Abstract

An estimated 200,000 British Columbians are afflicted with some degree of chronic renal disease in which the kidneys can no longer remove toxins from the body and they need a machine to perform this function. Hemodialysis is the most common way to do this and involves the creation of an access directly into the patient’s blood stream that connects to the machine. Two types of vascular accesses are arteriovenous fistulas (AVF) and central venous catheters (CVC). There is limited research available that discusses why patients choose to dialyze with AVFs or CVCs and there is no research that could be found that addresses the transition experience of patients who have utilized both accesses. The purpose of this study was to explore the experiences of hemodialysis patients who had utilized and transitioned from a CVC to an AVF. An interpretive descriptive design was used. Eleven patients participated in semi-structured interviews. Constant comparative analysis was used to analyze the data that uncovered three main themes: Impact, Coping, and Factors influencing impact and ability to cope. Participants experienced the impact of their vascular accesses within the larger context of living with end stage renal disease (ESRD). Regardless of the access, participants’ lifestyles were significantly affected and superimposed on physical and psychosocial impacts. They coped using a variety of strategies including exercising control, focusing on the positive, and struggling to accept. Participants described several factors that influenced the impact of their vascular accesses and their ability to cope including patient education, trust in health care providers, transportation, and family. Participants’ stories of vascular access transition revealed the sense of burden vascular accesses were for self and loved ones, the threat to body image, the all-consuming fear of the unknown, and information challenges. This study elucidates the need for further exploration of issues related to improving the patient experience of vascular access with attention to body image, fear of cannulation, access to resources and trust in health care providers and the information they provide.
Preface

This study was conducted as a requirement for completion of my Degree in Masters of Nursing. Data collection was completed by Angela Romyn with guidance from committee members. Analysis of the data was completed collaboratively with my Committee Supervisor, Kathy Rush and Committee member, Rachelle Hole. Kathy Rush is listed as the principal investigator as required by UBC Okanagan Research Ethics Board.

The writing of this research was done in collaboration with Kathy Rush and Rachelle Hole. Documentation was reviewed by committee members, Rachelle Hole, Kathy Rush and Alietha Martin. A harmonized ethics review and approval by UBC-Okanagan and Interior Health, [H11- 00791] was obtained prior to beginning this study.
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Dedication

Shannon and Nicole, Thank you for your friendship, your support and your shoulders to cry on. I could not have done this without you both.
Chapter 1

Introduction

In 1836, a dialysis patient named Richard Bright described a patient with renal failure:

He is usually subject to constant recurrence of his symptoms; or again, almost dismissing the recollection of his ailment, he is suddenly seized with an acute attack of pericarditis, or with a still more acute attack of peritonitis, which, without any renewed warning, deprives him in eight and forty hours, of his life. Should he escape this danger likewise, other perils await him; his headaches have been observed to become more frequent; his stomach more deranged; his vision indistinct; his hearing depraved; his is suddenly seized with a convulsive fit, and becomes blind. He struggles through the attack, but again and again it returns; and before a day or a week has elapsed, worn out by convulsions, or overwhelmed by come, the painful history of his disease is closed” (Meyer, p.102, 1995).

One hundred and fifty years ago, this story of peril and inevitable death was a reality for people who experienced renal failure. Looking forward to present day, renal disease continues to be a challenge to treat but renal replacement therapeutics have evolved, allowing better management of what often becomes a chronic disease. Renal disease is one of the fastest growing health concerns in British Columbia, in part due to an aging population. Diabetes, hypertension and glomerulonephritis are three of the most common causes of renal disease. An estimated 200,000 British Columbians have some degree of renal disease and many do not even know it (BC Provincial Renal Agency, 2012). While renal disease often progresses at a slow rate, when a person’s renal function declines to a certain point, intervention is needed in order to sustain life.

Dialysis, transplantation, and palliation are the three treatment options for patients with end stage renal disease (ESRD). If a transplant is not available by the time a patient’s kidneys have failed, treatments such as hemodialysis or peritoneal dialysis
are required in order to sustain life. Each dialysis modality comes with benefits and risks. Factors such as patient body type, lifestyle, cognitive ability, and social support critical considerations when selecting the modality appropriate for each patient.

Hemodialysis is a renal replacement therapy (RRT) that involves the removal of blood from the body where it is cleansed throughout a dialysis circuit and then returned back to the body. Hemodialysis requires a vascular access to safely and effectively access a patient’s blood stream for each hemodialysis treatment using one of three options: native arteriovenous fistulas (AVF), synthetic arteriovenous grafts (AVG) or central venous catheters (CVC). AVFs and AVGs are created under the skin in a patient’s arm, leg or chest region using arteries and veins. CVCs are externally located catheters that are inserted through a vein in the neck (jugular), subclavian (upper chest), or thigh (femoral) vein. For a variety of reasons, patients may undergo a change in treatment modality, with the most common involving transition from a CVC to AVF. No studies have looked at the patient experience of making a change in vascular access for hemodialysis treatment. This study will focus specifically on understanding the experience of patients on renal hemodialysis transitioning from CVCs to AVFs.

Given the complexity of all elements of ESRD, the purpose of this research study was to examine one particular aspect of ESRD - vascular access and the patient experience of transitioning from central venous catheters (CVC) to arteriovenous fistulas (AVF). Prior to discussing the purpose further, I will provide some background information regarding ESRD and the various treatment modality choices.
Definitions

- **Arteriovenous Fistula**: A vascular access used for hemodialysis treatments as a way to access the blood stream. Surgically created in the arm, leg or chest area by connecting an artery and vein. Arterial blood flows through the vein, strengthening the vein wall allowing the vessel to be cannulated for each hemodialysis treatment.

- **Arteriovenous Graft**: A vascular access used for hemodialysis treatments. Surgically inserted polytetrafluorethylene graft in the arm, leg or chest that connects an artery to a vein. This graft is used when patients to do not have veins of a suitable caliber to create an AVF. AVGs can be cannulated for each hemodialysis treatment.

- **Central Venous Catheter**: Externally located plastic type catheter that is inserted into neck or leg veins. The catheter is advanced down the main vein that is attached to the heart and the tip rests in the upper one/third portion of the right atrium. The catheter allows access to the blood stream for hemodialysis treatments. Catheters can also be placed in the groin area via the femoral vein.

- **Cannulation**: The process of inserting dialysis needles into an AVF or AVG for the purpose of hemodialysis treatments.

- **End Stage Renal Disease**: Also known as Chronic Kidney Disease, ESRD is the progressive loss of kidney function resulting in the body's inability to clear waste products and excess fluid. Once function has decreased to a certain level, life sustaining treatment is required such as dialysis or transplantation.

- **Peritoneal Dialysis**: A mode of dialysis that involves the use of a patient's abdominal cavity as a membrane across which fluids and waste products such as creatinine and urea are removed from the blood.

- **Health Care Providers**: Includes the renal multidisciplinary team that consists of nurses, nephrologists, dieticians, pharmacists and social workers.

- **Hemodialysis**: A treatment modality for patients with end stage renal disease that involves the removal of waste products, such as creatinine and urea, and
excess fluid through the use of a dialysis machine, artificial kidney and the processes of diffusion, osmosis and ultrafiltration.

- **Vascular Access**: AVFs, AVGs and CVCs that are used for hemodialysis treatments as a way to access the blood stream.

**Treatment modality context**

Dialysis is the mainstay of patients with ESRD until kidney transplantation becomes possible. Although kidney transplantation is the renal replacement therapy (RRT) of choice for many people with ESRD, providing the greatest potential for a longer, healthier, more productive life (Owen, 2003), it is often not an immediate option. Not all people with ESRD have family members or friends who can donate a kidney for transplantation and must therefore be added to a wait list. The waitlist in British Columbia for an adult cadaveric kidney donation is approximately 2 to 6 years, depending on blood type. As of June 14th, 2012 there were 393 people in BC waiting for a cadaveric kidney donation (BC Transplant, 2012).

In British Columbia, as of December 31st, 2011 there were approximately 2033 patients on hemodialysis (PROMIS database). Most dialysis patients will receive a total of 12 to 48 hours of dialysis per week. Patients on hemodialysis require vascular access to the bloodstream by one of three main routes: CVC, AVF or AVG. CVCs are large intravenous lines that are inserted into a neck (internal/external jugular), upper chest veins (subclavian), or thigh veins (femoral) and are left in place as long as the catheter is needed. Risk of multiple complications such as infection, narrowing of the veins, or air in the veins can make care of a dialysis patient with a CVC more complex (Gilpin, 2010).
In contrast, an AVF is created by surgically connecting an artery and vein, usually in a patient’s arm or leg. Over a period of approximately 6 to 12 weeks the AVF matures and the vein wall grows tough and thick enough to tolerate being cannulated 6 or 8 times per week and also to withstand the pressure of the patient’s blood being withdrawn and reinserted via the dialysis needles. For patients without adequate natural vessels for an AVF creation, an AVG can often be created instead.

Comparison of vascular access treatment modes

National and international standards related to vascular access do not consider all accesses equal but give preference to AVFs. The National Kidney Foundation (2012) has published Kidney Dialysis Outcomes Quality Initiative (KDOQI) clinical practice guidelines for vascular access that apply to patient’s with ESRD throughout North America. The most recent guidelines recommend an AVF prevalence of 65% or greater and use of central venous catheters as a permanent access (greater than 3 months) in less than 10% of all hemodialysis patients (KDOQI).

AVF prevalence rates have varied internationally. The 2008 Dialysis Outcomes and Practice Patterns International study revealed that since 2005, Japan, Italy, Germany, France, Spain, the United Kingdom (UK), and Australia have used 67-91% AVFs in their population. As of April 2012, the United States (US) had an AVF prevalence rate of 60.6% (Fistula First, 2012). Canada’s prevalence rates are amongst the lowest, comparable to Belgium and Sweden at 50-59% (Ethier et al., 2008, p. 3219). British Columbia and the Interior Health Authority (IHA) both maintain prevalence rates of 47% AVF, 6% AVG and 47 % CVC (PROMIS database, December 2012). The high CVC rates are well above recommended guidelines.
The Canadian Society of Nephrology published guidelines in 1999 that recommended AVFs as the hemodialysis access of choice because of the associated reduction in mortality, morbidity, and cost compared with CVCs and to a lesser degree, AVGs (Moist, Trpeski, Na, & Lok, 2008). A study out of the US taken from the CHOICE (Choices for Healthy Outcomes in Caring) study in 2004 revealed that patients in the US who were using a CVC for a hemodialysis vascular access were at approximately 50% higher risk for mortality compared to those using an AVF. Patients who were using an AVG were at a 21% higher risk for death than those using an AVF (Astor et al., 2005). Although AVGs have a higher incidence of infection and thrombosis compared to the native AVFs, they are still the preferable access when compared to the CVCs. The National Kidney Foundation’s Dialysis Outcomes Quality Initiative (K-DOQI) recommends the use of AVFs and AVGs to avoid the use of CVCs as the former offer higher blood flow rates and less incidence of stenosis (vessel narrowing), septicemia (infection in the blood), thrombosis (clot formation), and infection. They further recommend the use of AVFs over AVGs as AVFs have been found to have even fewer complications (Astor et al., 2005). Rates of thrombosis are much lower for AVFs than AVGs. AVFs require fewer radiology and surgical interventions while also boasting longer access survival rates. Grafts average approximately 0.5 – 2.0 episodes/graft-year thrombosis events (KDOQI). In regards to infection, approximately 1-4% of all access related infections are associated with AVFs, 11-20% with AVGs and the remainder with CVCs (KDOQI). It is based on these high infection and thrombosis rates along with the various other risks for increased mortality that dialysis programs around the world are focusing on achieving high AVF and low CVC incidence rates.
Transitioning from CVC to AVF

Often the goal of the hemodialysis team is to transition the patient initiating dialysis with a CVC to an AVF or AVG as soon as possible. Despite the staggering statistics related to vascular access, dialysis programs around the world remain challenged in their attempts to increase AVF incidence and prevalence rates. Factors such as timing of surgical referral, vessel adequacy, access complications, limited access to resources and patient refusal can all affect a program's ability to increase its AVF prevalence and incidence rates (Astor et al., 2005; BC Provincial Renal Agency, 2012; Gilpin, 2010). Many patients in the US cannot afford adequate health care coverage and as a result are not diagnosed with ESRD until they are acutely ill. This leads to an urgent dialysis start using a CVC (Gilpin & Nichols, 2010; Graham, Hiremath, Magner, Knoll, & Burns, 2008). Lack of government funding can result in limited hospital resources to create and maintain various vascular accesses. There is a great deal of pressure on renal staff to monitor patients closely and attempt timely referral that will allow patients to consult with a surgeon, have the AVF access created and maturation completed all before a patient is required to start on dialysis. This ability to adequately create AVFs in the pre-dialysis population requires a group effort from the renal multidisciplinary team.

A 2006 Hemodialysis study reported that patients who started dialysis with a CVC and subsequently switched to a fistula, reduced their risk of death by 1.4 fold greater than baseline, whereas patients who remained with a CVC were at a 3.4 fold greater risk (Lacson, Lazarus, Himmelfarb, Ikizler, & Hakim, 2007, p.382). The higher incidence of mortality, morbidity and complication rates amongst CVCs and to a lesser
degree, AVGs, might be expected to prompt patients to choose the safer modality. Data from the Centers for Medicare and Medicaid Service ESRD Clinical Performance Measures Project (1999-2003) showed that once started on dialysis using a CVC, patients of black race and female sex were likely to maintain CVC use for greater than 90 days after the initial dialysis treatment. Another study found a greater likelihood of patients with ischemic heart disease and peripheral vascular disease remaining CVC dependent (Wasse, Speckman, Frankenfield, Rocco, McClellan, 2007) and acknowledged the need for further research to understand this dependence. Moist et al. (2008) discussed that “understanding patient preference, beliefs, values and reasons for refusal will be necessary to appropriately address in this significant proportion of eligible patients those who simply refuse a more permanent access” (p.1731).

Renal health care providers encourage the use of AVFs in the renal population both to reduce the risk of complications linked to CVCs and to comply with national and provincial guideline recommendations. No research could be found that has addressed the experiences of patients who have had both types of vascular access and the transition from CVC to AVF use. Quality of life is a major determinant in whether an individual chooses to start hemodialysis treatments (Hakin & Lazarus, 1995). While dialysis can affect physical health, psychological well-being is also altered by dialysis. Because psychological considerations play an important role in a patient’s perception of their quality of life, equal efforts should be focused on research that pertains to patient perception and experience. The findings from this research are important to enable health care providers, particularly nurses, to develop effective interventions to improve patient’s experiences and quality of life (Cleary & Crennan, 2005). Nurses need to
understand the experiences of patients living on hemodialysis from the very perspectives of those who are receiving the care, the patients. Understanding patients’ experiences can give nurses guidance in tailoring care to what patients feel are their greatest needs. Further, the knowledge generated from the study will assist renal health care providers in organizing vascular access care services, allocating funding and developing front line care strategies that will help provide exceptional care for the renal patient population.

**Purpose**

The purpose of this project was to explore the experiences of hemodialysis patients who have utilized and transitioned from a CVC to an AVF. In this research, I focused specifically on understanding the patient’s experience of each type of vascular access and its impact on the client’s physical, emotional and mental well-being as well as the transition experience of changing from one type to another. This study sought to answer the question ‘What are the experiences of hemodialysis patients who initiated dialysis using a CVC and then were transitioned to an AVF’?

The patient experiences that were revealed through this study helped identify what patients find important with their vascular access care. Through the understanding of a patient’s experience, we hoped to be able to understand the process of their transition, their ability to cope and the supports needed as they travel through their vascular access journey.
Chapter 2

When a person’s renal function declines to a point where the body is unable to filter out harmful wastes or extra fluid effectively, aggressive treatment becomes necessary. The decision to start hemodialysis is one that requires copious amounts of information and clarification. If a patient does decide on hemodialysis there are three main types of vascular accesses that are used: AVFs, AVGs and CVCs.

In his 1982 paper, Eric Cassell discussed how suffering occurs in whole persons who encounter the destruction of the known self until the threat has passed or a new sense of identity has been achieved. Health care workers have the ability to relieve or perpetuate patient suffering depending on the quality of care provided. “ESRD is not one health state but many different states with difficult and challenging transitions between them. Patients need help in negotiating these transitions in order to experience an optimal quality of life” (Hutchinson, 2005, p. 276). Although psycho/social/spiritual transitions and high mortality cause suffering in ESRD patients, they are also an opportunity for healing (Hutchinson, 2005). Vascular access concerns and complications can be a source of stress for hemodialysis patients. It is imperative that we begin to understand how patients cope with the stress and suffering associated with the various vascular access types as well as the suffering that occurs with transitions from one access type to another.

“Kutner (1987) suggested that supports from existing and emerging social worlds are key factors influencing a person’s ability to rebound from the initial jolt of the diagnosis (i.e. sudden vs. insidious onset of kidney failure); to positively deal with the ambivalence concerning the quality of life on dialysis; and to effectively manage uncertainty associated with longevity, the risk and benefits of

Once a patient has a vascular access in place, they often endure a long road of complications and revisions to ensure the vascular access remains functional. In the Interior Health Authority, there are 12 dialysis units located over an extremely vast geographical area. Most radiology and surgical procedures required for the maintenance of these accesses are located in the tertiary centres, Royal Inland Hospital (RIH) and Kelowna General Hospital (KGH). Some complications with CVCs such as blood clots (thrombosis) and infection can be managed with pharmacological agents at the patient’s home dialysis site. Complications with AVFs and AVGs almost always require surgical or radiological intervention that is only available at the tertiary sites. This means that some patients are required to travel distances of up to 6 hours over multiple, often snow covered, passes to have procedures performed on their vascular accesses, which are their lifelines to the life sustaining treatment of hemodialysis. Since a large population of dialysis patients are elderly and many are retired or on disability, most patients find it difficult to find transportation to these tertiary areas for treatment, let alone afford the cost of travel to these places.

As the IHA Renal Vascular Access Coordinator (RVAC), I see the struggles that all renal patients go through on a daily basis. Physical complications such as blood clots, vessel narrowings, and bulging weakened areas on the vein require urgent medical attention in an environment where those resources are already stretched with limited numbers of vascular surgeons, operating room (OR) time and hemodialysis treatment availability. The stress of the physical complications associated with the
vascular access cause emotional stress for patients and their families as they are often required to travel for medical procedures, which contributes to financial stress as well.

**Experiences of Hemodialysis Patients Literature Review**

Over the years there has been a strong focus on providing ESRD patients with the evidence-based knowledge needed to follow and comply with treatment requirements. Although a few research studies have investigated how family members cope with the adjustment to ESRD, there has been little research that has addressed the patient’s experience and their ability to cope with their disease (Tsay & Hung, 2003; American Nephrology Nursing Association, 2006).

To understand the currently available research related to the experience of hemodialysis patients, an extensive search of the databases: CINAHL with Full Text, MEDLINE with Full Text, PsycINFO, Sociological Abstracts, and EMBASE was performed using the broad terms ‘qualitative’, ‘hemodialysis’ and ‘haemodialysis’, resulting in 800 articles.

Of the 800 abstracts that were reviewed, only 17 articles addressed the patient experience. Of the 17 articles, 7 addressed the concept of current hemodialysis patients in a tertiary or community based unit (Curtin, Mapes, Petilo, & Oberley.,2002.; Gregory et al.,1998.; Hagren, Pettersen, Severinsson, Lutzen, & Clyne.,2001.; Hagren, Pettersen, Severinsson, Lutzen, & Clyne., 2005.; Kaba et al., 2007.; Mitchell et al., 2009.; & Sadala & Lorencon., 2006). The remaining 10 papers included patients who were on peritoneal dialysis, home hemodialysis or had previously been on dialysis but had since been transplanted. These papers were excluded because patient experiences
in these situations were expected to differ vastly from the tertiary and community based hemodialysis group. The findings from the key studies addressed the sense of loss patients experienced when they were diagnosed with renal failure and the unfamiliarity of the physical and emotional symptoms. Key emotional factors related to technology, family/peer support and health care provider interactions. Participants struggled to regain a sense of self after their diagnosis and to feel “whole” again following the disruption of their personal worlds by illness.

