister, & Clark, 2010; Nordgren, Asp, & Fagerberg, 2007). This study revealed that despite identifying a restricted life which was dominated by a constant struggle, participants adopted specific strategies to assist in improving the struggle they experienced. Despite these strategies, participants were still faced with constant reminders of no longer being able to consume fluids freely without consequence. This psychological cue, in tandem with the unnatural requirement to ignore a natural physiological stimulus compounded the experience.

This research has added a richer understanding to this aspect of management that is cited to be the most difficult for patients yet, has been poorly described in the literature. This study also provides a basis for understanding not only what it is like to live with fluid restrictions but also some of the strategies required to successfully

negotiate living with them. This understanding could inform practice and future research to improve HCPs interactions with people on HD when discussing the management of fluid restrictions.

This study encourages HCPs to consider their approach regarding the management of fluid restrictions and subsequent IDWG. Health care professionals, and more particularly nurses, must consider the individual experience of each patient during each and every therapeutic interaction. Dialogue must be informed by a respectful understanding of the unique meaning of fluid restriction for each patient rather than a biomedical view of achieving figures of 'compliance' that may have little or no meaning in the context of the individuals overall life experience.

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Appendix 1: Summary of studies in literature review

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
1. Al-Arabi (2006)	QoL: subjective descriptions of patient challenges	USA	n=80	Semi-structured interview	'Naturalistic inquiry'	1. Life restricted 2. Staying alive 3. Feeling good	Content analysis Constant comparison technique
2. Burnette & Kickett (2009)	'You are just a puppet'	Australia	Purposive n=6	Semi-structured interview	Narrative ethnography	Disempowerment: 1. health professional interactions 2. dependence on dialysis 3. foreign nature of hospitalisation 4. challenges of self-care 5. lack of education	Indigenous Australians.
3. Clarkson & Robinson (2010)	Life on dialysis: A lived experience	USA	Not stated n=10	Five predetermined questions (structured interview) determined	Not stated	1. Life changes on dialysis	Did not use Phenomenology despite title. Appears

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
				by author based on past experience		2. Coping 3. Area lacking	to be content analysis
4. Curtin & Mapes (2001)	Health care management strategies for long term dialysis survivors		n=18 snowball HD>15 yrs	Semi structured interviews 2-6.5 hrs in duration	Exploratory descriptive Orem's model of self-care (paper assessed true to model)	Themes: 1. Managing health care professionals 2. Impression management 3. Vigilant oversight of care	Is self-management from the patient's perspective about managing the system and those who represent it? Ability to self-manage potentially influences functioning and well-being.
5. Curtin et al (2002)	Long term HD survivors: transformational experience		n=18 snowball HD>15 yrs	Semi structured interviews 2-6.5 hrs in duration	Exploratory descriptive Orem's model of self-care (paper assessed true to model)	4. self-affirmations that required the restructuring of self within the context that the extant self still existed, transition from 'normal' self to 'comprehensive self-manager through an adaptive process of reforming self through self affirmation and restructuring the illness	Contributes to understanding the transformative process of restructuring self within the context of ESKD

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
						experience'	
6. Faber (2000)	Investigation of life with ESKD	Canada	n=4	Socio-cultural case study design: Patient (~10 interviews), support person (1 interview) and health care professional (1 interview) from renal department undertook unstructured interviews 30/60 - 2/24 in duration; participant tape recorded diary (x3 occasions for 1/7); researcher observations in clinical area & home plus review of patient notes	Socio-cultural theory (cultural, historical and institutional) (paper assessed: well guided by theory)	THEMES: ESKD is WORK, family work to live (the work of others); living with the losses of ESKD	Patient vs Person: the dichotomy of us versus them.

