Husbands Living with Women on Dialysis: Embracing Their Transformed Life

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Abstract

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The purpose of this qualitative study was to explore the adjustment process of husbands living with women on dialysis. Using Glaser's (1978) grounded theory methodology, data were collected from 18 husbands through semi-structured face-to-face or telephone tape-recorded interviews. In using the constant comparative method of data analysis, the most central issue for these husbands was dealing with multiple changes imposed by the demands and impact of kidney failure and its treatment regimens on various dimensions of their lives. The changes impacted roles and responsibilities at home and work, social and recreational activities, finances, relationships with their spouse and others, home environment, daily routines, and future plans, as well as health and/or sleep patterns. Although the impact of these changes created many hardships for husbands, witnessing their wives' suffering was more distressing. In response, these men involved themselves in supporting their wives and engaging in the basic social process of embracing their transformed life. The four stages of embracing a transformed life are becoming aware, involving themselves, centering life on their wives, and striving to achieve balance. The marital relationship, the women's health status, as well as the presence of informal support and formal support are conditions which significantly influenced the process. The theory of embracing a transformed life provides a framework for understanding and explaining the complex interplay of strategies undertaken by these husbands to respond to, adjust to, and integrate changes in their daily and future lives. Moreover, the focus on husbands living with women on dialysis contributes towards closing an existing gap in knowledge and the findings underscore the husbands' abilities to learn and carry out complex roles, responsibilities, and routines that require sophisticated observation, decision making, and technical and problem-solving skills. The discrete stages of the theory guide nurses to better understand the various changes dialysis-caregivers may experience during different phases of the patients' illness trajectory and to implement supportive care to enhance their adjustment and sustain their efforts.

Keywords: dialysis, spousal caregiver, dialysis-caregiver, adjustment, change, chronic kidney disease, end-stage renal disease.

Résumé

Les hommes habitant avec une femme dialysée: Accepter la transformation qui s’effectue dans sa vie

Le but de cette étude qualitative était d’examiner le processus d’adaptation des hommes habitant avec une femme qui subit des traitements de dialyse. Les données ont été recueillies au cours d’entretiens semi-structurés enregistrés, réalisés en personne ou au téléphone, auprès de 18 hommes mariés, conformément à la méthode de la théorie ancrée décrite par Glaser en 1978. Selon la méthode comparative constante d’analyse de données, il s’est avéré que la préoccupation centrale de ces hommes était de composer avec les multiples changements, aux différents aspects de leur vie, qu’imposaient les demandes et les répercussions de l’insuffisance rénale et du schéma thérapeutique correspondant. Les changements ont en effet une incidence sur divers aspects de leur vie, notamment les rôles et les responsabilités à la maison et au travail, les activités sociales et récréatives, la situation financière, les relations de couple et les relations amicales, l'ambiance à la maison, les activités quotidiennes, les projets futurs, la santé et la structure du sommeil. Bien que ces changements aient occasionné maintes difficultés pour ces hommes, il leur était encore plus difficile de voir leur femme souffrir. Ils se sont donc appliqués à leur apporter du soutien et à entamer le processus social fondamental qui consiste à accepter volontiers la transformation qui s’effectue dans leur vie. Les quatre étapes à suivre pour accepter la transformation d’une vie sont la prise de conscience, la participation, la centralisation de la vie sur la conjointe, et la recherche d’équilibre. La relation de couple, la santé de la femme et la présence d’un soutien formel et informel sont tous des facteurs qui ont une grande incidence sur le processus. La théorie qui consiste à accepter la transformation d’une vie propose un cadre qui permet de comprendre et d’expliquer l’ensemble complexe de stratégies qu’emploient ces hommes pour répondre aux changements, s’y adapter et les intégrer à leurs activités quotidiennes et à leur avenir. En outre, le fait de diriger le regard sur les hommes habitant avec une femme dialysée contribue à combler une lacune existante sur le plan des connaissances, et les constatations soulignent la capacité de ces hommes à apprendre et à mettre en pratique des rôles, des responsabilités et des routines complexes qui demandent des compétences avancées en observation, en prise de décision et en résolution de problème de même que sur le plan technique. Les étapes subtiles de la théorie guident les infirmières vers une meilleure compréhension des différents changements que les fournisseurs de soins de dialyse peuvent observer durant les différentes phases de la maladie de la patiente et leur permettent d'adopter des méthodes de soins de soutien qui facilitent leur adaptation et les poussent à poursuivre leurs efforts.