Health is often taken for granted until someone is stripped of it, with sometimes devastating results for both self and others. This holds true for individuals who are required to start dialysis. Life as they knew it is forever altered due to ongoing health concerns and required changes to personal routine. A diagnosis of renal failure and the need for dialysis to sustain life is accompanied by an abundance of emotions, ranging from fear to anger to despair. A patient in a study by Kaba et al., (2007) described their realization of the powerful effect that hemodialysis had on the self.

“This disease is very difficult, and no matter how hard you try, no matter how much strength you have, you will be weighed down with anxieties and get depressed. You are losing your self-control. I personally very often feel depressed because I asked ‘why me?” (p.871)

Quite often the diagnosis of renal failure came as a complete surprise to the patient. Sadala & Lorencon (2006) discussed how the patients in their research study talked about the reality of being thrown into a life that was limited by rules and restrictions. Along with the rules and changes in lifestyle came anger, bitterness that life could not continue as it once was, and a feeling of loss of control.
Patients do not always have a choice as to what vascular access they receive. If starting on hemodialysis acutely, they are often forced to have a CVC inserted to allow for treatments to start immediately. After a patient has had a chance to adjust to their hemodialysis treatments, they may wish to switch from a CVC to a more permanent access such as an AVF or AVG. Factors such as the condition of their vessels and cardiac status all need to be considered when determining a suitable access. Occasionally these factors eliminate options for the patient and the decision is no longer theirs to make. The ability to choose the access of their choice can affect how a patient adjusts to hemodialysis.

When a dialysis patient starts their hemodialysis journey, numerous physical and emotional obstacles act as daily reminders of the life that they once had. Strict dietary limitations, fluid restrictions and large quantities of medications to take are not only mentally hard to adapt to but can increase the personal burden of the disease on the patient. Lok (1996) stated that inability to be physically active due to fatigue and muscle cramping was often a major complaint amongst dialysis patients.

Patients diagnosed with renal failure, come to rely on various support systems to help them through their renal replacement journey especially the multidisciplinary health care team. Much of a patient’s time is spent with nurses and physicians often with dependent relationships developing as dialysis patients “surrender” themselves to the medical staff in order to feel cared for. Gregory (1998) & Hagren et al., (2005) reported that patients described their need to feel welcomed by the staff and to be surrounded by staff who were experts in their field. There was also a strong need to be seen as an individual who was still valued despite the need for dependence on others. Some
participants in the studies conducted by Gregory (1998) & Hagren et al., (2005) described how inexperienced staff, cluttered work environments and lack of adequate staff, contributed to a negative dialysis experience. The availability of nursing staff and willingness of these staff to listen had a strong influence on how patients perceived their experience.

Participants in all studies acknowledged the need to accept the new norm in their lives and learn to live with the disease. Some participants decided to start “living in the moment” and to start “taking each day as it came and making the best of it” (Curtin et al, 2002, p. 619). For many participants, coming to terms with the limitations that were now imposed on their lives was key to the adjustment process.

Patients who rely on dialysis for survival are all too aware of this fact and live with the constant reminder that their very existence is dependent on a piece of technology. In the article by Hagren et al. (2005), Merleau-Ponty’s Machine-Body philosophy was discussed. According to Merleau-Ponty (1962), when an instrument or tool is connected to a person’s body, it stops being its own “thing” and becomes part of the person it is attached to. The hemodialysis machine then becomes part of the patients’ body because without the machine, the self is no more. Dependence on the machine can result in life being sustained but there is also a loss of freedom. Hagren et al. (2005) revealed how one patient felt about the lack of freedom associated with hemodialysis. “Time is the worst part of it, because it takes too much time. From you, that is. You can’t do anything spontaneous, you become very tied down” (p.296). Another patient in the same study stated the following:
I have five hours of it, so I’m the first to come and the last to leave. We lie there for four hours. Then you start wrapping it up, which means there is some action. But honestly, I have to say that often when I come here; it seems more grey and dismal each time…” (p.296).

Vascular access issues can also relate to the machine-body philosophy. An arm or a leg can be considered an extension of the self but after a body part is surgically altered to allow for life sustaining treatment, it can be looked at as a machine, an extension of the dialysis technology that has now consumed the patient’s world. For patients with vascular access creations, seeing the needle marks, the plastic tubing protruding from the neck, or feeling the distinct pulsatile thrill of an AVF or AVG can be a constant reminder of the treatments that now have encapsulated their lives and have robbed them of time that should be spent living their lives the way they wish to.

Maintaining a functioning vascular access can be a challenging task for renal patients, especially considering that they are usually stricken with multiple co-morbid conditions that can negatively affect their vasculatures. A patient in Sadala & Lorencon’s (2006) study stated the following.

I live 100 km from here and I have a complicated fistula. Not everybody can reach it. They are used to me here and I don’t want to go anywhere else. I want to feel good too, right? So I come here despite distance” (p. 138-139).

Hemodialysis patients rarely have an access created that functions smoothly. There are often follow up surgical procedures to improve blood flow, remove thrombus, repair aneurysms or replace damaged catheters. Veins and arteries come in a variety of different diameters and depths beneath the skin. Radiology procedures are often required to expand the diameter of narrowed veins, confirm placement positioning of a CVC and to remove fibrin coating that can build up on the internal lumen of a CVC. Many patients require these procedures multiple times to maintain the life of their
access regardless of access type. It’s unfortunate that patients must worry about whether their access will work properly for them when the task of having to undergo hemodialysis can be daunting enough.

Given the staggering statistics regarding vascular access morbidity, mortality, and complication rates, it is surprising that the national and international AVF prevalence rates are not higher. When taking the statistics into consideration, it seems extremely important for health care providers to understand what vascular access works best to meet the physical, mental, and social needs of each and every patient. It is also important to understand the experiences of patients who have had both a CVC and an AVF to gain insight into why the existing prevalence rates provincially, as well as locally, remain so low.

Vascular Access Patient Experience Literature Review

A literature search was conducted specific to the patient experience of vascular access with AVFs and CVCs. AVGs were excluded from the search since they are not considered the best option for permanent vascular access and are not encouraged because of the high rate of mortality and morbidity due to the synthetic material used (Moist, Trpeski, Na, & Lok, 2008). They are considered the middle ground in terms of vascular access and the goal of the literature search was to examine the patient experience in regards to transitioning from a CVC to an AVF.

An extensive literature search was performed using the databases, CINAHL, Medline and PubMed using the search terms: “arterio-venous or arteriovenous and
patient experience or interview, “hemodialysis or haemodialysis”, “catheter*”, and “vascular access”.

**Table 1. Vascular Access Literature Search (2012)**

<table>
<thead>
<tr>
<th>Search</th>
<th>Spring 2011/Fall 2012</th>
<th>Articles Found with Search</th>
<th>Non Renal Related Articles</th>
<th>Articles Relevant to Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1st Search</td>
<td>“arterio-venous or arteriovenous and patient experience or interview”</td>
<td>69</td>
<td>49</td>
<td>0</td>
</tr>
</tbody>
</table>

The extensive literature searches uncovered six papers that related to venous access, one from a nurse perspective (Wilson, Harwood, Oudshoorn, & Thompson,
Wilson et al. (2010) addressed the increase in CVC incidence and prevalence and low AVF use across Canada. The purpose of the study was to describe the culture and everyday practice of vascular access cannulation of AVFs from the perspective of the hemodialysis nurse. Themes such as lack of fistula prevalence, difficulty convincing patients to have an AVF, lack of cannulation skill, and cookie cutter care practices emerged from the study (Wilson et al., 2010). Nursing staff study participants thought AVF prevalence was thought to be low for a number of reasons. First, patients with CVCs that are working well may not understand the need to switch to an AVF. Second, some patients have an extreme phobia of needles and this may prevent them from agreeing to an AVF creation. Third, patients see other patients with AVF complications and do not want to go through a similar experience (Wilson et al, 2010). While these are valuable observations, they are told from a nursing perspective and are not the direct views of the patients involved.

Axley and Rosenblum (2011) surveyed patients who had CVC accesses, and were candidates for, but resisted AVF creation. The purpose of their study was to uncover their reasons why patients resisted having an AVF created. They found that patients resisted AVF creation because of previous negative surgical experiences, previous AVF attempts that had failed, fear of pain/cannulation, feeling too old for
surgery, waiting for a transplant, and body image concerns (Axley and Rosenblum, 2011).

Xi et al. (2011) reported similar findings from their small qualitative study aimed at understanding the attitudes, beliefs, preferences and values of patients who refused creation or use of an AVF (Xi et al., 2011, p.3302). They found that patient’s decisions to refuse an AVF were influenced by poor previous experiences with AVF including cannulation and appearance, information from other patients, and the refusal to be influenced by the mortality risks of a CVC due to the desire to live day to day (Xi et al., 2011). Peer influence was held in high regard with this study’s participants and was noted to be a significant knowledge source for them. Trust in the health care providers was important to the study participants and when it was lacking participants did not fully embrace or acknowledge the information they were given (Xi et al., 2011).

These findings are corroborated by Chaudhry et al. (2011), whose prospective observational study sought to understand why patients persistently used their CVCs. Patients chose the CVC rather than the AVF for non-medical reasons such as convenience and comfort. They also decided against the AVF because of esthetics and past access complications.

Only one study reported how patients with ESRD on hemodialysis negotiated living with an AVF (Richard & Engebretson, 2010). Participants in the study acknowledged the difficulties surrounding the creation and maintenance of AVFs and described vulnerability, body awareness, dependency, mistrust of health care providers and stigma. There was concern regarding the required dependency on health care
providers and the mistrust in regards to the creation and cannulation of AVFs. This mistrust in the health care providers was in response to participants’ feelings of vulnerability. The vulnerability was the participants’ way of holding on to and protecting their holistic self (Richard & Engebretson, 2010). Patients were unsure that the AVF was actually an access that would work well for them. Internal stigma such as gender identity, access appearance and body awareness were identified. Some patients were strongly affected by the physical disfiguration that an AVF occasionally caused. External stigma was also present and associated with the strong physical and verbal responses that people had to seeing a patient’s access (Richard & Engebretson, 2010). People often treated them differently because they were now presumed to be “sick”. There can be an element of pity that is portrayed that is not wanted by the patients. Although this study included informants who had a history of several types of vascular accesses, focus was on their experiences of living with an AVF.

Few studies have addressed patient perceptions of converting from one type of access to another. Wasse et al’s. (2007) quantitative study is the only study found within the literature that examined patient perceptions of utilizing both CVCs and AVFs. Patients were surveyed who used an AVF at first dialysis and day 60 of ESRD, AVG at first dialysis and day 60, CVC at first dialysis and AVF at day 60, CVC at first dialysis and AVG at day 60, and CVC at first dialysis and day 60. The findings showed that chronic AVF users reported lower family burden while those who started dialysis on a CVC and then converted to an AVF reported less satisfaction that those who were long term CVC users (Wasse et al., 2007).
No studies to date have captured qualitatively the transition from one type of vascular access to another. Understanding the experience of patients who have had both an AVF and CVC at some point in their ESRD experience and transitioned from one to the other has the potential to fill gaps in knowledge about current prevalence for each of these vasculature access modes. Further, it may provide insights about the impact of switching vasculature access modalities. There is a plethora of literature that documents the importance of AVFs and the dangers of CVCs from mortality, morbidity and complication perspective, however, the story of the patient behind the access is missing. The proposed research was intended to help bridge the gap between patient perspective and the health care workers need to understand this important perspective.
Chapter 3: Methodology

Qualitative Research

There is a sign that hangs in Albert Einstein’s office at Princeton that reads ‘Not everything that counts can be counted and not everything that can be counted counts’ (Harris, 1995). This clearly illuminates the debate between qualitative and quantitative research methods and their relevance to the nursing profession. Although quantitative research methods such as the gold standard randomized controlled trials have provided the medical system with extremely valuable information, there are certain aspects of health care that are not addressed with traditional quantitative methods. “Qualitative researchers aim not to limit a phenomenon – make it neat, tidy, and comfortable – but to break it open, unfasten, or interrupt it so that a description of the phenomenon, in all its contradictions, messiness, and depth, is represented” (Mayan, 2009, p.11). Kearney (2001) acknowledges that perhaps the most helpful aspect of qualitative research within the health care field is for conceptual use whereby “nurses gain access to the experiences and observed actions of patients and others and thereby expand their stores of theoretical understanding, which reveal more helpful approaches to care” (p.146).

Within qualitative research itself, there is often a struggle to determine the proper framework or method for conducting research that is particularly meaningful to one’s area of interest. Nursing is no stranger to this struggle and as a result, new and innovative research methods, such as interpretive description, have been conceptualized based on a need to use frameworks that truly meets the needs of this profession (Thorne, 2008). Interpretive description was developed from a desire to
better meet the research needs of the nursing community. Developed by Thorne, Kirkham and MacDonald-Emes in the late 90s, interpretive description is described as a strategy for excavating, illuminating, articulating, and disseminating the kind of knowledge that sits somewhere between fact and conjecture, but which is of central importance to the applied disciplines such as education, community development, human geography, and the health professions (Thorne, 2008, p.15).

As such, “[t]oday’s nursing science seeks as its truths a set of ideas that have application potential but remain amenable to reconsideration in the light of varying contexts, new concepts, new ways of understanding and new meanings” (Thorne, Reimer Kirkham, & MacDonald-Emes, 1996, p.172).

**Design**

This study uses an interpretive description design. This design acknowledges the personal contextual components of an individual as well as relationships between individual and societal influences. The foundation for this methodology is that of a “smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding.” (Thorne, Reimer, Kirkham, & Flynn-Magee, 2004, p. 5). Simply put, interpretive description provides for a classic method to research an idea and relate the findings back to nursing practice.

Based on the philosophical underpinnings of constructivism and naturalistic inquiry, interpretive description follows key axioms: the absence of pre-selection or manipulation of variables and no a priori theory is encompassed. The “philosophical framework of interpretive description assumes that absolute, wholly objective knowledge is unattainable through empirical analysis” (Hunt, 2010, p.1285). The
theoretical and practical knowledge that researchers bring to the project is also acknowledged within this methodology.

The purpose of pursuing research guided by interpretive description comes from an actual practice goal and from an understanding of what we know and don’t know based on empirical data (Thorne, 2008). Questions that best fit with the interpretive description methodology attempt to coax out an inductively derived description of a phenomenon that is in need of an interpretive lens. Taking inspiration from hermeneutic tradition, interpretive description acknowledges that individuals in a clinical setting are not content with raw description but rather with the themes, ideas and relationships that are uncovered through description. Constant reflection and re-examination of themes and ideas is where the clinical practitioner begins to truly understand the story behind the phenomenon and relate the inductive process back to practice to improve client care.

**Researcher Positioning**

I am a clinical nurse specialist who has spent many years working as a bedside nurse; as such, I am committed to ensuring that front line staff have access to research findings that illuminate the patient experience. It is this patient experience that can help mold care for current patients as well as future patients.

Thorne (2008) discusses how scaffolding within the interpretive descriptive methodology requires that the study be grounded “in the discipline to be able to discern its scope and boundaries, its angle of vision on problems of concern, and its philosophical underpinnings in relation to what constitutes knowledge” (p.67). Being able to consider a study’s disciplinary nature and to consider the manner in which it
aligns itself with the knowledge and practice of the discipline is very important (Thorne, 2008). For this present study, front line hemodialysis staff were the individuals who most closely interact with hemodialysis patients and facilitate the utilization of the various vascular accesses. Thus, scaffolding was achieved through the existing strong knowledge base that was provided by front line staff, renal multidisciplinary team members, and myself in the vascular access specialist role.

Given my position as the IHA RVAC, I have a great interest in understanding the patient experience as it is this experience that helps direct the care I give each and every renal patient within the health authority. Thorne (2008) discusses how positioning “helps us understand what the motivation for the study entails and what the potential audience for any new knowledge that arises from the study might be” (p. 69). Constant reflection regarding the desire to explore this topic was necessary throughout the study to ensure biases were kept in check and data was not skewed based on personal motivation. In my current role I have face-to-face contact with many of my patients on a daily basis and I hold a perspective of how the interactions with each of these patients have developed the way I practice today. It was not my intention to allow my own perspective of a client’s experience or my own practice experiences to enter into the study in a way that would influence the findings. However, as a vascular access nurse with many years of experience, the knowledge that I brought to this study was extremely valuable as it provided insight into patient responses and also helped direct questions during the interview that allowed for deeper, more thoughtful responses leading to a strong inductive analysis. My background allows the question to be asked, “What is the patients experience in relation to what I already know as a vascular access expert?”
My position as the RVAC also allowed me to consider factors relating to hemodialysis that many may not be aware of, such as geographical distances and availability of resources. I made a conscious effort not to bring any personal factor or related theories into the study as I did not want to direct the data analysis based on these pre-existing thoughts. I did, however, use my `hunches` and existing knowledge to help direct the interview questions in a way that would allow for greater reflection and sharing of experiences. Any prior knowledge or biases were clearly identified before entering into the research project to allow for project integrity. Thorne et al. (2004) explained that “newer researchers need considerable external guidance to support the kind of disciplined reflexivity required to avoid clinging to the assumptions with which they entered the study or, conversely, to prevent premature closure as a way of making sense of the emerging conceptualizations” (p.10).

**Selection of Participants**

The participants selected for this study were patients who received hospital/tertiary or community unit based hemodialysis treatments within the IHA. Purposive sampling was used as it allowed the selection of individuals who could help in forming an understanding of the area of interest and meet the needs of the study. The intent of purposeful sampling is to obtain a group of individuals with common traits, concerns or conditions to allow eventual findings to produce data that are as true or reasonable as possible to the clinical audience (Thorne, 2008). While the purposive sampling allowed us to specifically target patients who all suffered from renal failure and had all started dialysis on a CVC then transitioned to an AVF, we did attempt maximum variation within this narrowed selected group. Maximum variation was sought by
including participants from tertiary/hospital and community based dialysis units, with short and longer term histories of living with a CVC (two months to up to five years) before transitioning to an AVF. By including participants who had utilized CVCs for varying lengths of time, there was hope that participants would be able to provide in-depth discussion of potential complications related to length of use. In terms of demographic information, both male and female participants were included with an age range younger than 30, older than 70 and all ages in-between to uncover age-related variations in transition.

Recruitment Process

Once ethical approval was received from the University and Health Authority Ethics Board, recruitment began using a third party, arm’s length strategy. A letter (See Appendix A) was sent to the renal educators and patient care coordinators (PCC) at the various renal program sites in Royal Inland Hospital, Penticton Regional Hospital, Kelowna General Hospital, Kootenay Boundary Regional Hospital, and East Kootenay Regional Hospital explaining the study and asking them to participate in the recruitment of study participants. The educators and PCCs were asked to distribute recruitment flyers (See Appendix B) to all dialysis patients who met the age and vascular access life span inclusion criteria. These flyers asked the potential participants to contact me directly if they wished to participate in the study. Recruitment flyers were also placed in the patient common areas at each dialysis site that allowed all patients to visualize the flyers when they arrived for and departed from their dialysis treatments.
**Data Collection**

Interviewing, the most commonly used method of data collection within the interpretive description framework, was used to understand participants’ experiences with vascular access devices. By spending time with individual patients who had experienced a similar phenomenon, I was able to hear the stories and experiences that, although told by the sole individual participant, collectively brought enlightenment to areas of interest for health care providers. The emotion and depth of each patient’s experience of transitioning from a CVC to an AVF allowed important concepts or themes to unfold.