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
7. Gregory et al (1998)	Experiences with ESRD and HD treatment	Canada	Not stated n=36	Semi-structured interview	Grounded theory	'dominant constructs': 1. redefinition of self 2. quality of supports 3. meanings of illness & treatment. Emergent theory suggested that a <i>"new sense of self</i> is an emotional/psychological state that fluctuates with the evolving meanings of illness and treatment and perceived quality of supports" p764	
8. Hagren et al (2001)	HD machine as a lifeline: experiences of suffering	Sweden	n=15	Semi-structured interview: focused on daily life, needs and expectations of future	Qualitative interpretive	1. HD machine as a lifeline sub-themes- a) loss of freedom b) dependence on caregiver c) disrupted marital,	

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
						family and social life 2. Alleviation of suffering a) gaining sense of existential optimism b) achieving sense of personal autonomy	
9. Hagren et al (2005)	HD patients' experience of life situation	Sweden	n=41 from 3 units	"Examine how patients express their life situation" paper focus on "how treatment encroaches on time and place and how patients experience care". Semi structured interviews 20-60 minutes in duration. Content analysis undertaken	Content analysis	Existential struggle: not finding space for living; feelings evoked in care situation; attempting to manage restricted life.	HCP not aware of existential struggle experienced by participants. This contributes to emotional distancing and vulnerability
10. Kaba et al (2007) Describes how patients receiving	Problems experience by Greek HD patients	Greece	Purposive n=23	30-60 min 'face to face' interviews	Stated: grounded theory (resembles descriptive content	Themes: Problems relating to symptoms, limitations in	Further strengthens the understanding of the experience of HD, BUT the description of

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
long term HD perceive their problems and the impact of treatment on their lives.					analysis)	life, uncertainty, dependence, changes in personality.	research methods and the actual methods used appear flawed.
11. Krespi et al (2004)	HD patients' beliefs about renal failure and its treatment		Qual n=16 Quant n=156	Mixed method study; Qual interview (identification of beliefs about ESKD and its treatment; 60-90 min semi-structured) informed construction of quant survey (including 8 fluid specific items r/t fluid restriction). Prevalence of beliefs measured by frequency (%)	Thematic analysis HBM (paper assessed true to model)	Attributed ESKD to lack of self-care, inadequate medical care, Lacked understanding of why dietary control was necessary (Ambivalent/Sceptical); Saw dietary control as "externally imposed challenges that dominated life"; accepting vs owning restrictions	Mixed method approach allowed prevalence of patients' beliefs to be quantified
12. Namiki et al (2009)	Living with home based HD	Australia	Purposive n=4	Semi-structured interviews	'exploratory qualitative' approach	1. Accommodating HD at home: 2. Partnership	Consider partnership as support

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
						3. Sense of self (in the present: living with ups and downs; The future: hope and uncertainty	
13. Polaschek (2003)	Living on dialysis: concerns of clients in renal setting	New Zealand	Purposive n=6	Semi-structured interviews (x3)	Critical interpretive methodology (Foucault)	1. Suffering from continued symptoms of ESKD and dialysis 2. Limitations resulting from negotiating dialysis into their life style. 3. Ongoingness and uncertainty of life on dialysis 4. Altered relationship between autonomy and dependence inherent in living on dialysis	Contextualised within the renal setting (see p45 theory; distinguished from other research by using a critical interpretive methodology derived from a Foucauldian lens of the renal setting) "Four concerns that characterise the perspective of people living on dialysis" p45
14. Ravenscroft (2005)	How individuals with diabetes experience kidney failure	Canada	Purposive n=7	In depth interviews	Interpretive descriptive	<u>Dominant themes</u> 1. Diagnosis 2. Illness intrusion	Adjusting to life with ESKD: Personal control and hope Accepting versus managing?