Semi-structured interviews took place in a location of each patient’s choice away from the dialysis unit. The decision to conduct the interviews away from the dialysis unit was intended to allow patients to feel at ease in an environment where they could freely discuss all aspects of their care without fear of repercussion. All interviews were face-to-face to allow for observation of non-verbal behaviour. In assuming the researcher role, although impossible to fully disconnect myself, I attempted to separate myself from my clinical role and the comfortableness that is associated with it. Thorne (2008) describes this disconnect as if “you are taking on the role of someone who does not know, who has entered the study participant’s world in order to know, and who cannot bring that expertise into shaping the conversation as it unfolds” (p.110). Interviews ranged in length from 30 to 90 minutes and with each participant’s permission was audio digitally recorded. The semi-structured interview guide was developed (See Appendix D) to help patients freely share their experiences and tell their detailed stories. Through the interview process I aimed to uncover emotions related to the need to start dialysis, to
have a CVC inserted, and adjust to life with a CVC. I also wished to uncover experiences of the patient regarding their experience with CVCs and AVFs as well as the transition from the CVC to an AVF. A background demographic questionnaire was used to collect information about the participants, such as the number of access surgeries and procedures they had undergone as well as their perceived satisfaction rating of both their CVC and AVF (See Appendix E). Field notes were kept detailing interviewer thoughts, questions and participant non-verbal’s that would complement the digital recordings. These notes were reviewed and added to immediately following each interview. My thoughts, feelings and questions pertaining to the research process and findings were recorded in a reflective journal.

Data Analysis

Interpretive description requires an analytic form that allows one to look deeper than the superficial meanings of ideas and concepts. When exploring research using interpretive description, nurse researchers need to get to know each of their cases intimately, abstract relevant common themes from within these cases, and produce a species of knowledge that will itself be applied back to individual cases. In order to undertake this effectively, “they must engage in both the ethereal abstractions of theorizing and the earthbound concrete realities of the practice context in order to produce sound and usable knowledge” (Thorne et al, 1997, p.175). In other words, nurse researchers undertake a process of thinking critically about the patient experience to uncover valuable knowledge that can be related back to future practice.

The analysis technique utilized was constant comparative analysis. This analysis strategy is used for examining individuals with similar illnesses or who share similar
experiences. This technique is useful “to study those human phenomena for which the researcher assumes that fundamental social processes explain something of human behaviour and experience, such as stages of grieving or processes of recovery” (Thorne, 2000, p.69). Interpretive description can utilize this analytic process to develop ways of understanding human phenomena within the context in which they are experienced. The process of data collection and analysis occurred concurrently.

After each individual interview, I listened to the digital recording and reviewed my field notes from the interview. A transcriptionist was used to transcribe the data verbatim; a confidentiality agreement was signed by the transcriptionist before the first interview was submitted (See Appendix F). When each transcript was complete, it was returned to me whereupon I conducted accuracy checks (comparing the written transcription with the digital recording). Concurrent data gathering and analysis informed the ongoing data collection and subsequent interviews.

In line with a constant comparison approach, data analysis began with the very first interview and involved a systematic approach to organizing the data into meaningful chunks for further in-depth analysis. Transcripts were read and re-read, and any themes, ideas or important statements were highlighted. The use of various coloured highlighters allowed for themes and like statements to be classified into similar or relatable categories. Open coding was utilized which involved “fracturing the data – taking it apart and examining those discrete parts for the similarities and differences they reveal[ed]” (Thorne, 2008, p.145). In collaboration with my committee, a coding framework was developed. Once this framework was finalized, all the interviews were analyzed again using the common themes. The use of an appropriate coding schema
allowed for the grouping of like thoughts and ideas and for distinction between thematic
groups. Broad, open coding is encouraged in Interpretive Description as it allows for the
incorporation of statements and general ideas into categories (Thorne, 2008). These
broad based groupings then allow ideas to be narrowed down and filtered in a variety of
ways depending on the researcher(s) analytic lens. As future interviews were
transcribed and labelled for themes and ideas, it was necessary to return to previous
interviews to uncover new thematic groups that had surfaced. By transcribing and
reading each interview immediately after it was conducted, it allowed me to pose
questions in future interviews that had the potential to uncover deeper meanings and
hidden themes. As each level of coding occurred, I approached my committee for
guidance as their various perspectives gestured to themes previously not recognized.

As data was gathered, collection strategies and thoughts were carefully
monitored in the form of an ‘audit trail’. An audit trail provided the ‘eventual audience
with sufficient information about the decisional processes made along the way to be
able to recreate the logic whereby the data exist in the way that they do and the analytic
process takes its eventual shape’ (Thorne, 2008, p.138).

Morse (1995) discusses the importance of content and the meaning behind the
content rather than quantity in determining when saturation has been reached or the
point at which interviewing more participants will not bring additional content to the data.
Morse (2000) outlined several factors that can help determine elements of saturation
which were considered within this study. These elements included looking at the quality
of the data, the scope of the study, the nature of the topic, the amount of useful
information acquired, the number of interviews conducted, and the type of qualitative method and design used.

The findings were conceptualized with the aim of informing practice and advancing clinical care in new directions. As Thorne (2008) explains, this involved ‘an interpretive manoeuvre within which you consider what the pieces might mean, individually and in relation to one another, what various processes, structures, or schemes might illuminate about those relationships, and what order and sequence of presentation might most effectively lead the eventual reader toward a kind of knowing that was not possible prior to your study’ (Thorne, 2008, p. 163).

As such, my analysis and findings were shaped by my research aim to inform clinical practice for renal multidisciplinary teams.

**Rigor**

As with all qualitative methods, maintaining credibility and rigor is extremely important to consider when utilizing interpretive description. Interpretive description has evaluative criteria that can be applied in an attempt to maintain credibility and rigor. These principles include epistemological and representative credibility, analytic logic and interpretive authority (Thorne, 2008).

Epistemological credibility outlines how the research question must be in line with the epistemological standpoint. Interpretive description requires an actual practice goal and offers the opportunity to deconstruct previously assumed knowledge of a phenomenon, allowing new insight and interpretation of experiences that can be related to practice (Thorne 2008). This study clearly stated a research question that was aimed at enhancing practice. Surface answers to generic questions can lead a researcher to deeper meanings particularly when examining the entire context of the interview. Because discourse is so embedded within human experience and societal norms, the
researcher must take this into consideration in the interview process so as not to confuse the subjective truths. As the researcher, I engaged in reflexivity through self-awareness and critical self-reflection in my role as the Vascular Access Coordinator. This reflection revealed any potential biases and predispositions that I held that had the potential to affect the research process and conclusions such as my thoughts on access to care within IH or why patients choose not to have AVFs created. This reflexivity enhances the epistemological credibility within the study. As interviews constituted my main form of data, I retained some humility about what I was uncovering and felt obligated to acknowledge the particular relationship to time and place that my findings reflected. This humility also ensured that the dominant aspects of my own personality and passion did not steer the interactions in predictable directions (Thorne, 2008).

Representative credibility details how the theoretical claims must be in relation to the phenomenon that was studied. In regards to this study only the experiences of patients who had transitioned from a CVC to an AVF were sought with no reference to the experience of patients who utilized other forms of accesses. No assumptions were made about patients who utilized these accesses or failed to meet the inclusion/exclusion criteria of the study. Flexibility with sampling allowed for the greatest diversity of participants who met the selection or inclusion criteria. Given the small sampling population available, expanding age limits, open gender selection and expansive geographical boundaries helped ensure the greatest possibility for diverse participation.

Analytic logic surrounds the need for the researcher’s reasoning for interpretation of findings and knowledge claims to be clearly reported. Through the use of constant
comparative analysis of the written interviews and audio recordings along with multiple sessions of colour coding using both broad and detailed themes, the inductive reasoning process is evident within this current study. I also met regularly with my supervisory committee to discuss the coding framework and analytic process. This clearly defined process of analysis supports the scaffolding of this study.

Finally, interpretive authority ensures that the researcher’s interpretations are trustworthy by revealing their own biases or experiences. Within this study, the incorporation of quotes for all themes based on patient experience was used to support and demonstrate trustworthiness. The principles that were generated to ensure rigor and credibility within qualitative research ‘all derive from an appreciation of the knowledge claims within which a method is grounded and an awareness of the social context into which our research reports will be directed’ (Thorne, 2008, p 225).

Aside from the need to ensure rigor and credibility in terms of research design, there were also other factors considered. Since interpretive description is focused on helping uncover information that can be related back to the practice, the research was designed to actually benefit the patients. Moral defensibility demands that we ensure our participants are necessary to the process and that the data collected will truly provide benefit (Thorne, 2008). In a way one would see this as a benefit versus risk analysis. With this current study there was a clear benefit to the renal patient population. Through the examination of patient experiences, there is the potential for future renal patients to benefit through enhanced health care services and greater understanding by the health care providers. The strict maintenance of confidentiality allowed the participants to tell their stories while providing little to no risk to them.
Another aspect of ensuring credibility of the project is to examine whether the knowledge that is created from this research will actually aid my specific discipline. With contextual awareness, it is important that research findings are seen as contextual in the recognition that many supposed realities will not easily withstand the test of time and with probable truth, researchers must acknowledge that there is value in recognition that certain knowledge is a probable truth or as close as we are to going to get to it (Thorne, 2008). The knowledge that was uncovered within this study indeed has the potential to help shape future nursing practice within the renal population. The findings show various areas where practice can be enhanced ranging from emotional to facility system support service care.

These various guidelines and evaluative criteria help show rigor and credibility within the study but the basic questions always remain: Why were we asking this question? How do we know that the knowledge gained will help clinical practice? How might practice change based on what the research has shown? These are important questions that I asked myself over and over as the research was being carried out.

**Ethical Considerations**

Working under the guidance of my thesis committee members, Kathy Rush and Rachelle Hole, I adhered to the guidelines of my professional bodies including the Canadian Nurses Association, College of Registered Nurses of British Columbia, and the Canadian Association of Nephrology Nurses and Technologists ethical codes. I obtained written approval from the University of British Columbia Clinical Ethical Board, the Interior Health Authority Research Ethic Board and the Interior Health Renal Director for permission to conduct this research. I completed the Interagency Advisory

Participants’ rights were protected through use of third party recruitment strategies. Renal educators and patient care coordinators within the Interior Health Authority were informed of the study via an informational letter (See Appendix A). They recruited interested patient participants with the assistance of a recruitment letter. Patients were able to contact me via telephone or email. Patients who contacted me were asked to sign a Consent form (See Appendix C) which outlined the research study’s background information, purpose, process and ethical considerations. Risks, benefits, voluntary guidelines and confidential processes were disclosed. In addition to the signing of the consent form, participants were asked to complete a demographic questionnaire (See Appendix E). Participants had access to the consent for more than twenty four hours before the interview took place. Participants were informed that they could withdraw from the study up to 2 weeks after the interview had taken place and when doing so, could request that the information they provided be removed from the study and/or destroyed. During the research period, all transcripts and field notes were kept under lock and key in a secure place in the primary investigator’s office at UBC-Okanagan. Files were kept on an USB data stick that was kept in the secure primary investigator’s office and backup copies were stored on a password protected computer in accordance with ethics board requirements. Only myself and my thesis committee had access to the information generated from this research. This research will be destroyed after the mandatory five year hold period for all research material.
Participants were permitted to choose the location for their personal interview. Allowing participants to choose a location, facilitated their comfort and ensured confidentiality during the sharing process. Participants were reminded that their names and any personal identifying markers would be removed from the study and replaced with numeric codes. Anonymity was more likely given that participants were spread out geographically amongst the various sites across IHA. Participants will be provided with a copy of the research findings once the study and analysis is complete.

As the IHA RVAC, I provided care for my participants during the course of this study. I took special care to ensure that the line between researcher and access coordinator was not blurred. It is challenging for clinical researchers to ensure that participants do not view the research interview time as an opportunity to have one-on-one privileged care with their nurse specialist (Thorne 2008). To ensure that participants were clear about my role, I clearly defined that I was meeting with them for an interview in my capacity as a researcher. I explained to each of my participants why I was interested in understanding their subjective experience from a professional perspective and from a research “learner” perspective. I informed my participants that during the interview session I would not be in the role of their vascular access nurse but rather in the role of a researcher who wanted to understand their story. I explained that the interview would not be a time to answer questions related to their personal care but rather it would be an opportunity for them to be able to speak freely about their feelings and emotional experience, free of repercussion.

Throughout the interview process my personal opinions or concerns were not expressed as this had the potential to alter the participants’ perceptions of what was
appropriate to share. In my role as the vascular nurse, I was very conscious not to force my beliefs on the participants, but rather to allow each interviewee to decide what treatment option was best for them. As their nurse, it is my job to provide them with the tools and education that can allow them to make an informed decision. It is for this reason that I felt the participants were open to discussing their experiences related to vascular access.

Informed consent that utilizes interpretive description can be a difficult and ongoing process. It can best be described as “an ongoing moral obligation, enacted in verbal as well as non-verbal behaviour, with the goal of creating the optimal conditions to ensure that the people we study reveal what they are comfortable with and no more” (Thorne, 2008, p. 114). Discussing personal experiences can be tricky and requires careful attention from the researcher. For this study, I used a semi-structured interview guide that included gentle probing questions that helped guide experiential discussions to deeper levels. The interview guide helped participants understand the general direction of the experience that the researcher was wishing to explore. Discussing certain aspects of a personal experience can be difficult or even traumatic for patients. As the researcher, I paid close attention to the verbal and nonverbal cues of the participants to ensure that they were not feeling coerced into discussing any aspect of care with which they were not comfortable. Participants were reminded regularly that they had every right to not talk about any aspect of care that made them feel uncomfortable.

Throughout the research process, harm and benefit were constantly being considered. As stated earlier, I entered into this study with participants who knew me as
their nurse specialist, someone who guided their care and had a higher level of expertise. The risks associated with the study included the potential for participants to feel restricted as to what they could share for fear of repercussion. This risk was addressed through a full disclosure process at the beginning of the study that clearly stated the objectives of the study, the capacity in which I was involved and the participants right to share as much or as little as they felt comfortable doing. There was the risk that participants might worry that their identity would be revealed to fellow patients and staff. By reviewing with each participant the steps that would be taken to ensure confidentiality, I believe that this risk was addressed. Participants were reminded that the information they shared during the interviews would not be part of their medical chart and would in no way dictate the care they received from the health care staff in the hemodialysis unit. By reinforcing my positioning as a researcher who was wishing to understand the experiences of patients who transitioned from CVCs to AVFs, I was disclosing that I was their equal during this research process and held no power over their decisions regarding the level of disclosure they were comfortable with.

I believe that the steps taken to address risks allowed the potential benefit of the study to emerge. The experiences of the participants helped uncover themes that can potentially enhance the resources available to all hemodialysis patients. Participants may or may not see a personal benefit from having participated in this study. It was my hope that the experiences shared by each participant will have allowed for personal reflection in addition to providing information that will help shape vascular access care and guidelines for years to come.
In attempting to locate myself within a discipline, I acknowledged that my primary goal was to perform research that would ultimately address issues related to my clinical environment. As a result, I found myself explicitly located within my nursing domain. I stayed true to the inductive nature of inquiry and entered the field without the intention of confirming preconceived theories; instead I worked to uncover themes that would aid in the development of theory and implementation of change within the clinical environment. Thus, building on existing knowledge, I aimed to produce research findings that will enhance practice and will inform tools on how best to organize structures that affect all aspects of vascular access care, thus enhancing patient care experience.
Chapter Four: Findings

Description of Study Participants

Eleven patients participated in interviews over a two month period in the fall of 2011 (See Appendix G). All participants started hemodialysis using a central venous catheter (CVC) and transitioned to an arteriovenous fistula (AVF). There were five male and six female participants who ranged in age from 31 to 68 years. Three male and 3 female participants received their hemodialysis treatments from a tertiary care dialysis unit while the remaining 2 male and 3 female participants received care at a community based dialysis unit. The length of time that these participants had been on dialysis ranged from 18 months to 8 years. Length of time that the participants spent using their CVC for dialysis ranged from 6 months – 3 years while the length of time that the participants had been using their AVF’s ranged from 9 months – 6 years. At the time of interview, all participants were on hemodialysis using an AVF as their current vascular access.

A patient who is on hemodialysis does not start their journey with ESRD at the time they start hemodialysis treatments. Their story begins hours, days or even years before hemodialysis becomes a reality and no two stories are ever the same. One chapter of a patient’s ESRD story revolves around their vascular access journey. In this chapter the findings from the participant interviews regarding their vascular access journey with AVFs and CVCs will be discussed according to three main themes: Impact, Coping, and Factors influencing impact and ability to cope. While the three themes are presented as discrete sets of findings, there is a relationship between the three themes that truly tells the story of how these participants experienced their vascular accesses.
All three themes are connected through the evolving stories of each participant. These 3 themes and their accompanying subthemes will be described and supported through the use of quotes from the interviews.

Once the decision to start dialysis was made, the choice of having a CVC inserted or an AVF created was determined by the urgency for treatment, patient preference, and the best option for the patient based on medical and physical needs. Regardless of whether the participants had an AVF or CVC, there were various factors that affected how each access impacted the participants’ lives and their experience with hemodialysis.

**Impact**

Participants experienced the impact of their vascular accesses at multiple levels within the larger context of living with ESRD. Starting on hemodialysis began the vascular access journey that was often long and plagued with many challenges. Having a vascular access created was often not straightforward and required strength and courage for participants and their loved ones. Many patients who required a CVC did so under urgent circumstances when dialysis was desperately needed. The process of having a CVC inserted was extremely traumatic for many participants as they had to cope with the reality of their disease in addition to this external device that was essentially their lifeline. For some participants, achieving a well-functioning AVF was a long, tedious process as there were numerous complications requiring multiple surgical and radiology interventions. The necessity of these multiple procedures took an emotional and physical toll on participants and their loved ones. Participants described
the impact of vascular access according to three main themes: Physical, Lifestyle and Psychosocial.

**Physical**

When participants were required to start dialysis, this meant the creation and utilization of a vascular access had a physical impact that was measurable, tangible and easily described. These physical impacts affected the participant's internal self in ways that could be felt or visualized. Participants described the physical impact of their AVFs and CVCs both negatively and positively. Physical impact sub-themes that surfaced in relation to both AVFs and CVCs were Pain, Complications, and Benefits.

**Pain.** Physical pain was experienced in relation to both AVFs and CVCs but to a greater extent with the former. Only 2 participants described physical pain associated with their CVCs and these were episodic situations associated with catheter removal and infection. One middle aged female participant described her experience with pain at the time of CVC removal. “When it came time to pull it (CVC) out though, that was pretty bad, pretty painful because the calcium build up around it so bad that they had a heck of a time getting it out”(Participant 5).

In contrast, pain was mentioned multiple times in association with AVFs on an ongoing basis. One middle aged female participant referred to pain associated with the creation of the actual AVF while four participants described painful cannulation, so intense at times it required “be[ing] put on Ativan because I pass out just from the pain” (Participant 5). Participants described the need to endure the pain related to the AVF. According to one young male participant,
...it hurts some days too, my shoulder will start throbbing and got to get a bag of ice cause you can’t take the needles out or, I don’t know exactly what would happen if you have to start all over and there’s no way I want to start all over again. So it’s like you kind of got to put up with the pain. (Participant 2)

Complications. One of the most significant impacts of the vascular access devices for participants were the complications that developed. Complications were associated with both CVCs and AVFs but presented differently depending on the access. Physical complications specific to the CVC related to the functioning of the access such as blood clot formation in one or both of the CVC lumens or malposition of the catheter tip within the vein. One young female patient described the physical manoeuvres she needed to do in order for the CVC to function.

...then all of a sudden the machine would start honking at you and you’d have to like, cough this way or lean this way, or you know, like put the bed this way and oh my goodness! Then try to stay still that way for four hours. (Participant 6)

Complications noted which were AVF access specific included numbness and pain around the surgical incision, painful and cold access hands, bruising on the arm after surgery or difficult attempts at putting needles in, and large bumpy areas on the vein. The impact of these complications was heightened by a lack of preparation as detailed by one middle aged female participant.

...they didn’t tell me that I was going to get a cold hand all the time or a numb hand afterwards, or pain shooting down my arm afterwards, or some nerve involvement or whatever...numbness. None of that was told to me. I discovered that on my own. (Participant 3)

Benefits. Although the impacts of the venous accesses were primarily negative – pain and complications– participants identified benefits, particularly with AVFs. Participants discussed how the AVF provided them with more effective dialysis;
...a few months after I started using it (AVF) then I just started realizing “Oh, this is the best I’ve felt since my kidney first failed” and I was back doing pretty much everything that I had been previously, other than just a little bit lighter. (Participant 9)

The AVF was much easier to keep clean which resulted in a perception of fewer infections for one middle aged female participant.

I think the fistula is better for me. Both physically and emotionally. It’s easier to clean. Like the areas are easier to keep clean so there is...I know there is still a chance of infection, but in my mind there is less of a chance because it is easier to keep clean. (Participant 4)

**Lifestyle**

Often the physical sequela of both CVC and AVF accesses had a direct impact on a patient’s lifestyle, although the impact for each access presented quite differently. Time, Financial, Inconvenience and Access Protection were the major impacts on participants' lifestyles.

**Time.** Time was a common element that emerged in participants’ experiences with their accesses. Participants described the onerous time and exhaustion involved in traveling to and from the dialysis appointments, being attached to the machine for a minimum 12 hour period per week, and physically recovering after a dialysis treatment. Consequently, participants had little interest in spending any additional time on issues related to their kidney disease.

The impact of time was experienced differently depending on the access. When using their CVCs for dialysis, participants were able to leave the dialysis unit almost immediately after their treatments. A couple of participants found the CVC required less time to start and stop their dialysis treatment, which allowed them to regain valuable time for themselves. One middle aged male discussed his thoughts regarding this time
issue. “The only thing I miss about having the catheter was just a tiny bit of convenience, because you came in, opened your shirt and you were hooked up, then unhooked and you were out of here” (Participant 9).

In contrast, with their AVFs, participants needed additional time for needle removal after treatment was complete to allow the bleeding to stop. A middle aged male participant discussed the time convenience of the CVC versus the time inconvenience of the AVF. “It’s easier (with the CVC). You don’t have to hold your sites after and it’s a long time as it is four hours in there, and then you gotta hold the site (on the AVF) for another fifteen-twenty minutes” (Participant 11).

Complications that developed with CVCs often increased the time participants spent receiving their dialysis treatments. Blood clot formation within the catheter lumen that prevented blood withdrawal or instillation through the catheter into the vein, required interventions to remove the blood clots that disrupted patients’ time. When blood clot formation was severe, patients had to go home without treatment and return the next day to attempt the dialysis treatment again. One young female participant described how this extra time spent in the dialysis unit disrupted the limited amount of free time she already had.

So I had this thing in my neck so I had one run, and then the next day for the next run I came in, and from the beginning it was beeping and honking and it was just put in two days before that. And I didn’t even get a full run that day from the central like so ya, that was pretty freaky. (Participant 6)

Participants described the time consuming process of having an AVF created. Surgical consults, pre-surgical screening appointments and surgical dates were required in order to achieve a desirable end result: a well-functioning access. Many
participants narrated, often in great detail, the multiple surgical attempts required in order to achieve a working AVF. Time spent travelling for multiple appointments related to vascular access was a major imposition for some participants from rural communities. Participants who voiced concerns over travel times needed anywhere from 1 to 7 hours in order to get to a hospital centre where their selected procedure could be performed. One middle aged female based in a community dialysis unit discussed her concerns regarding the time needed to travel. “...it was a pain because you get tired of travelling back and forth just about every six months or whatever (for radiology procedures)” (Participant 5). Another community program based middle aged female participant discussed her unhappiness with the extremely time consuming travel to vascular access tertiary care centres.

I live 7 hours from the hospital that does all the fistula repairs. I have had so many problems with my fistula that it seems that we are travelling quite a lot. One time we drove all the way there and then they told us that they couldn’t fix my arm until next week so we had to drive all the way home. I cried all the way home cuz I was so frustrated. All that time spent driving...for nothing. (Participant 4)

Surgical procedure bumping was an issue participants faced in conjunction with their vascular access creations. Study participants travelling for their AVF creation often had a CVC in place being used as a vascular access. As a result of having an alternative access, surgical personnel did not view the AVF creation as a life or limb emergency and these patients were often bumped from the OR slate or replaced by more urgent procedures. One young male participant from a community unit discussed his concerns regarding surgical bumping.

So we drive all the way to Vancouver for surgery and I’m all dressed in the gown and everything and they come in and tell me my surgery is cancelled until next week. I was so mad because it took my dad 5 hours to drive me here and we
have a hotel room booked and everything. My dad even took time off work and now he needs to do it again next week. It’s not right. (Participant 2)

Most of the study participants found themselves in need of urgent surgery at one point in their vascular access journey. For many participants it occurred as a result of clot formation in their AVF, requiring hospital admission and being placed on the surgical waitlist. If the surgeons were not able to complete the surgery that day, the participant was put on the OR waitlist for the next day and often required to stay overnight in the hospital.

**Financial.** Participants felt a strong financial impact directly associated with the need to have vascular accesses created and maintained. Patients waiting for basic AVF creation are often not admitted to the hospital prior to surgery, and can spend multiple days in a hotel room waiting for their surgical time. Persistent bumping of their surgical procedure can result in patient’s accruing large financial bills in order to have a safer vascular access created.

The cut off for financial social assistance made it impossible for some dialysis patients to receive the funding needed to travel for multiple vascular access procedures. For one middle aged community based male participant, the financial strain placed on his family due to his inability to work, along with the need to travel for multiple renal related medical appointments, caused him and his family great emotional stress. He described the need for his wife not only to work two jobs to support the family but to take time off of work to travel with him for vascular access procedures and lose the precious income that helped them survive.
I can’t drive when I have an operation done so that means the wife has got to take time off work and stuff like that. It’s financially draining. Because like gas and those hotel rooms aren’t cheap anymore. (Participant 8)

The often dire financial circumstances for many of the participants made travel for urgent vascular access care quite difficult to arrange on short notice. Patients, such as this older adult female participant, were forced to pay out of pocket and then seek reimbursement after the travel had been completed since social assistance was not in the practice of providing advanced financial assistance.

They (social assistance) won’t give you money to go up there for your procedure but when you came back with all your bills and receipts....I mean all your receipts, and then they would reimburse you a certain amount of money, not all of it but a certain amount. (Participant 7)

Another participant, a young female participant who relied on social assistance as her only source of income discussed her struggles with the ability to fund trips for urgent surgical care.

I fight like crazy with social assistance every time I need to go for surgery, to the point where I am bawling my eyes out on the phone because they are so rude to me and we actually filed formal complaints and stuff because they are just like giving us the run around and it was like “I have to go in for surgery right now” I don’t have the time or energy to deal with this crap. So that was rough. (Participant 6)

The strict income cut off to qualify for social assistance-related emergency funding created considerable financial burden for patients. Many patients, much like this middle aged female participant, earned just slightly above the financial cut off point and had to come up with funding for travel on her own.

My husband and I both work. We don’t earn a lot but it’s enough that we don’t qualify for assistance to travel. I mean, don’t they (social assistance) understand how much it costs to travel and stay in the big city for my surgery? Even when I’m in the hospital, my husband has to stay in a hotel. It’s so expensive. And my husband has to take time off work too so that means we have even less money coming in each month. (Participant 4)
**Inconvenience.** Some participants detailed the inconvenience of access creation and maintenance of functioning that affected their physical functioning and lifestyle. For some, the inconvenience factor was greater than for others. A significant inconvenience was the limb that was chosen for an AVF creation. One middle aged female participant stated that the only vein with a diameter that was adequate to use for an AVF creation was in her dominant arm, that required her to learn how to use her non-dominant arm for simple household tasks as well as needling for self-cannulation. Additionally during her dialysis treatments she was forced to keep her dominant access arm immobilized to prevent the dialysis machine from alarming. Self-cannulating with the non-dominant hand was a scary process because of the delicacy of the procedure.

...they said it wasn’t as good as the right (the vein), but if it was adequate that I was willing to try that but they didn’t give me that option. So now I’ve got it (AVF) in the right arm and I need to write, and I can’t write with my left. I’ve got a needle with my left, I’ve got a...it’s like learning...the learning is twice as hard because it’s with my left hand. (Participant 3)

Due to the potential for vascular access issues to arise, some participants, such as this middle aged female, described missing out on elements of their lives such as family functions and not being able to make spontaneous plans.

I was not happy because that means I can’t visit my grandchildren in Ontario without a lot of pre-planning. There is no spur of the moment “I’m coming” anymore. (Participant 3)

The inconvenience of not being able to make spontaneous plans added to this participant’s stress burden. One older male adult participant stated that it was an inconvenience to have to find someone to look after his animals while he was away for his surgery.

Well, I’ve got animals at home. You know you gotta hire somebody to look after them and to look after your house, especially when you’re going to be....Like
okay, say my appointment is for 10 o’clock in the morning. Okay we leave here at 5, we get down there and “oh no, you gotta stay another day”. (Participant 8)

**Access protection.** Protecting the accesses had a significant impact on participants’ lifestyles although the need for this protection differed between the CVC and AVF. The external nature of the CVC and its direct access to the blood stream via a vein through the chest wall put participants at constant risk for infection. One middle aged female participant described the challenges of preventing infection with the dressing often falling off due to sweating and making it difficult to keep the CVC exit site clean and dry, “...during the night I roll around so much and it would catch and I’d even tape it down and then sweating and stuff the tape would undo and it was just very uncomfortable” (Participant 5).

The risk of bacterial infection due to trapped moisture under the participant’s CVC dressings restricted or required adjusting how they performed day to day activities. Protecting their accesses from infection meant they could no longer take showers or swim as one middle aged female participant laments: “It wasn’t very good because you can’t shower. You had to sponge bath all the time because you can’t get that wet. If you get it wet, you have a chance of infection and then it complicates things” (Participant 10).

Participants spoke of times when they forgot about self-protection such as this middle aged male participant.

There was an incident out on the street where somebody was being harassed and without thinking about it I was out there getting involved and right away I just thought of if somebody grabbed a hold of my chest with the catheter. Then I was just standing there and I just all of a sudden focused on that and I found myself putting my left shoulder forward and everything and I got out of that situation, but that’s ...I just walked away thinking “What was I thinking?”. (Participant 9)
Although AVFs are located underneath the skin, in a vein within an arm or a leg, they also required the patient’s protection. Regardless of the overall reason for protection, the AVF was their lifeline. Participants altered how they performed their day to day activities. Sometimes this involved taking care to protect the AVF from being bumped in activities such as wrestling with their son or ensuring the vessel was not compressed and blood flow impeded by avoiding the lifting of heavy objects like firewood with their access arm.

Despite the need to protect the access from damage, participants commented on the benefits of having an AVF and how it positively affected their lifestyles. There was no longer the worry that the CVC would get in the way of their daily lives and get caught on things. In a sense, some patients felt they could resume their normal activities as did this middle aged male participant.

...a few months after I started using it (AVF) then I just started realizing “Oh, this is the best I’ve felt since my kidney first failed” and I was back doing pretty much everything that I had been previously, other than just a little bit lighter. (Participant 9)

**Psychosocial**

Although participants described multiple physical and lifestyle impacts of their accesses, the psychosocial impact was discussed to a great extent. Participants described the psychosocial sub-themes of Fear and Body Image. Along with these sub-themes, there were statements made that praised the benefits of having an AVF that were notably absent from the discussions focused around the CVC’s.

**Fear.** Without a well-functioning access, hemodialysis could not be performed and a patient’s life was threatened. Participants expressed fear that the access would
not work when they showed up for dialysis. They often queried whether health care professionals could fix a non-working access. Participants’ fears stemmed from the literature they had reviewed when learning about their accesses, or from vascular access complications they had experienced or witnessed of fellow dialysis patients. A middle aged female participant described her fear of a dysfunctional CVC. “Every time I would come in (to dialysis) I would dread whether you know if it (CVC) was going to you know stop working again and again and again”. (Participant 5)

AVFs evoked greater fear than CVCs for the majority of the participants. The primary fears related to potential complications, cannulation, and the surgical experience. Participants expressed considerable fear of the unknown future as they waited for their newly created AVFs to mature and be used. The waiting period for the maturation of the AVF was difficult and at times participants, such as this young male, wanted to hurry it along. “I thought maybe you know I’m rushing too quickly or maybe I’m going to be the one guy in the whole hospital that can’t use a fistula”. (Participant 1)

One middle aged female was concerned that she would never have an AVF that would mature to the point where it could be used. “…the first two (AVFs) didn’t work at all. They didn’t even mature. They didn’t connect for some reason and they weren’t positive the third one would work…” (Participant 4).

Just because a participant’s AVF matured to the point where it could be used for dialysis, there remained the risk of complications and a failure to function in the future. Participants described living in fear that their accesses would stop working and whether they could be fixed. One young male participant discussed the fear of what would happen to his access if it stopped working.
I guess I just don’t get how it (AVF) started to shrink or plug up and that; I guess that’s kind of a concern. It’s like is it going to happen again? And how many times can it before something else happens? Mmm, it’s kind of nervous like, what happens after this one collapses? What happens now, do you start on the other arm? (Participant 2)

A young female participant relayed her fear of this particular complication,

I mean I was kind of scared because I’d never gone through it (AVF clotting) before so I didn’t really know. Um, but, I ended up doing it and I think I was pretty...I was scared but I also wasn’t because I was more scared of the unknown in a way... (Participant 6)

Infection is another potential complication that can occur with AVFs as with CVCs. Infections were only mentioned by participants who had previously experienced an access infection such as this older adult female participant.

I don’t know maybe not everybody looks after theirs (AVF) as well, but I’ like to take care of it. Ever since I got that infection, that’s it for me. I’m scared not. I have to keep it clean and I think I overly do it. (Participant 7)

Cannulation was a major source of fear for participants with AVF accesses. Access into the AVF requires two needle insertions into the vessel each dialysis run in order to access the blood and allow it to be removed from the body, cleansed and returned back to the patient. Cannulation of an AVF is not always straight forward and can be affected by location, size and depth of the vessel within the limb. Needle phobia was a very real concern for several participants in this study such as this middle aged male participant.

...I was scared of the needles. That was my big concern was with the needles and I didn’t want to get poked every time I come in and stuff so, that’s why I liked that catheter because it worked good. (Participant 11)

At times the fear of impending cannulation produced a strong visceral response as one young female participant describes,

So I’m like okay, I’m a tough girl I can do this. And then she (nurse) is about to go in with this needle and I’m looking at it and going “Oh my gosh, this is going to be
crap!” And you get a little sweaty and clammy and just kind of like okay. (Participant 6)

This participant mentally prepared herself for the cannulation process through the power of self talk which enabled her to work through the fear. The idea of self-cannulation was daunting and fear of self-cannulation was one of the reasons participants insisted that the nursing staff insert the needles into the AVF for each dialysis treatment. One middle aged male participant discussed his fear. “I don’t like them (needles). I still don’t like them. That’s why I’m not going to do it (cannulate) myself” (Participant 8). Another middle aged female patient discussed her fear of self-cannulation which was often overwhelming for her.

...the first time they put the needle in they blew my vein and I ended up with a huge bruise, so they couldn’t take me back for a few days to try again, so then the second time I was really scared because I didn’t want that to happen again. It was quite painful. It was very frightening because I thought “how am I ever going to do that myself without injuring myself? (Participant 3)

Participant’s fears sometimes stemmed from a lack of confidence in nurses’ abilities to cannulate. A few participants intimated that some nurses were more skilled cannulators than others and this inconsistency led to some uncertainty about whether the AVF cannulation would be successful. One middle aged male participant discussed his experience with nurse cannulators.

Oh it’s hard to explain…I mean it (needle) goes in and you know, a couple of times there is a certain nurses would just nhh, nhh, nhh (sound of pushing)...takes a run from the other side of the room to stick it in. I can’t really say that for sure (if it is nurse error why the cannulation attempts are not successful). They do their best. (Participant 8)

The participant’s journeys towards a well-functioning and well maintained AVF were often long and circuitous, involving multiple surgical and radiology procedures. All participants experienced multiple surgeries, anywhere from 2 to 9, and anywhere from 1
to 6 radiology interventions in order to achieve and maintain a well-functioning fistula.

Participants who had required fewer surgeries or interventions to maintain their vascular access did not discuss the psychosocial impact related to their AVF to the same extent as participants who had experienced numerous radiology and surgical interventions

Some participants expressed the fear of potentially needing multiple medical interventions to achieve a functioning AVF and maintain it. A young female participant described her fear of the unknown in relation to her AVF.

...I was more like scared of the unknown in a way. And I think now it’s even worse knowing what happens because now when you come in and you, you know, you realize you are not getting the needles and all of a sudden like my stomach will drop and I’ll get all panicky and like sweaty and like, just dread and upset and angry and pissed off that you know, it’s (AVF) clotted again. (Participant 6)

Along with the fear associated with the need for surgery, this same participant expressed the sense of relief when one of her surgeries was a success.

I talked to the surgeon myself. He said it was beautiful. He saved it. He got rid of all the infection and that no, no, no you still have it. And the relief that I had from that because I thought “okay good”. Now I get to have this beautiful fistula in my leg. It’s something that works for my body and be able to use it and not have to start from square one again. (Participant 6)

**Body image.** Feelings of self-consciousness in relation to body image were particularly prevalent amongst the young male and female participants with CVCs because the access was highly visible on their chest wall or groin area. This was less of an issue for older adult participants. Emotions such as embarrassment and being “grossed out” by the lines surfaced within the participants’ stories much like with this young male participant.

...I just remember I couldn’t look at my lines for the longest time. It just grossed me out to see it sticking out of me. And so I looked at the line and that kind of made me even more woozy... (Participant 1)
Young and middle aged participants expressed concerns about how other people would react to the CVC if they saw it, whether it was in the privacy of their home or out in a public setting such as a beach. One middle aged female felt extremely self-conscious. “I didn’t like it (CVC). I felt very self-conscious. I felt like everybody could see them. They couldn’t but I thought they could...” (Participant 4). One young male participant longed to feel comfortable around friends or in public settings.

...I mean I’m young. I like going to the beach in the summer time. You know, like it’s just embarrassing having that. You know? And like I was saying I couldn’t even look at it in the mirror or nothing....I have a roommate. I can’t walk around the house with my shirt off. (Participant 1)

Patients’ self-consciousness led them to keep their CVC’s hidden from public view or in some cases, from themselves.

Although participants understood the need for the CVC to provide their life sustaining treatment, some participants voiced feelings of ugliness as a result of having the CVC sitting externally where it was visible to the world. One middle aged female discussed her body image concerns.

...I didn’t actually feel very appealing to my husband at the time. I felt not really...not a good body image. Very upset about the whole thing because of all these wires and tubes coming out of my body. I thought I was really ugly at the time. (Participant 4)

Another participant, a young female, discussed her body image concerns with her CVC.

Well, first of course being a young woman it is sort of like kind of you know its vanity right? You’re young and you’ve got these ugly tubes sticking out of you and it’s not exactly a cute accessory to be you know stylin’ but um, then again, it’s like “Well at least I’m alive”, so okay I’ll have to live with it. (Participant 6)

Not only was the CVC associated with feeling ugly but many participants viewed the catheter as a physical reminder to themselves, as well the outside world, that they had an actual illness that made them different from everyone else. Both young and
older adult participants discussed feelings related to other people knowing they were sick with a chronic disease such as this young female participant.

...just because the catheter is so...they are such a visual reminder you know...but to the world looking in on you, they see the line sticking out of your shirt or whatever, so they know something is wrong with her right. (Participant 6)

An older adult female participant also talked about how she felt having other people stare at her CVC and have them wonder was what wrong with her. “Oh it kind of bothered me around people because they would look and stare and then you know, you’d have to explain what it (CVC) was and so on and so forth”. (Participant 7)

Young male and female participants, in particular struggled with feeling comfortable with their bodies as a result of having a CVC inserted. Two middle aged female participants voiced concerns over feeling attractive towards their spouses. Both young and middle aged participants were self-conscious about the impact of the catheter on sexual intimacy with their partners as they felt less attractive and desirable. Those who were in new relationships or had no long term relationship were especially affected. One middle aged female discussed her issues with intimacy and her CVC, “…to be sexually intimate with a man makes me feel very self-conscious. I don’t like that” (Participant 3). A young male discussed his thoughts around intimacy and his relationship with his new girlfriend.