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
						3. interactions with HCP <u>Adjusting to life with ESKD</u> 4. learning to manage 5. finding a balance 6. accepting illness	
15. Rittman et al (1993)	Living with renal failure		n=6 ‡=5	Semi structured interviews; several stages of hermeneutical analysis	Heideggerian phenomenology	Three themes: taking on a new understanding; maintaining hope; dwelling in dialysis. One constitutive pattern: Control: the meaning of technology	How do you maintain caring in a technological enframed world?
16. Salvalaggio et al (2003)	Experiences of relocated first nation dialysis patients	Canada	Not stated n=12	Semi-structured interviews	“Qualitative research methodology”	1. Somatic issues 2. Loss of Independence 3. Impact on relationships 4. Psychological adjustment	Does not describe methodology other than “Qualitative research methodology” Obvious lack of referencing to substantiate research design including a

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
							quote explaining the chosen “immersion/ crystallization” method for data analysis
17. Smith et al (2010)	Patient perspectives on fluid management in HD	USA	Convenience n=19	Semi-structured focus groups	Content analysis	Barriers and facilitators of knowledge, self-assessment, psychological factors, social, physical and environmental factors	Substantially different approach to analysis of data compared to present study. Pre-determined categories guided formation of ‘themes’
18. Tijerina (2009)	Mexican American women’s adherence to HD	USA	Purposive n=26	1. Orally administered survey 2. In-depth interviews 3. adherence data collected from records	Social constructivist Mixed method	Qualitative analysis only 1.Loss (of personal freedom; of identity [because of changes to body image]; of functional ability, independence and ability to maintain social roles) 2. Heightened awareness of death (uncertainty of being a dialysis patient; possibility of problems	

Author/Date	Short Title	Country	Sampling method (n=)	Data collection	Methodology/ Framework	Analysis/Themes	Further comment
						during treatment; death of fellow patients; near death experiences)	
						3. Family dysfunction	
19. Walton (2002)	Spirituality: finding a balance in HD patients	USA	Not stated n=11	1. Semi-structured interviews 2. Field notes	Grounded theory	Finding a balance occurred in four phases: 1. confronting mortality 2. reframing 3. adjusting to dialysis 4. facing the challenge Categories of spirituality were: 1. Faith 2. Presence 3. Receiving 4. Giving back	

Appendix 2: Hunter New England ethics approval letter

19 December 2007



Mr P Sinclair
Clinical Nurse Educator
Department of Nephrology
John Hunter Hospital

Dear Mr Sinclair,

**Re: Patient Perspective on Managing Fluid Gains between dialysis sessions
(07/12/12/5.05)**
HREC reference number: 07/HNE/133
SSA reference number: 07/HNE/134

Thank you for submitting an application for authorisation of this project. I am pleased to inform you that authorisation has been granted for this study to take place at the following sites:

John Hunter Hospital

The following conditions apply to this research project. These are additional to those conditions imposed by the Human Research Ethics Committee that granted ethical approval:

1. Proposed amendments to the research protocol or conduct of the research which may affect the ethical acceptability of the project, and which are submitted to the lead HREC for review, are copied to the research governance officer;
2. Proposed amendments to the research protocol or conduct of the research which may affect the ongoing site acceptability of the project, are to be submitted to the research governance officer.

Yours faithfully

Dr Nicole Gerrand
Research Governance Officer
Hunter New England Health

Hunter New England Human Research Ethics Committee

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Appendix 3: University of Newcastle ethics approval letter

HUMAN RESEARCH ETHICS COMMITTEE



Notification of Expedited Approval

To Chief Investigator or Project Supervisor:	Dr Ashley Kable
Cc Co-investigators / Research Students:	Dr Margaret Harris Mrs Vicki Parker Mr Peter Sinclair
Re Protocol:	Patient perspective on managing fluid gains between dialysis sessions
Date:	15-Apr-2009
Reference No:	H-2009-0077

Thank you for your **Initial Application** submission to the Human Research Ethics Committee (HREC) seeking approval in relation to the above protocol.

Your submission was considered under **Expedited Review of External Approval** review by the Chair/Deputy Chair.

I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective **09-Apr-2009**.

The full Committee will be asked to ratify this decision at its next scheduled meeting. A formal *Certificate of Approval* will be available upon request. Your approval number is **H-2009-0077**.

If the research requires the use of an Information Statement, ensure this number is inserted at the relevant point in the Complaints paragraph prior to distribution to potential participants

You may then proceed with the research. Best wishes for a successful project.