(It was hard) Definitely the way that other people would see me right? Like having a brand new girlfriend. You could imagine like you know you’re going to have sex with them right, well you know you don’t want to have this thing in the way you know? Right? (Participant 1)

Surgical scarring and discoloration of skin surrounding the access was of particular significance for participants with AVFs following multiple surgical procedures to achieve and maintain a well-functioning access. This scarring was associated with
body image concerns for five of the young and middle aged participants, both male and female.

I don’t like the discoloration in my arm and stuff like that either because I’ve got to cover that up when I go out...It’s actually being discoloured in the area of the needles. It’s turning dark, which is quite noticeable. (Participant 3)

A middle aged female discussed how she felt ugly from her AVF surgical scars.

I don’t like the scars. I still sometimes have trouble with the scarring that I have (from the AVF surgeries). Um...sometimes I say to my husband “I feel so ugly”, but it is a relief because it is better than having tubes coming out of your body. (Participant 4)

One middle aged female participant described how the sense of ugliness even seemed to make the vein look bigger and increased her sensitivity to others reactions.

So I have this big vein in my arm now and the longer I have it, the bigger it seems to grow. It looks like a big snake under my arm. I think it looks kinda creepy and sometimes I will catch my husband looking at it and then I try to hide my arm. I know I got have this thing (AVF) but really, I feel really ugly with that thing in there. (Participant 10)

Despite fear and body image concerns, participants discussed benefits associated with having the AVF rather than a CVC. Since there was no external component to the AVF, participants did not experience restrictions on swimming and showering as with the CVC as noted by a young male participant, “…I thought “Oh good” because now I can have a shower again and then be able to go swimming, because I really miss swimming” (Participant 2). A couple of the female participants expressed happiness at being able to wear certain items of clothing that they were not able to wear when they had a CVC in place.

...I ditched the ugly tubing sticking out of my neck and I could wear like normal clothes, with like a v-neck or whatever now all that kind of stuff. Ya, it was, ya I was kind of glad I had it (AVF). (Participant 6)
A young female participant expressed the benefit of having an AVF as putting the control back in her hands as to whether she disclosed her chronic disease.

...with a fistula, you wouldn’t know that I am sick at all. So that is kind of nice. When you are done dialysis, you take out the needles and then it heals right up. You hold ten minutes and then you’re good to go. So that is kind nice too...dialysis is my little secret. (Participant 6)

Coping

As patients travelled through their vascular access journey, they were met with events that proved challenging. These events had an impact on the patient’s physical being, lifestyle and psychosocial experience. The ability of the patients to continue their journeys depended on how they coped with the circumstances that confronted them. As participants shared their personal stories, they discussed various aspects of coping that were reflected in three sub-themes: Exercising Control, Focusing on the Positive, and Acceptance. Although presented separately they were intertwined since participants relied on all of their coping mechanisms, collectively, in facing challenges during their vascular access journey.

Exercising Control

The time frame from becoming symptomatic and diagnosed with ESRD to starting on dialysis greatly affected participants ability to understand what was happening and to cope with what was to come. While some participants had a significant time period between the point of diagnosis with ESRD to the point when they needed to start dialysis, 9 of the 11 participants interviewed were diagnosed with ESRD and needed to start dialysis urgently or with little warning. One significant factor affecting how study participants’ coped with vascular access challenges was their level of control. Control for study participants related to being a part of, and having a voice in
how their health care was delivered. The ability of participants to have some degree of control regarding their health meant that their personal needs, desires, and wishes were taken into consideration when decisions were made that helped steer the direction of their care. Participants used several strategies to exercise control in coping with their vascular access experiences. Sub-themes emerged such as Harnessing Determination, Questioning, Making Choices, and Making the best of their situation.

Harnessing determination. The ability to harness inner strength and determination helped participants feel more in control of what was happening in terms of their health and their vascular access experiences. Despite knowing the potential need for multiple surgeries to maintain a well-functioning AVF, many participants had the determination and willpower to handle whatever obstacles they faced. An older adult female participant discussed her determination and willpower. “I’ve had a lot of things happen to me health wise you know, in my lifetime and I’ve got this willpower you know, so I think I could have handled it (multiple surgeries for their AVF)” (Participant 7). One middle aged male discussed how he would get to his scheduled vascular access appointments despite the challenges.

...I mean I’ve walked 25 miles in cowboy boots to get home before and I mean ya sure my heels were really sore and my calves didn’t want to stretch out for a long time but I mean I can do things that need doing and I mean if I try to worry about something that isn’t really up to me, it just won’t go anywhere (Discussing how they would get to their AVF surgical appointments out of town if needed). (Participant 9)

Questioning. Although the majority of the participants in this study were passive in acquiring information regarding their various accesses, questioning was an important coping strategy for others. Only two of the 11 people interviewed for this study, one young male and one young female, actively sought out additional information in order
to feel comfortable and prepared for their access choices. The young male participant was extremely active in seeking out information regarding his vascular access options and specific complications such as CVC infection, especially when health providers were not forthcoming. “I think it was a nephrologist, anyways she came in and started explaining to me what was going to be done and I just kept pressing her to give me more information about what was going on”. (Participant 1)

One young female participant chose to gain some control over her health when she was forced to start dialysis with a CVC. Throughout the process of having her CVC inserted and then transitioning to her AVF she asked numerous questions of the nurses and doctors who cared for her.

I asked a lot of questions about my CVC and fistula. I’m pretty keen on knowing what is going on with my health and everything. Ya and they always were really good about telling me what is going on and why we have to do this and why you can’t do that. It was good. I feel kinda like I’m making the decisions when I ask questions. I understand. (Participant 6)

By asking questions and becoming knowledgeable regarding her access procedures, side effects and potential complications, this participant felt that she had a say in the direction of her care and felt more prepared to deal with the unexpected.

The majority of study participants had their CVCs inserted urgently due to rapidly declining health. Under these urgent circumstances little time was available for health care providers to explain procedures. Patients also had little time to truly understand the creation process and ongoing care of the catheter.

**Making choices.** The decision to insert a CVC is often made when dialysis is needed urgently and the CVC is often the only vascular access that will provide immediate access to the patient’s blood stream for dialysis. There is not always the
opportunity for patients to ask questions regarding what is happening; they are simply
told what is being done. Since the choice of access type is often taken away from the
patient in this situation, making other decisions in relation to the CVC gave patients a
sense of control that aided in their ability to cope. Choice was a significant factor in how
participants were affected by their vascular accesses and coped with all issues
pertaining to their ESRD and vascular access. Two participants, such as this older adult
male, described the lack of choice and involvement in decision-making in determining
access type.

I don’t believe that I was ever given a choice about whether I wanted a catheter
or a fistula. The catheter was an emergency thing so that was just a given but I
was told that I was getting a fistula and then I was told when I was going to see
the surgeon. No discussion, just told. That’s not right. I mean, I think the fistula is
better for you but I like to have a say in things you know. (Participant 8)

Although they acknowledged the need for the device, participants expressed the
importance of being involved in decision making, despite the urgency of access
creation. Choice seemed even more important for those who learned of their need for
access at the same time they learned of their diagnosis, as one middle aged female
participant expressed in frustration:

I mean I was really sick but at the same time I’m really scared because it’s all
happening so fast. So then they tell me they are gonna stick this line in my neck
and it all became too much to take. I knew in my mind that I didn’t really have a
choice. (Participant 3)

When participants were not given choice about their accesses they found ways
to gain some control back in their life. A middle aged female participant who was going
to train to do her dialysis at home, but who was not given a choice regarding what
access type she started dialysis with, directed her care and regained a sense of control
by increasing the pace of learning how to use her CVC,
I am choosing not to be pushed or prodded (in regards to learning how to hook the machine up to her CVC). I’m learning at the pace I’m comfortable with and they’re fine with that, which is great, but I still…I’m still learning that there are other things to learn. (Participant 3)

Similar to the experiences with CVCs, participants expressed the ability to make AVF decisions for themselves as a way of gaining a sense of control over their care. Whether it was a decision regarding access choice or the direction in which they wanted their care to go, participants felt optimism and strength through their sense of control.

Two participants interpreted their lack of choice related to AVF’s as coercive and associated with threatened withdrawal of care should they seek another option. One of the participants, a young female, felt that she was discouraged from seeking a second opinion from an alternative health care provider regarding potential access options.

When I said I wanted a second opinion, the one doctor in particular basically said “um, well you don’t believe in us anymore. You don’t trust us anymore” or something like that and “Fine if you go to see someone else, if you ever have a problem with it, we can’t fix it for you.” So that scared me. (Participant 6)

Another participant, an older adult female, acknowledged that even though she was not given options regarding access choices, after she had an opportunity to review the literature and talk with other patients she felt that the AVF was in fact the best access option for her personally.

They (health care providers) told me that I was getting a fistula and I was getting it because it was better for me. I didn’t like being told but after I read about it a bit, I agreed that it was best for me. I didn’t want another health issue. So that was enough reason for me to get a fistula. (Participant 7)

Participants were given varying levels of information and time to process an AVF creation prior to the procedure. Additionally, there was time needed post-creation when the AVF was being used to retrospectively work through and validate their decision based on what was best for them and how it had improved their overall well-being.
For some of the participants, the first cannulation experience was very scary and frustrating. When participants needed to rely on nurses to successfully cannulate their AVF, a few felt helpless because of a lack of control over the situation. The frustration experienced by some participants, male and female, young and middle aged, motivated them to gain control of the situation by making the choice to learn to self-cannulate or demand that an alternative access be used until the situation resolved. One older adult female participant discussed her thoughts on the cannulation process.

I’m not scared of needles but you know, when you have to have it three times a week it kind of gets on your nerves (having multiple cannulation attempts). And so it did. I just made the decision to do it. It did get on my nerves at first. But then I started doing it...And I thought, well this just, this is the most craziest thing I’ve ever seen in my life! So then I started to learn how to do it myself and it didn’t seem so crazy now. (Participant 7)

One young male participant discussed his ability to gain some control by making the choice to have the staff cannulate his AVF.

…my fistula takes time to heal so I was every day, anxious asking is it ready, you know? Can you just check it? Telling the nurses, Can you just check it and see if it’s good to go? And can we not put one needle in, I’d just keep saying. Like I said, it was me pushing the whole process. Trying to get it done and intact. Pushing it really helps because you’re supposed to have six weeks to heal (before you use an AVF) and I [laughs] only needed four [laughs]. (Participant 1)

One young male participant expressed the wish for the future that all ESRD patients would be able to determine what the best vascular access was for them personally and have that access created first.

I don’t think that the caregivers um could do anything more than just give all the information and allow people to make up their own mind about what type of access is the best for them (to start dialysis with). I mean, I think the fistula is the best option for me and that’s why I pushed for it but I know that some people really hate needles. The guy who has his dialysis next to me is so freaked out by needles. He said he hates his fistula so maybe he should not be forced to use it. (Participant 1)
Making the best of their situation. Aside from the opportunity to question what was happening in relation to their care, the ability to make the best out of the situation at hand was noted by participants as being helpful in coping and making them feel that they were more in control of what was happening in their lives. They recognized the need for their treatments and chose not to be bothered by things that were beyond their control. This realization allowed participants to focus precious energy on gaining control over aspects of their care that truly could be changed. One young female participant discussed this ability to adapt.

You’ve got these ugly tubes (CVC) sticking out of you and it’s not exactly a cute accessory to be you know stylin’ but um, then again, it’s like “well at least I’m alive”, so okay I’ll have to live with it. Maybe I’ll just buy some funky scarves or something, um…ya. It’s you know…but ya it is all about staying alive… (Participant 6)

This participant attempted to make the best of her situation while at the same time weighing her options. With her CVC, it was either choose death or having the “ugly tubes” stick out of her neck. The choice was not a difficult one for the participant to make but the small amount of control that she developed through her method of adapting helped her cope with the situation. This same young female participant described her use of humour as a way to cope with a difficult situation that occurred while she was in an emergency room with an AVF related issue.

…my family, what we usually did (especially my mom and I) we’ve got millions of stories like late nights in the ER, waiting to be bumped from surgery after surgery and starving all day and thinking “I just want to eat something! Give me an ice cube please!” It’s black humour actually. Taking these horrible crappy things and ya, just making fun of it and just laughing it off, you know…ya. That’s for sure, black humour. (Participant 6)

Some participants made the best of their situations by looking towards the future to harbour their strength and feel more in control of their care and health. One middle
aged female participant discussed the ability to look past the current struggles of her illness and focus on what could be possible down the road. This focus on the future gave her the determination to succeed and to control the direction of care. “A fistula means a bit more freedom and control for me. I need to learn how to needle myself to go do my dialysis at home and so I am determined to learn. I can do it” (Participant 10).

**Focusing on the Positive**

Participants, regardless of age and sex, expressed the desire to focus on the positive and not dwell on the negative. This positive attitude allowed them to cope with dialysis in general or in specific situations such as needing urgent surgery. Staying alive motivated participants to focus on the positive. One young male participant discussed his positive focus on being alive in dealing with life at the moment. “I tried not to let it bother me (needing urgent surgery), just, kind of, you let that stuff keep bothering you and it’s just going to drag you down and I was just more happy cause I was still alive…” (Participant 2). Similarly a young female participant harnessed a positive attitude to work past the difficult situations that occurred with her vascular access. “Right now it’s all about staying alive and that kind of thing so…I always try to turn things into positives though so ya, it’s not exactly my choice (having more surgery) but it has to be done so…” (Participant 6).

Participants discussed using a positive outlook to envision a more promising future. One middle aged female participant channelled her energy and desire to help other dialysis patients in her unit. She discussed how she was able to envision herself as making a positive difference when she sat and talked with other patients in the dialysis unit who were having problems with their accesses. By helping her fellow
dialysis patients, she was able to find strength and healing within herself as she also travelled through her vascular access journey. She felt as if she was a role model to those who were not coping as well.

I think a lot of people would have needed somebody to help them out (getting to dialysis and getting needles put in their AVF). That is why where there are people at dialysis that don’t really have other people to help them out, it’s good to give them a little love and care of your own because then they feel better, you know… I try to make them feel better. That’s the only way to go, you know. I mean why let them be sad and afraid, you know. It’s just not right. (Participant 7)

Focus on the future aided in the coping process for these participants. One young male participant envisioned attending university in his future. “I’m feeling much better with my fistula now. If I keep feeling this good I hope I can go back to school soon. Umm, yah that would be so good” (Participant 1). A middle aged male participant chose to be very optimistic about his future and the potential for future transplants in order to deal with the vascular access issues that he was currently facing.

I have this new fistula now and it’s great. I feel really great. I have so much more energy and I can shower and I can swim. Now that I feel so much better I pretty much think the sky is the limit. I wanna start doing stuff in my life...not everything in life is good. We just do it (have CVC/AVF creations and dialysis) knowing that that there should be a light at the end of the tunnel. For me, that light is feeling like myself again or getting a transplant. (Participant 9)

At the time of their interviews all participants were dialyzing with AVFs with the potential for multiple surgical and radiological interventions to maintain, but yet expressed the benefit of holding a positive attitude as a way to cope with whatever they faced regarding the AVF. Two young participants discussed trying to pick out the positive in their story to make the best out of an otherwise difficult situation.

You know what… I try (to stay positive)... I don’t want to ever think about it (potential AVF complications) because um... I just want to stay in the moment and live in the moment and just enjoy my amazing fistula because I have my life back. I actually have… on my days off I can do things and you know I don’t sleep
as much and I have more energy and it’s just so wonderful and I don’t want to think about the problems that could happen. (Participant 6)

When this same young female participant’s arm AVF had clotted, she saw the positive in the situation as she recognized that she now had a leg AVF that was mature and ready to use. The leg AVF was ready to use and she chose to look at the positive in this current situation.

I was like, “YES!” Because I don’t have to be admitted and have surgery, I have another one (AVF) on my leg! So ya, we [did] it that day and I was totally excited. I was so happy because I wasn’t scared, I wasn’t. I was so happy and I was like “Ha Ha, I have a second one. So ya, we needled it and it went great. It was fantastic, ya. (Participant 6)

One young male participant looked at the need for surgery as an excuse to take a holiday and a way of living and dealing with his current situation. “I guess I tried looking at it (needing to travel for surgery to fix his AVF) a different way, like I guess a little holiday or different scenery” (Participant 2).

Despite having to endure repeated cannulation attempts, some participants, such as one young female participant, acknowledged the cannulation situation and then chose to move on. This choice to focus on the positives and not the negatives of cannulation reflects how a patient’s disposition has the ability to enhance the ability to cope.

…it didn’t feel nice (having the AVF cannulated) that’s for sure but I think it….I had worked it up to be such a big thing and it wasn’t really. Like I mean it wasn’t comfortable but it wasn’t too bad so um, ya. And it ran beautifully for the first time in forever. I was actually like enjoying laying there for, you know watching TV and not having to worry about where I was, how I was laying or whatever. (Participant 6)

Another participant, a middle aged male actually saw his need for an AVF as a bonus as it led him to other beneficial aspects of his life.

So in many ways I look at this as being a bonus (having limited AVF options), because I mean I wouldn’t have ended up getting on the pancreas transplant list
right out of the blue. So it’s a bonus and it’s just a matter of time so...It’s almost beneficial, whatever has happened with my fistulas. (Participant 9)

Not all patients had the ability to see past the difficult aspects of their vascular accesses and focus on the positive. One middle aged male participant in this study was not convinced, despite the literature and quantitative data presented in terms of his lab work, that an AVF was more beneficial for him. For this participant, it was difficult to look past the negative aspects. This decision to focus on the negative prevented the acceptance of his AVF and, therefore, his ability to cope with the access that he was using.

They (health care providers) said you would get a better dialysis with a fistula, so at that time, I wasn’t really concerned with how good of dialysis I was getting...They said I would get better dialysis. I don’t know how much better because I’m already going to dialysis 4 times a week. Like is there anything that you have here that tells you, you know, like if we were doing it with the lines four times a week you’d probably have the same, instead of doing it 3 times a week. So they’re telling me I would get better dialysis...I am not convinced. (Participant 11)

Acceptance

Struggling to accept. Not every patient chose to or had the ability to accept their actual vascular access. Two participants used elements of avoidance as a way to cope with their new vascular accesses. While avoidance of problematic areas in care can be viewed as non-acceptance, participants in this study discussed this element as a necessity to moving on and accepting what had been thrown their way. One young male participant discussed how he tried not to think about his access and the issues involved so that it wouldn’t bother him. “I was kind of thinking about it (the CVC) but I didn’t want to think about it too much because I didn’t want it to start bothering me” (Participant 2). While this coping mechanism of avoidance is a reality for many patients, it can add to access-related fear. For this participant, avoidance prevented the ability to
accept the CVC. This lack of acceptance provided the participant with added incentive to pursue having an AVF created. One middle aged female participant discussed that while she accepted the need for the CVC, she still did not accept the access device itself. She recognized the lack of alternative options and chose not to complain about it.

If it (CVC) was going to help me live I was willing to accept anything because I knew I was sick. I needed dialysis urgently. I was near death and when you are that sick, you don't question what needs to be done. That being said, I hated every minute with that line. I never accepted it as part of me. (Participant 3)

While this participant’s dislike of the CVC prevented her from truly accepting the access, she understood the need and was able to accept the situation at that particular time.

With all the potential complications and interventions a patient with an AVF may experience it is hard not to internalize feelings of sadness and anger. One middle aged male participant discussed his extreme fear of needles and how this negatively affected his ability to cope with his AVF.

I hate needles and it was just the idea of the goddamn pain with the needles. I hated needles ever since I was a little kid. I wasn’t too happy about it but I guess this is what you have to do so I really don’t say too much. I come to dialysis; I put my arm out, think of a tropical island and try not to think about how scared I am. (Participant 11)

The ability of patients to process problems that occurred with their AVFs and move past them towards a state of well-being again depended on the patient’s personal coping mechanisms and their ability to see the positive aspects in a world of negatives.

For the participants in this study, learning to cope with and accept vascular access challenges were affected by their disposition and the level of control that they felt they had over the situation. For most of the participants there was an acceptance of their disease and the need for dialysis, however, the ability to accept the particular
vascular access devices nevertheless proved extremely challenging. In relation to acceptance of their vascular access, participants discussed the element of normalizing.

**Normalizing.** As the participants transitioned from one vascular access to another, there were various points when the new and uncertain started to become more of the familiar and routine. Participants described the need for cannulation, or the need to prevent their CVC dressing from getting wet when bathing, as tasks that were awkward or uncomfortable in the beginning but soon became familiar as they experienced them repeatedly. This sense of familiarity contributed to the participant’s quest to regain a sense of normalcy in their everyday life, a new sense of self.

Participants described making light of situations that others might find daunting by normalizing the routine of coming for dialysis or having problems with their accesses. One older adult female participant described her AVF cannulation as a weekly chore that people normally do in everyday life, “I just treat it like I’m going to work (coming to dialysis and having to use the AVF) or like I’m going for an oil change and make big laughs out of it, you know” (Participant 7). One middle aged female participant discussed how tasks such as cannulating the AVF were tough in the beginning but then became easier as time went on.

I was a bit nervous at first…and I was afraid it (the AVF) wasn’t going to work. I was really nervous about it at first. But after we got through the first couple of weeks and it was working okay and the more we needed it, it became easier for me. Like even now it’s like “okay, do this”. (Participant 4)

One young male participant acknowledged his belief that all patients must go through the same struggles as he was facing so he accepted the normalcy of the situation and got into a routine in regards to his care.
In the beginning I was feeling pretty sorry for myself but then I looked around the dialysis unit and saw that I wasn’t alone. Everyone was going through having needles stuck in them (their AVF) and they were surviving, so then so could I. It’s just part of my day now…just like when I put on my shoes …it’s normal to me. (Participant 1)

Factors influencing Impact on Participants and their Ability to Cope

Participants experienced the impact of vascular access physically and psychosocially and their lifestyles were significantly altered. Their ability to handle vascular access challenges depended on the coping mechanisms they had used throughout their lives. Participants described several factors that influenced the impact and their ability to cope with their vascular accesses including Patient Education, Trust in health care providers, Transportation, and Family.

Patient Education

Participants described variability in the amount of education they received about their accesses. Education that participants received differed depending on the type of access they had and the circumstances surrounding each access creation. Four of the participants felt well prepared for their access journey. The remaining seven participants felt that they were not fully prepared for their vascular accesses due mainly to a lack of, or misinterpretation of, information they received from their health care providers.

**Adequate information.** The majority of the participants in this study discussed how they were given adequate amounts of information or were presented with information with enough time that they were able to understand the creation process for their AVF creations. Given the urgency of most of the CVC insertions, the participants did not feel their CVC information was adequate. One male participant felt that he was
given a good amount of information prior to his AVF creation but misunderstood the health care providers and ended up being surprised with what an AVF actually was.

   Basically my only unawareness of the fistula was the fact that there wasn’t a rubber plug protruding through your skin. I totally didn’t understand that you needed to poke needles through my skin. The catheter was painless; I just assumed the fistula would be too. (Participant 9)

The AVFs were planned procedures that allowed participants to receive advanced education both formally and informally through discussions with healthcare providers supplemented with educational pamphlets. One older adult female participant discussed the ease with which she could get information from the hospital staff, “The dialysis nurses are really good too if you have a question or whatever and they’ll let you know or they will phone somebody to you know, inform you on it” (Participant 5). One middle aged female participant talked about how she received an abundance of information regarding her various accesses.

   They (health care providers) give you lots of information before the surgeries (AVF and CVC) and then when you’re going to just have the fistula made they talk to you so you know what is going to be happening. I got lots of information and really knew what to expect. It was great. (Participant 10)

The abundance of quality information from a variety of sources allowed participants to understand what was happening to them in regards to their AVF creation and this eased their fears. Any information that was given regarding CVC’s was seen as beneficial such as the case with this older adult female participant.

   Everyone explained a lot to me. The nurses explained everything to me before I went down to have my surgery. So did my doctor and so did the people where I was going. So it was very good because I was so scared before and after they all talked to me I wasn’t afraid, just maybe a bit of nervous energy. Everybody treated me really good. (Participant 7)
Some participants felt that all of the benefits and risks of their AVF surgery were explained to them in a way that was easy to comprehend and that they were given adequate time to think about the procedure before it was performed. One participant, an older adult female, added that the abundance of information helped improve her comfort level.

The more information I was given by the staff, the more comfortable I felt. My nurses really helped me with needling myself. By the time I was doing it on my own, I felt really really comfortable. That was great. (Participant 7)

**Inadequate information.** Participants in this study described receiving inadequate amounts of information or receiving information at times when they were not able to fully comprehend what was being presented to them. One middle aged female participant discussed how she felt ill prepared to deal with the CVC or the AVF due to the lack of information she received.

I don’t think the CVC plan was ever explained to me because I thought I couldn’t move a muscle or everything wouldn’t work, so I lay there like a statue which I found to be the hardest... I also know that I was told very little about the fistula except that I was having one. That was hard. I didn’t have any clue what to expect. How am I supposed to prepare for something I don’t know anything about? (Participant 3)

Since the CVCs were inserted under urgent circumstances for the majority of the study participants, most information that was received regarding this vascular access device, if any, was delivered in an informal manner through rushed interactions with health care providers. Participants were left wanting more information, not understanding the information that was given, or not being able to concentrate on the information given. Some participants discussed how being so sick meant that they were unable to comprehend or understand what was fully involved with having a CVC in place. This lack of information or the inability to understand it made it difficult for patients to
internalize and reflect on their current health status. One middle aged male participant discussed his struggles with being so ill and being unable to comprehend all that was going on around him.

I was so sick when I finally gave in and came into the hospital. It wasn’t just my kidneys that were crapping out on me but my diabetes was just messing with my entire body. I have never vomited so much in my entire life. I heard the docs rattling off some info to me but like I was even in a state to pay attention. After it was in (CVC) and I was feeling better I didn’t even know what to do. I didn’t understand and I didn’t know where to start understanding. (Participant 8)

A couple of participants, such as this middle aged female, discussed how they wanted more information about the CVC before it was inserted.

It was all so fast but not so fast that they (health care providers) couldn’t give me an idea about what was going on. You know how on those science fiction movies when people get beamed up by aliens and they are in a space ship all confused, well that was me. I had no idea what all the poking and prodding was doing to me and what I was ending up with. (Participant 3)

One young female participant felt she had not been given enough information to fully comprehend the potential AVF complications.

What happens when the fistula clots? You just can't sort of go in there and just go...you know you actually have to have surgery and have it fixed and I didn’t really know that. I wasn’t aware that the fistula could have big problems, sometimes even worse than the catheter. I didn’t really know that you can run into bumps. (Participant 6)

Participants described information as coming from a variety of people including nurses, physicians, social workers and other patients on dialysis. Even when participants felt they had received adequate information about the various accesses, some participants, such as this middle aged female, felt that they were unable to psychologically begin to process the information or chose to ignore the information all together. “I did get lots of information from everyone but I didn’t really know how to psychologically process how it would make me feel to have these surgeries” (Participant 4). This older adult male
participant discussed his thoughts in relation to processing information that was given to him.

I had been told that it was quite easy to get blood poisoning from the catheter and they had to make sure you kept it clean and such. Not that I disregarded that information, well I kinda did, but it (getting an infection) wasn’t a concern to me at all. (Participant 9)

**Trust in Health Care Providers** Participants discussed trust in health care providers as a pivotal factor that affected their experiences and coping with the vascular access process. Trust related to the information participants were given or in the care their health care team provided. This element of trust was associated with individual health care providers as well as the collective health care team, depending on the vascular access issue.

Participants discussed how history and familiarity with their health care provider was a significant factor in engaging trust. The time between diagnosis and initiating dialysis appeared to be a key factor in the extent to which participants trusted what their health care providers were telling them. Two participants described trusting their doctors and nurses opinions because they had been their care providers for an extended period of time. One young male participant elaborated his good history with his doctor that fostered trust:

I’ve gone to my doctor for years and so I have lots of trust in him. He has been right about a lot of my other situations...so I have a lot of faith in him about which is better for me to do my dialysis with, the catheter or the fistula. (Participant 2)

In contrast, lack of familiarity with providers undermined trust. This was especially the case for participants who had to travel to a hospital outside of their hometown for a vascular access procedure. This lack of familiarity heightened anxiety.
and made it difficult for the participant to trust the information and care they were receiving, as one middle aged female participant described.

When I had to go to the different hospital it was kind of scary because I didn’t know who the doctors were. I didn’t know the hospital. I didn’t know a lot. It’s hard to trust that care you get when you don’t know anyone. Thankfully I really liked my surgeon. He did a good job. (Participant 4)

Trust varied from provider to provider with participants expressing trust in some providers and a lack of trust in others. Participants often spoke of trust in their surgeons, who played a key role in creating and revising their AVF accesses. Two participants felt trust in their surgeons because they had good experiences in the operating room. The surgeons were very friendly, explained the procedure and potential complications well and added humour to the conversation that, in turn, fostered a sense of ease. One young male participant discussed how the surgical team was able to help him relax throughout his surgery.

The surgeons were really funny and they made me feel really relaxed. And obviously I’m a nervous guy when it comes to having stuff stuck in me. They were keeping me distracted while the doctors was like freezing my wrist and then, you know it was just like a combined team effort to keep me distracted and keep me in a good mood. They were telling great jokes and before you know it he’s (surgeon) was like yup, yup, yup you’re all done. And wow, awesome. Easy-peasy. (Participant 1)

Another participant, a young female, described having a leg AVF created in a neighbouring health authority, only to discover that a mere handful of these accesses had ever been created in the province. The inexperience of the surgical team created doubt and a loss of confidence in the care she was receiving.

I was only the second person that the doctor had put a leg fistula in B.C. usually they put a graft in. When I asked how the first one went he goes “Ya, well we did have to go in and revise it” So I’m thinking “Okay...does this guy know what he’s doing?” (Participant 6)
Health care providers who were unfamiliar with how to manage AVFs affected the participants’ sense of trust. Trust was affected in situations involving care by multiple providers, at different sites, giving inconsistent information. One participant, a young male, elaborates his difficulty in trusting the various nephrologists caring for him within the first few months of his diagnosis. “So one nephrologist is telling me that the catheter is better and then one tells me that the fistula is necessary. I was so confused. I didn’t know which end was up” (Participant 1). A middle aged female participant, who felt neglected by the nephrologists’ altogether, was grateful for the nursing staff that provided all of her information regarding dialysis treatments and access choices.

I felt absolutely neglected by the doctors. The entire time I was having treatments at the hospital they didn’t pop in once to talk to me. My nurses were the ones who did everything. I could hear them on the phone tell the doctors stuff and whatever but it’s not right when you can’t see a doctor. Dialysis is scary. Thank goodness for the nurses. (Participant 3)

This feeling of being neglected by the nephrologists fostered a sense of mistrust in the participant and caused her to feel wary of any information she received from the medical staff. This same participant felt that even though the nursing staff was her primary source of knowledge regarding access options, her underlying distrust made her suspect that key information was held back such as access types, procedures and what to expect with ongoing access care.

I don’t know if it is the doctor’s responsibility or if it is up to the renal staff but there is a lot of information that is lacking about the things they put in you and make for dialysis. I don’t know where to access that information either so I have to rely on the staff to give me what I need. (Participant 3)

One young female participant felt that she was dissuaded by the surgical and nephrology team from seeking a second opinion in another health authority.
When I said I wanted a second opinion, the one doctor in particular basically said “um, well you don’t believe in us anymore. You don’t trust us anymore” or something like that and “Fine if you go to see someone else, if you ever have a problem with it, we can’t fix it for you.” So that scared me. (Participant 6)

After the access was created, this same young female participant, developed complications in her access limb and found the local emergency department staff unfamiliar with a leg AVF or how to address the complications.

We saw the docs in the ER in the middle of the night and you know it’s bad when the doctors are scared and the nurses are scared and they’re running around and like, they’re putting you in the Trauma Room and you’ve been in the ER for over 12 years on and off and everybody knows you by name and they’re actually sticking you in that room. And you’re thinking “Okay, this isn’t good”. They weren’t really familiar with a leg fistula so I think that made them more frantic which only freaked me out more. (Participant 6)

Sensing the fear in the health care team caused this same young female participant to question her decision to seek urgent medical help within her hometown. Despite the urgency of the situation the participant considered risking her own safety to travel several hours to seek medical care at the hospital where the access was created. In this situation, fear of the unknown was weighed against the urgency of the situation.

One middle aged female participant's fears were elevated when she overheard a conversation between two nurses when she was in the OR having her AVF created.

Right in the operating room when they were doing my fistula. She (the nurse) said, “it’s too bad or quite a shame or something to that effect that she’s so fat” and that just cheezed me off. I mean that hurt, they don’t have to criticize you when you are already scared. So now when I go in for surgery I tell the surgery staff, “You know now that I’m awake, so if you have any criticism about me then you know to just keep it to yourself”. I don’t need to hear anything like that. (Participant 5)

The participant wanted to tell the two nurses that she could hear them but felt that the health care team might get upset for being called on their behaviour and, as a result, she would receive substandard care.
Transportation  In addition to educational and health provider factors that influenced the reality of living and coping with vascular access, patients also experienced transportation issues associated with the creation and maintenance of their vascular accesses. Approximately half of the participants in this study relied on public transportation to get to and from their various renal appointments. Dialysis treatment times follow a strict schedule and often have little room for adjustment based on the large volume of patients that each unit must accommodate. Patients are often unable to be choosy when it comes to booking times for surgical and radiology interventions. Often these procedures are booked urgently and the patient must take the first available spot. Participants noted how public transportation was not always reliable as pick-up/drop off times were often confined to limited hours. Half of the participants lived in outlying areas where public transportation was not an option. Although the Handi-Dart bus was an economical option for dialysis patients to use as their mode of transportation to and from the hospital, it had limited hours of operation and strict pick-up times. For patients such as this young male participant from a community dialysis program, with unpredictable appointment schedules, the Handi-Dart bus was very difficult to utilize.

I just get a little paranoid sometimes because the one guy who picked me up in the evening with the Handi-Dart wouldn’t run after four pm. And I wouldn’t get off dialysis until five thirty and quite often the guy would forget me so I would be stuck at the hospital without a ride and with no money for a cab. So it’s like I had to rely on my family to come and pick me up. (Participant 2)

Patients unable to catch the Handi-Dart had to rely on taxis that were costly. The majority of patients were on some form of disability or social assistance.

In addition to the financial strain that transportation issues created for patients and families, travel time was also a stressor. Participants much like this middle aged
female from a community dialysis program, acknowledged the huge geographical
distance between their homes and the tertiary care centres where their vascular access
surgeries/interventions were performed.

I would like it if my tests and surgeries could be done closer to home. That was a
big issue for us. It takes hours and hours to get to the hospital that does the
surgery. Why can’t they get doctors in our hospital who can operate on your
arm? It’s really draining to have to travel all the time. (Participant 4)

For patients living in rural areas, the unpredictability of the weather affected
transportation through the multiple mountain passes to the health authority’s tertiary
care sites. One community program-based older adult male participant acknowledged
not driving and feeling uncomfortable asking his loved ones to drive dangerous
mountain roads, especially in the winter, to receive urgent care.

Summertime is ok but wintertime sucks. It’s like 3 hours to the nearest hospital
and once we are there it’s another day of sitting around waiting and then driving
home in the dark on the slippery mountain roads. My wife gets so scared.
( Participant 8)

A patient’s vascular access type determined where they went for intervention
when there was a problem with the access. Many of the hospitals affiliated with the
community based dialysis units performed minor diagnostic tests for CVCs and
occasional removal of CVCs if needed but travel to tertiary care hospitals was
necessary for the interventions and surgical procedures associated with AVFs. Patient
participants throughout the health authority had to travel to maintain a well working AVF.
Participants, such as this tertiary program based young female, voiced frustration over
needing to travel multiple times to ensure that her AVF was working properly.

It’s tough (travel) for many reasons. Um...first of all you’re not in your own home
but I mean I’m in the hospital anyways, but my parents who came with me they
have to stay in a hotel and they want to stay close to me right? So there is all that
figuring out of where you’re going to go, where you are going to stay if you are not admitted. Or it you are going to be admitted... if you’re not, you have to stay close to the hospital and because I’m on disability then financially it’s hard. (Participant 6)

**Family** The most emotionally charged discussion with the participants was in regards to their families. Whether talking about the importance of family support or the fear of causing family burden, the participants clearly voiced that family was at the forefront of their minds with every decision made. Family was considered a major factor in how patients were affected by, and coped with, their illness journey.

**Family support.** Regardless of whether a patient used a CVC or an AVF access, family support was extremely important for all of the participants. Family was a major source of support during hospitalization for procedures, spending time, and keeping participants company. A handful of participants, such as this young female, discussed how extended families were a great source of support throughout their vascular access journey.

I had aunts and uncles who came from the States and I don’t even remember them all being there but they were. I had support everywhere and I was definitely not alone in it all that is for sure. I couldn’t imagine not having you know at least one person with you, let alone the tons that I had. I wouldn’t have made it through. (Participant 6)

For one young female participant it was her mother who was a pillar of strength during the roughest times in the hospital.

We are best friends. She actually says “I don’t think we could have this kind of relationship if you weren’t sick, because you know you’d be off and you’d have a life” and I said “No mom, you know we’ve always been close, so I don’t think so. We’d be just as close if I wasn’t sick and having to have all of these surgeries”. She is my rock, that is for sure. She is definitely my biggest supporter. (Participant 6)

One middle aged female participant discussed her family support system during a hospitalization. “My friend was there every day and my daughter flew in and spent a
week with me a couple of times...My kids are great and they visited me every day. They are great helps too” (Participant 3). Another middle aged female discussed how family helped her through a difficult year. “It has been a very difficult year for us but we have managed with the help of family over and over again” (Participant 4). At one of the participant’s lowest emotional points, family was there to give her a reason to keep fighting and to endure procedure after procedure in order to achieve a well-functioning access.

Just being there for you, you know and bringing you...giving you humanity. Bringing you back to hang on to something. It’s worth going through all of that to...um...ya basically make everything worth it, you know. That life is worth going through all the bad stuff. (Participant 6)

Having to endure multiple procedures and encounter obstacles as they struggled to find a sense of normalcy in their lives was extremely frustrating for patients. One participant, a middle aged female, noted that family was essential in helping her keep her mood swings under control.

I’ve got my husband and my mom and then my daughter too, and they are all a great support team. They’ve had to help me out quite a bit because especially when I did stat my mood swings, they were really bad. I have to learn how to curb my temper and my family definitely helped. (Participant 5)

Spouses were described as being the backbone of the participants’ support system as was the case with this middle aged female. “My husband has been the greatest support through the whole thing. He has been my rock” (Participant 4). One older adult male participant discussed similar support from his spouse.

I don’t know if I actually would be here without my wife. She is the rational one in the relationship and she really keeps me in check. I kinda get freaked out about things and she is really good with me. (Participant 8)
Family burden. While participants’ spouses were acknowledged as extremely supportive and dedicated, participants also feared that they had burdened those who were closest to them. When participants, such as this middle aged female, needed to travel for multiple procedures, it was the spouse who needed to take time off of work to travel with her.

“My husband hates driving because he drives so much for his work already. So when I tell him that we need to go to the hospital for surgery I know he’s upset because it’s another full two days of driving and sitting around waiting for something to happen. Our family and friends are here in town so it would be nice to be able to stay close to home” (Participant 4)

One older adult male participant described his spouse’s fear of driving long distances. The spouse had to work past the fear to ensure that her loved one made it to their surgical appointment regardless of obstacles.