Associate Professor Alison Ferguson
Chair, Human Research Ethics Committee

For communications and enquiries:
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Appendix 4: Information letter



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Information Statement for patients to participate in the Research Project:

Patient perspectives on managing fluid gain between dialysis sessions

An invitation

Patients who undergo haemodialysis in community satellite units are invited to participate in a study designed to understand, from the patient's perspective, the best ways to manage fluid gain in between haemodialysis sessions. The chief investigators for this study are Dr Vicki Parker and Dr Yoni Luxford. Peter Sinclair, is participating in this study as part of his Masters of Nursing research.

The study aims to

1. Gain a better understanding of what patients believe they require in order to maintain adequate fluid gain in between each dialysis session and
2. Gather information that will assist in the development of a fluid management program that is relevant from the patient's perspective.
3. Inform the development of a questionnaire to be used in a second phase of this study

We hope that the results of this research will inform ongoing care and assist in the development of strategies to best help patients achieve satisfactory fluid gain in between haemodialysis treatments.

The study will draw on your views and experiences to make recommendations for improved practice and better management of patients who experience difficulties with fluid weight gain between haemodialysis treatments. Your participation in phase one of the study will not exclude you from the second phase of the study. After the completion of phase one of the study you will also be invited to participate in the second phase of the study if you so choose.

What would you be asked to do?

If you agree to participate in an interview, you will be asked to sign and return the attached consent form. The researcher will then contact you to arrange a date and time for the interview at your convenience. Interviews can be done in your home, before or after your haemodialysis treatment. Alternatively, a private room can be organised and the interview be done during your haemodialysis treatment. The choice is yours. You are invited to bring along to the interview a picture or pictures that you think may help describe your experience and feelings about having to deal with fluid gain in between dialysis sessions. There is no obligation to provide a picture and you may decline to do so should you wish.

The interview will take approximately 40-60 minutes. During the interview you will be asked to talk about your experience with managing your fluid restrictions and the effect it has on your life. With your permission the interview will be recorded on audiotape and later transcribed by a confidential transcriptionist. During interview you may request that the tape be stopped if necessary and edited or erased at any time. You may also request a copy of the interview transcript that you can edit if necessary.

Participation in the study is voluntary and your refusal to participate will not affect your treatment or access to service in any way. Should you choose to participate you can withdraw at any time without giving a reason. If you do decide to withdraw from the study you can elect for the information you have provided to be discarded.

Are there any risks or benefits of participating?

There are no known or potential risks to participating in this study and we cannot promise you any benefit from participating in this research. However it is anticipated that the information you provide will give us valuable information and assist in developing patient centred education initiatives in the area of managing fluid restrictions.

How will your privacy be protected?

You are assured that the information given to us will be de-identified to ensure anonymity.

All information received from you will be strictly confidential. Code numbers will be used in place of names throughout the research process. Completed consent forms and identifying data will be stored in a separate locked filing cabinet accessible only to the researcher and research assistant. No identifying information will be placed on any of the study materials. All data will be treated as strictly confidential and will be stored anonymously in locked filing cabinets or on a password protected computer. Pseudonyms (false name) will be used in publications derived from the research. A pseudonym will be used during the interview to further protect your privacy. On completion of the data collection transcribed audiotapes will be destroyed and all other data will be kept in a secure password protected directory for seven years, after which, all information and data will be destroyed.

How will the information collected be used?

It is hoped that the results of this research will inform the ongoing care and assist in developing patient centred education initiatives in the area of managing fluid restrictions. It may also help to inform applications for ongoing funding and research in the area of fluid management from the patient's perspective with the aim of increasing the effectiveness of care for patients on haemodialysis.

A study summary will be available to participants at the end of the study if desired. This can be indicated on the consent form if you choose to participate.

The information collected will also be used as part of Peter Sinclairs' Masters thesis with your permission. The findings of the study will be shared with health professionals through conference presentations and publication. Your confidentiality and anonymity is assured in any publication of this information.

What do you need to do to participate?

You can participate by agreeing to be interviewed about your experience. Please read this Information Statement and be sure you understand its contents before you consent to participate. If there is anything you do not understand, or you have questions, please contact the researcher.