“Those mountains can be scary to drive through. My wife hates night driving and in the winter it gets dark so early that we are always driving in the dark it seems. I feel bad that she is so stressed out.” (Participant 8)

Patients with vascular accesses often encounter unexpected obstacles such as clotted accesses, infections, narrowings or blockages. Despite the emotional toll that these obstacles had on patients, a couple of participants, such as this middle aged female, felt the need to keep their issues from their families to avoid burdening them with “their” problems.

“If I needed to talk to somebody I would probably call the social worker because I don’t want to lay my problems on my family. I think that they are so close to the situation now that all I would end up doing is upsetting them and there is no point to that. They’ve got their own lives to lead and I know they are concerned and they care but they don’t need any extra stress in their lives. That’s the way I feel.” (Participant 3)

One older female participant expressed sadness over the fact that she needed to rely on her family for financial support in order to travel for surgeries and tests. Social
assistance would not supply financial support until written proof was submitted that the procedure was completed so she needed to borrow money from her family to get to her vascular access appointment. This was embarrassing for the participant. "It’s so embarrassing to ask your family for money. I can’t pay them back right away. It’s really an embarrassing issue for me. I know that they would do anything for me but to me, it’s a pride issue" (Participant 7).

Others had to make arrangements for family members for whom they were caregivers and added to the already unimaginable fear that participants felt in regards to needing such an urgent procedure. In order to travel for vascular access surgery, one middle aged female participant had to scramble to find suitable child care for their disabled daughter while they travelled 6 hours to the nearest tertiary centre for urgent vascular access care.

Whenever I need to travel urgently for surgery I get scared about who is going to look after my daughter. She’s disabled and needs someone very patient to look after her. So when I’m stressed about surgery, I’m also worried about the people who are taking care of my daughter and if she is ok with them. (Participant 5)

Participants expressed many thoughts and emotions during the interviews. The three main themes that emerged were impact, coping and factors. These findings reflect the experiences of the participants who reflected upon their vascular access journey and shared their stories. It was the intent of this study to reflect on the participants' stories regarding their transition from CVC’s to AVF’s in order to uncover valuable information that will help health care providers, such as nurses, provide exceptional client centred care that meets all physical and psychosocial needs for these participants and all vascular access patients in the future.
Chapter 5: Discussion, Limitations and Implications

The purpose of this study was to explore the experiences of patients on hemodialysis who have utilized and transitioned from a CVC to an AVF. This research study focused specifically on understanding the participants’ experiences with each type of vascular access and its impact on their physical, emotional and mental well-being as well as the transitional experience of changing from one access type to another.

Discussion

The experiences of the hemodialysis patients who have transitioned from a CVC to AVF centered on impact of the vascular access experience, coping and factors influencing impact and their ability to cope. Participants discussed other elements that supported the triad of themes. While the focus of the current study was on the specific transition from CVC to AVF, participants’ experiences occurred within the context of a larger ESRD journey. The findings will be discussed in relation to existing empirical and theoretical literature and their contribution to knowledge development. Implications for nursing practice and future research will also be addressed.

While the findings from this study were separated into three main themes, the themes were integrally related (Figure 1). This diagram depicts how each theme influences and is influenced by the others.
The impact (physical, lifestyle and psychosocial) of the vascular accesses influenced participants’ ability to cope and was affected by level of control, patient disposition and acceptance. Surrounding the participants’ entire vascular access transitional experience was their personal context which included geographical, biological, gender, and age-related factors. This context is extremely important as it has a direct influence on patients’ experiences of transitioning from CVC to AVF and their ability to cope with challenges.

The current study is unique in exploring aspects of the patient transitional experience from one vascular access, a CVC, to another, an AVF. Existing research focused on why patients refused transition to an AVF (Axley & Rosenblum, 2011; Chaudhry et al, 2011; Richard & Engebretson, 2010; & Wasse et al., 2007). The
participants in the current study went beyond these earlier studies to give a more balanced experiential account of the perceived positive and negative aspects of each vascular access device.

**Burdening the Self and Loved Ones.** In the present study, participants emphasized the burden that vascular access care had on self and on loved ones. Burdens included time, finances, travel and inconveniences such as missing family functions or personal events. This finding is particularly relevant given that the concept of personal and familial burden of vascular access care has been studied to only a limited extent in the vascular access literature. The concept of burden – both for one’s self and for loved ones – has been theorized in the chronic illness literature. For example, Charmaz (1983) discussed how becoming a burden is a form of suffering for patients’ diagnosed with a chronic disease. This burden “typically demeans identity because these ill persons have little power over their situations and the quality of their existences” (Charmaz, 1983, p.188). Wasse et al. (2007) found that the issue of burden was a factor for patients using both AVFs and CVCs. Participants in their study reported a lower physical and emotional burden on themselves and their families with use of AVFs for dialysis. The researchers attributed this lower sense of burden to patients feeling better physically and more energetic when using an AVF that allowed them to be more independent and less reliant on family. The current study explored the transitional experience of patients who had started dialysis using a CVC and transitioned to an AVF. As a result of having utilized both accesses at some point during their dialysis journey, the participants in this study were able to express which access held a greater sense of burden for them and their loved ones. Participants described a
cumulative burden in which there was no single point of stress but rather a build-up of multiple stressors that intensified the vascular access related burden load.

Rural participants experienced a greater cumulative burden in relation to their AVFs. This appeared to be a result of the increased need to travel great distances for AVF care resulting in a combination of financial and time stressors. It was not unusual within the large geographical space of this health authority for participants to travel up to 8 hours over multiple snow covered mountain passes to receive urgent vascular access intervention especially for AVF problems. Previous studies on patients’ experiences of vascular access did not focus the contrast between on patients from urban and community dialysis (Axley & Rosenblum, 2011; Chaudhry et al., 2011; Richard & Engebretson, 2010; Wasse et al., 2007; & Xi et al., 2011). The exploration and comparison of experiences of patients from both urban and rural units is an important contribution of this present research as it adds beginning insights into the complexities of how patients from different geographic locations experience burden. Although they did not provide definitions of rural and urban, Moist et al., (2008) reported the greater burden for patients who had to travel more than 60 minutes of dialysis treatments compared to those who had less time to travel

Burden was accentuated for participants because of concerns for their spouses or parents. Half of the participants had elderly spouses, many who were on a low fixed income, and experienced increased stress related to financial worries and hazardous driving conditions. Further, the majority of participants were unemployed or on social assistance making it difficult for them to assist financially with travel costs or to support the household, contributing to feelings of stress and guilt.
CVCs were associated with a stronger sense of personal burden for participants particularly in their impact on lifestyle such as restrictions on swimming and showering. Although AVFs were praised for alleviating some of these lifestyle intrusions and for providing more effective dialysis, the unpredictability of living with the AVF and the concerns about the burden put on loved ones when it stopped working or developed complications led to a sense of a stronger overall burden load for participants and their loved ones.

Being unable to assist loved ones financially with travel costs or needing to rely on loved ones for emotional or physical support left some participants feeling powerless, insecure and with a sense of self-pity. When some participants started a routine with their vascular access and became stronger on dialysis, they felt that they were able to make more of a contribution to the relationships they had with loved ones. These feelings of reconnection aided in a sense of being valued and allowed participants to feel as they were less of a burden on their family and friends.

**Body Image.** The overwhelming range of emotions that participants experienced with creation of a vascular access, coupled with others’ reactions to it greatly affected their ability to cope with their chronic disease process and vascular access transition. Patients with chronic renal failure often cope with, and learn to adapt to, the disease without informing the public. That often changes with creation of a highly visible vascular access, a physical symbol opening up the patient to questions. While some patients may feel that they have been coping effectively with their health care challenges, questions, opinions or comments from the public may impact them
emotionally and threaten their sense of body integrity. These emotions were certainly represented amongst the current study participants.

Body image was a concern for participants in the current study regardless of access type. Although body image or awareness concerns related to AVFs were a common theme in the existing literature (Axley & Rosenblum, 2012., Chaudhry et al., 2011, Richard & Engebretson, 2010., Wasse, 2007., Xi et al., 2011), the current study found these concerns also strongly associated with CVCs. Price’s (1990) body image model assists in understanding how vascular access affected body image for participants in the current study. The model consists of three main components: Body Reality addresses the individual’s actual view of their body or other’s actual view of it; Body Ideal addresses how an individual wishes their body to be viewed; and Body Presentation addresses how an individual presents their body in society. Participants in the current study experienced changes in all three components of body image. Participants experienced altered body realities as their vascular access changed the appearance of their external self. Body ideal was affected as some participants wished that loved ones and people who had been in their lives for a long time would not view them differently. A patient’s body presentation was largely affected throughout the vascular access transition experience reflected in participants’ ongoing efforts to control the amount of visual exposure that others had of their vascular accesses. Some participants chose the type of clothing they wore based on its ability to hide their access while other participants avoided going to public places like the beach where removing their shirt would immediately identify them as being different from everyone else.
Regardless of age or gender, body image was a concern with both vascular access devices; however, the strongest emotions were displayed by young participants of both genders and middle aged females. The physical changes that occurred with the vascular access and placement contributed to participants of all ages experiencing feelings of disruption, uncertainty, and vulnerability. Richard and Engebretson (2010) found that participants in their study with AVF accesses felt susceptible to feelings of discrimination and rejection. Participants in the current study expressed fear of rejection and alienation because of the visible nature of the accesses, disfiguring scars from AVFs and/or ugly CVC plastic tubing protruding from their bodies. This made middle aged female participants feel unattractive to their significant others and threatened the spousal support connection, and sexual intimacy they valued and attempted to keep strong. Young participants similarly felt unattractive especially with CVCs as they were not only a physical indicator of their illness but prevented them from wearing the young, attractive clothing styles and accessories (e.g. jewellery) of their peers. Charmaz (1995) discussed how some people may not be affected by impairment or loss of function until a hidden loss becomes visible. Vascular accesses made visible what some participants wanted to remain hidden. This visibility forced participants to share their struggle with others as there were now physical alterations to what their body looked like before they had an access.

In other studies (Axley & Rosenblum, 2012, Chaudhry et al., 2011, Richard & Engebretson, 2010, & Xi et al., 2011) body image affected people’s decision making about accesses. For example, in one study people chose not to have an AVF created because of the disfigurement they observed in others. Participants in the current study
may have been more willing to accept AVF creation because they did not know the extent to which it would affect their body images. Several discussed how they never truly understood how their fistula would look once it was created and had had no discussions with the health care team about anticipated physical changes. Many participants also noted that they were not aware of what their CVC would look like once it was placed and admitted being quite scared of the appearance of the catheter once it was inserted.

**Fearing the Access Unknown.** With the exception of one study (Wasse et al., 2007); participants in other studies were utilizing a CVC as their vascular access at the time of the research. Participants in these studies had refused the creation of a permanent access, had not yet had the opportunity to have one created or had attempted an AVF creation that had failed. Previous negative AVF surgical experiences or the fear associated with potential AVF complications were found in several studies to directly affect a patient’s decision to dialyze using a CVC as opposed to an AVF (Axley & Rosenblum, 2012; Chaudhry et al., 2011; Xi et al., 2011). In contrast, all participants in the current study had an AVF and had experienced at least two vascular access surgeries because of complications. They emphasized the unknown outcome of surgery and the associated financial burden.

Requiring dialysis treatments three times a week was often seen as overwhelming for study participants but the additional element of fear associated with vascular access made the entire dialysis experience truly hard to bear. Fear was a constant reality for participants, regardless of access type, stemming from their histories of access insertions/ attempts and complications. They lived with a constant, almost
consuming fear in relation to AVF cannulation and the functioning and care of their accesses. In the existing literature, fear was associated mainly with the process of AVF cannulation (Axley & Rosenblum, 2012; Chaudhry et al., 2011; Richard and Engebretson, 2010; Xi et al., 2011; Wasse et al., 2007). In the current study, fears extended to AVF complications, similar to participants in Xi et al.’s (2011) study but who described them as “concerns” rather than fears. Although less pronounced, CVCs elicited fears related to potential infections or vein clots (thrombosis).

Fear related to the AVF cannulation process was prevalent among participants in the current study and was consistent with existing vascular access literature (Axley & Rosenblum, 2012; Bay, Van Cleef, & Owens, 1998; Chaudhry et al., 2011; Richard and Engebretson, 2010; Xi et al., 2011; Wasse et al., 2007). Bay et al., (1998) reported cannulation pain as patients’ most commonly ranked problem related to AVFs. Beyond physical pain, participants in the current study expressed fears related to nursing staff ability to successfully insert the needles, due either to access dysfunction or limited skill level. Participants in the current study described experiencing worry and stress between their dialysis treatments in relation to which nurse would be attempting to cannulate their access. Fears related to nurse competency in accessing or dealing with related complications is consistent with other study findings (Richard & Engebretson, 2010; Axley & Rosenblum, 2012; Wilson et al., 2010). In the current study, participants remained silent about their nurse related fears to avoid jeopardizing the care from the health care team they were so dependent on.

**Getting back to “Normal?”** Uncertainty characterized participants’ experiences with vascular accesses and made it challenging for transition to occur. Mishel (1988)
discussed how treatment that is routine, such as hemodialysis, reduces uncertainty due to the regular, familiar nature of the treatments. While hemodialysis became familiar to participants in the current study, the unpredictable ever changing status of their vascular accesses contributed to heightened uncertainty. Despite moving forward, patients with a vascular access often experience setbacks as they repeatedly experience various vascular access complications. Transition and adaptation theories theorize a process of resolution, such as becoming ordinary through transition (Kralik et al., 2010) or “surrendering to the sick body” through adapting to impairment (Charmaz, 1995). These theories in part, but not entirely reflect the vascular access experiences of study participants especially in the final stages.

In Kralik et al.’s (2010) transition model and the final phase of ‘Becoming Ordinary’, elements of change related to the chronic disease process are incorporated into new ways of living. In this final phase, patients can experience feelings of reconnecting, new beginnings, healing and familiarity. Participants in the current study expressed various emotions and found it a struggle to regain a sense of normalcy in their lives. Although Kralik contends that patients with chronic disease become ‘ordinary’ through transition the ever changing nature of a patients' vascular access experience made becoming ordinary difficult to achieve but acceptance more likely. This fluidity requires patients to be flexible and accepting of the care they require in order for their vascular accesses to function correctly. Many participants within this current study acknowledged this need to be accepting of the obstacles that confronted them. Their very survival depended on being resilient and learning to adapt to the required changes.
Despite the uncertainty they lived with, participants in the current study began to normalize the vascular access transitional experience and look towards the future as a way of starting to feel whole again. This is one of the first studies showing patients adapting to their accesses and integrating them into their everyday lives. One of the ways they did this was in taking responsibility for themselves which, according to Charmaz’ (1995) theory, is key to adapting. Learning how to live with the new constraints and challenges that the body faces allows “people to feel that they regain lost control over their bodies and their lives” (Charmaz, 1995, p.675). Some participants in the current study took responsibility by accepting and embracing what was happening to them. They recognized that their current reality of living with hemodialysis and a vascular access was not going to change and so they explored ways to adapt. Seeking out new information, becoming more familiar with the dialysis and cannulation routines as well as exploring tasks that they could master were all ways participants in the current study attempted to adapt to, and accept, their new reality. Yet other participants adapted to their need for dialysis and multiple needle insertions from a different perspective. Likening their repetitive thrice weekly dialysis treatments and AVF cannulation tasks to a job allowed a sense of feeling “normal”. Some participants began to recognize that they were adjusting to life on dialysis and to the process of cannulating themselves and were in a position to help other patients who were struggling to accept their new reality. These participants became mentors by showing other patients how self-cannulation was a way to regain some sense of control over their health.

A sense of normalcy for study participants came with emotional and psychosocial self-management. This resonates with Charmaz’s (1995) final stage of adapting to
impairment, surrendering to the sick body. Charmaz explains how surrendering means to “stop pushing bodily limits, to stop fighting the episode or the entire illness. The quest for control over illness ceases and the flow with the bodily experience increases” (p.672). Some study participants described being able to establish a normal routine and to feel more comfortable with their vascular accesses once they stopped feeling resentful about the complications that had occurred and started to focus on the positive aspects of their care. Participants emphasized that it was possible to adapt to changes that occurred as a result of having a vascular access; however, adaptation required that they no longer struggled against each health crisis in order to achieve this state of self-contentment.

Information. Participants in the present study found health care providers and other patients with vascular accesses to be their most important sources of information. The importance of receiving and understanding information in relation to the various access types, the procedures involved and potential complications, resonates with other vascular access research (Richards & Engebretson, 2010; Xi et al., 2011). Consistent with Mishel’s (1988) theory of uncertainty and its relationship to illness-related events, health care providers help reduce patients’ feelings of uncertainty and enhance familiarity with health care crises by providing information. Mishel & Braden (1987) discussed how “trust and confidence in the health care provider leads to a lower level of overall uncertainty, less ambiguity about the state of the illness and less perceived complexity concerning treatments” (Mishel, 1988, p. 228). Participants in this study expressed mistrust of health care workers when they perceived they had received inadequate or misleading AVF information. This contributed to a heightened sense of
uncertainty and fear amongst some participants. This mistrust had a snowball effect leading participants to doubt information from even credible sources like nurses. There was a sense from the participants that health care providers may have filtered the information that they provided in order for participants to choose vascular access options that the health care team deemed most appropriate. In a time when participants were felt vulnerable and lacked control over their health crisis, feelings of being swayed in a certain direction or coerced into doing something that made them feel uneasy only added to feelings of mistrust in relation to the health care team.

Charmaz (1983) discussed how suffering with a chronic illness undermines the self. One potential source of suffering revolves around living a restricted life. Chronic illness brings restrictions that prevent individuals from living their life as they normally would. Charmaz claims that “restricted lives are sometimes set into motion by professional practices. Not all patients are given sufficient information and treatment to reduce their suffering losses of self” (1983, p.173). The existing literature supports the disconnection that many participants felt in understanding all pertinent information regarding their new accesses. The present study complements the existing research as well as it adds to what is known regarding the need for information in relation to CVCs. Unlike other studies (Axley & Rosenblum, 2011; Chaudhry et al., 2011; Richard & Engebretson, 2010; Wasse et al., 2007; & Xi et al., 2011), participants in the current study had experienced the creation of both access types and also had the opportunity to live with these devices. Since the majority of the participants had required the urgent insertion of a CVC, there was little time to gain knowledge regarding this access type, which made coping difficult.
One of the biggest challenges/constraints to receiving adequate preparatory information and creating the greatest emotional and physical turmoil for participants in this current study was having a CVC inserted at the same time as being newly diagnosed with ESRD. They simply did not know what to expect and felt that additional CVC information would have aided in their ability to cope with their declining health. Kralik et al (2010) describes this state of turmoil and change as the ‘familiar life’ and ‘ending’ phases of transition where the predictability of life as they knew it changes for patients and they experience a change in their thoughts, feelings or attitudes. Unlike the acuity of the CVC which made timely access to information challenging, all participants slowly transitioned to an AVF which allowed the majority of them time to talk with health care providers, ask questions regarding the AVF creation and become more comfortable regarding the transition they were about to undertake. Many participants felt very prepared for their AVF creation and as a result, were able to focus on other aspects of their care.

Limitations

There were limitations in the current study. First, the specific nature of the selection criteria may have limited the number of participants who were eligible for this study, such as patients who currently dialyze with AVGs or those who do home hemodialysis. Including patients who had started dialyzing at home, with an AVG or were on peritoneal dialysis would have given a more complete picture of the transition experiences among accesses and added to the richness of the findings.

Time and resource constraints limited the sample size. Initial recruitment invitations to all eligible patients received approximately sixty responses from patients
willing to participate. The overwhelming responses from this patient population reflected they had stories to tell but in order to keep the sample to a manageable size, the first eleven responses that provided maximal variation were selected. Interpretive description has no solid rule as to sample size and saturation but maximizing the variation of the selected participants according to age, gender and geographic location, allowed for a range of experiences to be included. Furthermore, the appearance of recurring themes in the analysis suggests that saturation was achieved.

This study took place within one health authority with a vast geography and various types of interventional facilities. Study findings reflect the experiences, impacts and coping strategies of vascular access patients within Interior Health. Vascular access patients from other health authorities within the province or other health services within North America may have different access to health care resources.

I entered into this study as the Renal Vascular Access Coordinator who provides direct clinical care for the patients who participated in this study. While I acknowledged my role as researcher to each participant prior to each interview, it must be noted that my insider position may have influenced areas of this study including data collection and analysis. Study findings are based on participants’ personal experiences and were coded and represented according to themes based on my interpretation of the findings. Alternative researchers may have coded findings in different ways, slightly altering the interpretation of the findings. As a MSN thesis student, my experience as a researcher was limited and I did rely significantly on my committee members for guidance and support.
Implications for Research

There is very little available current research associated with the psychological impact that a CVC or AVF has on a hemodialysis patient. The current study illuminates the tremendous impact of vascular accesses on body image that needs to be explored further. Further research might explore strategies nurses and other health care providers could use to help patients cope with the physical and psychological changes associated with various vascular accesses. This research could be utilized as a basis for designing front line care interventions that could support patients with vascular accesses. Researchers could focus on how healthcare providers can adequately provide psychological support and help patients self-manage the emotional fluctuations that accompany their ongoing hemodialysis treatment and vascular access status. Further research should focus on identifying strategies/techniques that patients find helpful in alleviating AVF cannulation fear and developing and testing fear reduction interventions that nursing staff could incorporate into daily practice. Understanding relationships between cannulation fear and other outcomes such as body image and self-esteem are other important areas of research focus. Research that further examines the impact of vascular access creation and utilization on a patient’s body image could be used to develop a working framework and evaluative process to prepare health care providers to address any body image issues that may arise.

Future research might explore patient satisfaction with information exchange in relation to their vascular access procedures. Exploring the role of physical symptoms or emotional state in patient’s understanding and acceptance of information would help front line staff plan and initiate education based on a patient’s needs.
Limited access to resources close to home was a common area of concern for rural dwelling patients within this study. The time spent traveling to vascular access appointments and the financial costs of travel all contributed to a significant burden for participants and their loved ones. Research should focus on ways to incorporate vascular access surgical and diagnostic imaging resources into all centres that provide hemodialysis treatments. Further research could address strategies to improve financial funding allocation and distribution for patients who need to travel for these procedures. Due to the potential variations in care and access to resources, participants from other health regions may have differing priorities or areas of concern with their care. In order to obtain a greater understanding of this population’s personal experience, a broader range study utilizing various health authorities or health service areas may provide deep insight into the significant truths of the vascular access journey.

To my knowledge there is no existing literature that explores how rural geographic location impacts the transition experience for patients with ESRD requiring vascular access procedures. Moist et al. (2008) addressed the need for travel specifically for dialysis and did not draw attention to rural travel needs for vascular access procedures. Given the paucity of research in relation to geography and transition experience, there needs to be further exploration regarding this topic.

Implications for Nursing Practice

Two of the most prominent themes that surfaced in the current study pertained to body image and fear associated with cannulation of an AVF. It is the responsibility of health care providers to provide exceptional care in relation to all aspects of a patient’s chronic disease, such as ESRD. One factor that nurses often forget regarding vascular
access care is the element of stigmatization related to body image. Gaps remain in nursing's understanding of the overwhelming psychological impact and body image changes associated with vascular accesses on a patient. Some of this gap could be addressed within the nephrology nurse training course by strengthening content related to body image concerns associated with vascular access. Nurses who are aware of the issues involved but are uncomfortable addressing body image concerns with patients could benefit from the development of teaching tools that equip them to initiate sensitive discussions.

Currently, in the health authority where this study was conducted, there is limited vascular access education for pre-dialysis patients. The development of a specific vascular access introductory teaching session for all pre-dialysis and acute start hemodialysis patients that addresses the physical changes, potential fears, and maintenance regimes for both CVCs and AVFs may assist in reducing the psychosocial impact. Peer support that would come directly from the patients themselves, not the nurses involved with their care could be included in these training sessions. This peer support could incorporate the personal experiences and stories of triumph and struggle of current vascular access patients. “In relation to chronic illness, peer support and similar lay social interventions have become strongly linked with attempts to increase patient’s ability to self-manage their conditions and the drive to improve healthcare outcomes” (Hughes, Wood & Smith, 2009, p.397). Study participants described the influence of fellow dialysis patients and their desire to help out their fellow patients through mentorship and guidance. The development of a mentorship program for existing and new vascular access patients would be a direct benefit to all parties
involved. A peer support study (Hughes et al., 2009) showed that most participants felt reassured or encouraged and gained confidence, strength, a greater sense of control, and increased personal agency as a key benefit of receiving peer support.

Given that certain surgical and diagnostic imaging resources are not easily accessible for many patients in community/rural settings, finding innovative and convenient ways to provide care is important. Telehealth technology could be used to reduce the amount of patient travel for vascular access care allowing patients to spend time focusing on other areas of their lives. Telehealth, “a technique of delivering health care where communication with the client is achieved at a distance, rather than in person” aids in removing the time and distance barriers associated with rural healthcare and has the potential to increase access and decrease cost while sustaining high quality health care (Marineau, 2005, p.96). Nurses within the health authority have access to Telehealth technology and could use it to benefit the vascular access population. The use of telehealth would give nurses and renal multi-disciplinary team members the ability to assess various parts of the access device from a distance through visualization with the monitor and listening to an AVF with the use of an electronic stethoscope. Simple consults or follow up appointments with surgeons could reduce or eliminate the need for travel if they took place via telehealth. Nurses would also be able to provide extensive teaching and problem follow-up via telehealth. Not only would the use of this technology help reduce the personal and familial burden for vascular access patients but it also has the potential to lessen the resource strain felt by some of the tertiary care sites.
Study participants often described receiving inadequate amounts of information and expressed considerable mistrust of health care providers. As members of the large renal multidisciplinary team, nurses must ensure that all patients receive an adequate amount of information that is presented in a manner that facilitates understanding. Findings from the current study revealed that there were critical times when participants were overwhelmed and unable to absorb the information they were given - newly diagnosed with renal failure, when they were informed they had to start dialysis immediately, had complications with their accesses, or when they were suffering an acute flare up of their illness and felt physically unwell. At these critical times nurses must be sensitive to tailoring information and reinforcing it multiple times to ensure patients feel they have the knowledge they need and are able to understand what to expect with their care. Inadequate or selective information contributes to patient fear and misunderstanding and does damage to trust with health providers. It is important that health care providers offer all available information to patients, caregivers and loved ones so regarding the various vascular access complications and procedures. Participants in this study felt a lack of control when they were left out of decision making processes or were only given selective information. This prevents them from making informed choices and contributes to health care provider mistrust. By eliminating the potential for confusion and providing accurate and adequate information to patients, health providers reduce the risk of strain, tension or burden put on the patients and family. This reduction in strain and tension will ultimately facilitate a relationship built on trust between patients, family and health care workers.
Dedicated evaluation and subsequent follow up should be provided at various stages of a patient’s care. Psychological evaluation is extremely important for patients in all pre-dialysis assessments as it may identify any potential issues arising as a result of having physical alterations to the body (National Kidney Foundation, 2007).

Conclusion

In this study I explored the experiences of patients who started hemodialysis using a CVC and transitioned to using an AVF. Findings from this study illuminate an integral connection between the impact felt by vascular access patients, their ability to cope with situations they encountered throughout their journey, and the factors that affected their ability to cope. Study participants shared their personal stories of a journey that was rarely easy and was far from straight and uncomplicated. Once diagnosed with ESRD and needing to start hemodialysis, participants tested their physical and emotional resilience as well as their ability to cope with the personal and familial burdens placed on them by the unpredictable and often unapologetic nature of the vascular access experience.

This study elucidates what is needed from researchers and health care providers, particularly nursing staff, in regards to further vascular access research and improvements to vascular access care. Issues related to body image, fear of cannulation, access to resources and trust in the information that is provided all require further exploration and implementation into practice to ensure that patients and loved ones receive the care and support needed in their vascular access journey.

The question remains, is it possible for patients who are living with ESRD to truly experience a complete transition from their first CVC access to a well-functioning AVF.
Through the discussions and stories told by the participants I believe that it is clear that while it is not possible to completely transition from one access to the next, there is the ability to travel through the transitional process and along the way, learn to adapt emotionally and physically in order to regain a new sense of normalcy and routine in their lives.
References


qualitative study on vascular access decision making. *Nephrology Dialysis Transplant*, 26, 3302-3308.
Appendices

Appendix A: Letter of Intent for Renal Educators

Angela.Romyn@interiorhealth.ca

Renal Educator/ Patient Care Coordinator:
Interior Health

Dear:

I am currently enrolled in the University of British Columbia Okanagan Master of Science in Nursing program, and preparing to complete the thesis component of this postgraduate degree. As you know, Vascular Access has been a passion of mine for quite some time. I am conducting a study on an aspect of Vascular Access care involving patients in the IHA renal community.

The purpose of this research study is to explore experiences of hemodialysis patients who initiated dialysis using a Central Venous Catheter and transitioned to using an Arterio-Venous Fistula. Vascular Access is the Achilles Heel of renal disease. It is my hope by turning our attention to understanding the patient experience regarding the transition from a CVC to an AVF; we will identify factors that positively or negatively affect a patient’s physical, emotional and mental well-being. It is these experiential accounts that will allow us to identify themes that can shape the care for our patients.

I have obtained ethics approval from the Interior Health Research Ethics Board as well as the University of British Columbia Behavioral Research Ethics Board to conduct this study. I am seeking hemodialysis patients who dialyze in an in-centre or community dialysis unit. These patients must also have initiated dialysis using a CVC and transitioned to using an AVF. For those patients who consent, I will conduct semi-structured interviews, which will be arranged at a place and time that is convenient for them.

I would like to ask for your help in delivering a recruitment brochure (attached) to eligible hemodialysis patients inviting them to participate in the study. If you are unsure if a patient is eligible, please give them a brochure and I will determine eligibility once the patient contacts me. If a hemodialysis patient is interested in participating in the study he/she will contact me directly or he/she can ask you to contact me directly. I have also attached the Consent Form for the study.

Please contact me at the email address or phone numbers above if you have any questions regarding this request.

Your support for this project is greatly appreciated.

Sincerely,       Angela Romyn  RN, BScN, CNeph (C), IHA Renal Vascular Access Coordinator
Appendix B: Recruitment Flyer

Transitioning from a Central Venous Catheter to an Arterio-Venous Fistula

“The Patient Experience”

“If you are a patient on hemodialysis who started dialysis using a central venous catheter, like the one on the right, and later switched to using an arteriovenous fistula in your arm or leg like the picture below, we are interested in talking with you about your experiences about changing from one access to another.”

Sound interesting? For more information about this research project and/or to participate in this project:

Angela Romyn RN, BScN, CNeph(C),
IHA Vascular Access Coordinator

angela.romyn@interiorhealth.ca
250-862-4189 or cell 250-718-1643

Masters of Science in Nursing Student, UBC-O

Principle investigator:
Kathy Rush, Ph.D, RN

Associate Professor, School of Nursing UBC: Okanagan
Appendix C: Consent Form

Title: Transitioning from Central Venous Catheters to Arterio-Venous Fistulas: The Patient Experience

Principal Investigator:
Kathy Rush, Ph.D, RN
Associate Professor, School of Nursing
University of British Columbia, Okanagan
Email:

Co-Investigator:
Angela Romyn, RN, BScN, CNeph (C)
Renal Vascular Access Coordinator, Interior Health
Master of Science Student, University of British Columbia, Okanagan
Email:

Purpose:
The purpose of this study is to look at your experience as a hemodialysis patient, in a hospital or community dialysis unit, who started dialysis using a central venous catheter and then switched to an arterio-venous fistula. You are being invited to join in this study because you are a person who has used a central venous catheter and then switched to an arterio-venous fistula.

This study is part of a graduate thesis in the Faculty of Nursing at the University of British Columbia Okanagan.

Study Procedure:
Approximately eight to twelve patients are expected to join in this study.

You will be asked questions about your experiences with your central venous catheter(s) and arterio-venous fistula(s) in a one on one interview. Interviews will take place at a time and place of your choosing. The interview will take about 60-120 minutes. The person conducting the interview will take written notes during and after the interview. With your consent, the interview will be audio recorded using a digital tape recorder.

You will also be asked to complete a form that asks personal information such as your age, dialysis history and vascular access history. Additional information about your vascular access care may be obtained from the PROMIS (Patient Records and Outcome Management Information System) database. This database is the renal care community’s clinical information system that is currently being used in all of the dialysis units in Interior Health and will be used to collect information such as where you receive your dialysis treatments, how many years you have been on dialysis as well as information on your surgical and radiology history.
Potential Risks:

The time spent during the interview process is considered the only potential risk for this study.

Potential Benefits

The findings of this study may help develop and enhance vascular access care for hemodialysis patients in the future.

Confidentiality

We will keep your name and the information you provide strictly confidential. We will not use your name in the research presentations or reports and we will use number codes instead of your name in our notes and typed copies of the interviews. The results of this study will be communicated in written papers or oral presentations with all personal identification removed so that you will not be identified by anyone reading the findings. Information collected from the interview may be used in future research. Any future research will be approved by Research Ethics Board before it can occur. All data collected in this study will be stored in a locked file cabinet or in computer files that will be password protected. Data collected from this study may be used in the future for purposes other than this current research project, such as future renal care planning and development. Quotes taken from your interview may be included in the written research report. All quotes will remain anonymous and will have no information that would allow you to be identified.

Contact for information about the study:

If you have any concerns or question or would like further information about the study, you may contact Angela Romyn @ XXX-XXX-XXXX.

Contact for concerns about the rights of research participants:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-888-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832. You may also contact the Interior Health Research Ethics Board through the Research Office at 250-870-4602.
Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study up to 2 weeks after the date of your interview. Refusal to participate in the study or request to withdraw from the study will always be without repercussion. Anything discussed within the interviews will not affect the hemodialysis/vascular access care that you receive.

Your signature below indicates that you have received a copy of this consent form for your own records

Your signature indicates that you consent to participate in this study.

_______________________________________________________________________
Participant Signature         Date

_________________________________________________________________________
Printed Name of the Participant      Date

_________________________________________________________________________
Witness Signature                                           Date

If you would like a report of the findings please include your mailing address in the space below:

_________________________________________________________________________
Appendix D: Interview Guide

Introduction:

- Explain the study purpose and digital recording (reiterate confidentiality of the interview)
- Complete consent form and give one copy to the participant
- Ask participants not to use names of persons during the interview. Names will not be entered into the written transcripts or data analysis.
- Ask participant to complete demographic sheet
- Offer to answer any questions

Research objective: To explore how patients on hemodialysis experience the transition from a central venous catheter to an arteriovenous fistula through the following research questions:

- Research assumption: My assumption is that the decision to transition to an AVF is not an easy one for patients. My anecdotal experience seems to indicate that there are many factors that help and hinder the transition from CVCs to AVFs and I would like to understand what these factors are and how patients cope with these factors.

Interview Question

1) Can you tell me about your experience of being diagnosed with renal failure?

Probes:

- What incidents led up to your diagnosis?
- What were your interactions like with your health care providers? (Docs, Nurses – did you met regularly with kidney specialists like the nephrologist and/or renal health nurse)
- During this initial stage of your diagnosis what was helpful and what was unhelpful?
- If things could have been different in your care, what would you have changed/wanted?
Interview Question

2) I’m curious about your experience of making the decision to start dialysis. Can you share with me your experiences around deciding to start dialysis?

Probes:

- How far before starting hemodialysis did you first hear about the need to have an access created for treatment?
- How did you find this information out and from whom? And, what was that like for you?
- What information was helpful to you and what information was not helpful to you?
- Are there ways that education about vascular access could have been improved for you? If so, can you give an example?

Interview Question

3) In making the decisions about vascular access, what or who were influential in your decision making process?

Probes

- In what ways were they influential?
- What role did you play in the decision-making process?
- Are there ways that the decision-making process could have been improved for you? Can you give an example?

Interview Question

4. Can you tell me about your experience of dialyzing using a central venous catheter?

Probes

- Can you tell me about your first hemodialysis treatment?
  - Can you describe your emotions on that day?
  - Can you tell me how it felt using the central venous catheter?
• Were there any factors that stand out that were helpful for you during this time? If so, what were these (knowing what to expect, staff, physical comforts)? Were there things that made the experience difficult for you (staff, physical comforts)? If so, what were these?
• Were there any difficulties using the catheter while on dialysis? Bleeding? Line would not work? Infection?

Interview Question

5. Can you tell me about the decision to switch from a central venous catheter to an arteriovenous fistula?

Probes

• How was the subject of switching to an AVF introduced to you? (Example: how did you find out about the possibility of switching to an AVF? Health care worker? Another Renal Patient? Family Member?) What was your role in this process?
• If any, what kind of knowledge of vascular access options did you have prior to discussing AVF as an option? If so, how did you get this knowledge about AVFs?
• Can you tell me about the surgical consult and pre surgical screening experiences?

Interview Question

6.) Can you tell me about your experience of dialyzing using an arteriovenous fistula?

Probes

• Can you tell me about the physical healing process after surgery? Can you share with me what the emotional process was like for you?
• What did you know about the needling and care process of AVF? Was the needling and care of the fistula explained well to you?
• Can you tell me about the needling process and how it went for you?
• What kind of complications have you experienced with your access? Were the potential complications explained to you to your satisfaction?

**Interview Question**

7.) Can you talk about which access you preferred?

*Probes*

• Which have you found more physically comfortable? More emotionally comfortable? More convenient?

• Are there other factors that contribute to your preference of one vascular access over the other? If so, what might these be?

**Interview Question**

8.) From your perspective, what can health care workers do to help patients like yourself get the best type of access for the patient?

*Is there anything more that you would like to share with me about your experiences with your journey of living with kidney disease and the kinds of supports that have been helpful for you in making decisions about your health care?*

Thank you!
### Appendix E: Demographic Form

1. Gender: ☐ Female ☐ Male

2. Age: ____________


4. Are you on Disability/Social Assistance?  Yes _____ No ______

5. What year did you start hemodialysis?: ______________

6. Years/months CVC (Catheter) in use: ______________

7. Years/months AVF (Fistula) in use: ______________

8. How many CVC’s have you had put in?: ______________

9. How many AVF surgeries have you received?: __________

10. How many Linograms have you had involving your CVC?: __________

11. How many fistulograms or angioplasties have you had involving your AVF?: __________

12. How many CVC infections have you had?: __________

13. How many AVF infections have you had?: __________

14. Do you Buttonhole your fistula?: __________

15. Do you use freezing before using your AVF?  Yes ___ No ___  If Yes, Type ______

16. How many dialysis treatments do you have per week?: __________

17. Rate your satisfaction level with your CVC.
   - 1= Not satisfied  5= Very Satisfied
   - 1 2 3 4 5

18. Rate your satisfaction level with your AVF.
   - 1= Not satisfied  5= Very Satisfied
   - 1 2 3 4 5
Appendix F: Transcriptionist Confidentiality Agreement

TRANSCRIPTIONIST CONFIDENTIALITY AGREEMENT

The parties to this Agreement agree that all information whether in the form of data, or reports regardless of how communicated, recorded, or received by the research transcriptionist while employed on the graduate research project Transitioning from Central Venous Catheters to Arterio-Venous Fistulas: The Patient Experience by the Principal Investigator, Kathy Rush and/or the Co-Investigator Angela Romyn is confidential and proprietary and will be kept as such.

The research transcriptionist shall use all the project information in confidence solely for the purposes of graduate thesis research at the UBC Okanagan School of Nursing and shall not -

(a) Make any other use of the information except as expressly first authorized by the Principal Investigator in writing; nor

(b) Disclose or permit or cause to be disclosed the information to any person except as are necessary to properly report on the transcription done and only then under terms of confidentiality of the same or stricter effect as these.

Signature: ____________________________________________________

Printed Name: __________________________________________________

Date: _________________________

The University of British Columbia Okanagan, 3333 University Way, Kelowna B.C.

Masters of Science in Nursing Research