If you would like to participate please complete and return the attached consent form in the self-addressed envelope included. This will be taken as your informed consent to participate. You will then be contacted by the researcher to arrange an interview at a time and place of your choosing.

Should participation in any of the research activities cause personal distress or discomfort, you will be referred to an appropriate support service (social worker or counsellor) within Hunter New England Health or the community.

For further information about the project, please contact Peter Sinclair on 02 49223122 or Dr Vicki Parker on 0249855925.

Thank you for considering this invitation.

Yours sincerely

Peter Sinclair

Dr Vicki Parker

This research project has been approved by the Hunter New England Area Research Ethics Committee, **Reference No 07/12/12/5.04**. Should you have any concerns regarding your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to

Dr Nicole Gerrand

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Hunter New England Area Human Research Ethics Committee

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Appendix 5: Consent form

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Consent for patient to participate in an interview for the Research Project:

Patient perspectives on managing fluid gain between dialysis sessions

I agree to participate in the above research project and give my consent freely.

I understand that the project will be conducted as described in the Information Statement, a copy of which I have retained. I understand that I can withdraw from the project at any time and do not have to give any reason for withdrawing. I also understand that my rights and access to health care will not be affected as a result.

I consent to:

1. The researcher assistant contacting me to organise a time and location of my choosing for an interview.
2. The interview being recorded onto audio tape
3. Allowing the researchers to use the picture I provide (if I chose to provide one) in any future journal submissions or conference presentations.

I understand that my personal information will remain confidential

I have had the opportunity to have questions answered to my satisfaction

Print name: _____

Signature: _____ Date: _____

Preferred form of contact
to arrange interview: ☐ Phone
☐ In person at the Wansey Centre
☐ Either of the above

I would like a study
summary at the end of the
study ☐ YES ☐ NO

Contact telephone
number: _____

This research project has been approved by the Hunter New England Area Research Ethics Committee,
Reference No: 07/12/12/5.04

Appendix 6: Interview schedule

Interview guide for study: Patient perspectives on managing fluid gain between dialysis sessions

Initial Introduction

1. Seek permission to record interview
2. Introduction of self and purpose of interview
3. Reminder of ethical principles including right to stop interview at any time, stop and erase recorded information if given in error, withdraw from study at any time without fear of discrimination, and that all information will be withdrawn and destroyed at that time
4. Discuss what will be done with the information gathered from this interview.

Demographic data

1. Age
2. Gender
3. Years on RRT
4. Education level attained
5. Employment status
6. Number of dependants
7. Living arrangements
8. Marital status.

Interview schedule

Questioning style was in line with qualitative interview techniques using broad open-ended questioning including questions like:

Please tell me what it is like to deal with fluid restrictions as part of your day to day life?

How do you manage your fluid restrictions?

If artefact brought along: Please explain the meaning behind the item that you brought along today in terms of your experience with managing fluid gain?

Other questions that may be explored:

What do you think your average fluid gain is in between each dialysis treatment?

What is the ideal fluid gain to have in between each dialysis treatment?

What effects does excessive fluid gain have on your body in the short term (ie: day to day)?

What effects does excessive fluid gain have on your body in the long term (ie: over a period of years)?

In the past, what ways have been used to teach you about how to manage your fluid gain in between each dialysis treatment?

Describe the effect these teaching methods have had on you and your success?

What is the best way to assist you in achieving the right fluid gain to have in between each dialysis treatment?

Are there are other ways that this could be done that might not be ideal for you but may benefit other patients? If so, what are they?

Appendix 7: Abbreviations

Acronym	Meaning
CKD	Chronic Kidney Disease
ESKD	End Stage Kidney Disease
HD	Haemodialysis
HCB	Health care belief (model)
HCPs	Health care professionals
IDWG	Interdialytic weight gain
NSW	New South Wales
PD	Peritoneal Dialysis
RRT	Renal replacement therapy
TTM	Transtheoretical Model (of behaviour change)