Mots clés: dialyse, époux/épouse aidant, aidant en dialyse, adaptation, changement, insuffisance rénale chronique, maladie rénale terminale.

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Dedication

Je dédie cette dissertation à mes deux filles Gabrielle et Dominique avec lesquelles j'ai pu découvrir le plus beau rôle d'une femme. Merci pour enrichir ma vie à tous les jours.

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Chapter 1: Introduction and Statement of Problem

Chronic kidney disease (CKD) involves progressive, irreversible destruction of the nephrons in both kidneys. People at risk of developing CKD include “those with diabetes, hypertension, cardiovascular disease, the elderly, and those with a family history of kidney disease” (Churchill, 2002, p. 129). Although it is difficult to estimate the precise number of people with CKD, there may be up to two million Canadians who are living with kidney disease or are at risk (Canadian Institute for Health Information [CIHI], 2011). An individual may progress through five stages of CKD before experiencing the final stage (stage 5), which is referred to as end-stage renal disease (ESRD). In this final stage, the kidneys are at 15% or less of normal renal function (CIHI, 2011). Individuals who reach this stage are usually in the process of deciding about dialysis or are already actively receiving dialysis and may be considered for a kidney transplant (Schick-Makaroff, 2012). In addition to living with ESRD, many patients have other significant progressive and potentially life threatening co-morbidities such as diabetes, cardiovascular disease, and malnutrition (Axelsson, Randers, Jacobson, & Klang, 2012). All these factors combine make ESRD a uniquely difficult and challenging condition for patients, their caregivers, and health care providers. Treatment for kidney failure is complex and involves hemodialysis or peritoneal dialysis, fluid and dietary restrictions as well as prescribed medications to sustain life (Thomas-Hawkings 2006) (see Appendix A for treatment information).

For the patients, ESRD and dialysis impose episodic as well as long-term physical and psychosocial stressors that can affect their social, physical, and/or psychological functioning (Tsay & Healstead, 2002). These individuals often need to rely on others for assistance with illness management (Beanlands et al., 2005). Family members often shoulder the responsibilities of assisting and supporting these individuals. Researchers have found that the physical, emotional, and technical support provided by family members is vital to the patient’s adherence to treatment regimens, quality of life, and survival (Brackney, 1979; Campbell, 1998; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Gurklis & Menke, 1995). In fact, Campbell (1998) has argued that good outcomes in all dimensions of renal replacement therapy depend as much on the labor and support of family members as on technology and professional care.

During the last four decades, numerous researchers have investigated the impact of kidney failure and dialysis on family members in terms of stressors, burden, quality of life, coping, and adjustment of the marital dyad to dialysis. Consideration of these impacts began to emerge in the literature shortly after the advent of dialysis as long-term therapy for kidney failure. Research published in the 1970s and 1980s identified the psychosocial impact of dialysis on spouses or family members, including restricted social activities (Atcherson, 1978; Baldree, Murphy, & Powers, 1982; Gurklis & Menke, 1988; Maurin & Schenkel, 1976) and change in role as spouses often assumed the partner's role responsibilities (Mass & Kaplan De-Nour, 1975; Maurin & Schenkel, 1976; Peterson, 1985). In a study of 1179 dialysis carers by Bryan and Evans (1979), 80.8% of the sample reported having to relinquish certain activities to assist the patient with illness-related care. From interviews with 29 family members, Atcherson (1978) reported that the stressfulness associated with home hemodialysis affected the caregivers more than it did the patients which resulted in the discontinuation of home dialysis. In contrast, Srivastava (1988) reported that although spouses found assisting with continuous peritoneal dialysis (CAPD) time consuming, most perceived themselves to be adjusting well.

Over time, other researchers have focused on the family members' experiences with adjusting to new role responsibilities and lifestyle, financial changes as well as dietary restrictions to accommodate the demands of ESRD and dialysis treatment (Brunier & McKeever, 1993; Campbell, 1998; Devins, Hunsley, Mandin, Taub, & Paul, 1997; Klang, Bjorvell, & Cronqvist, 1996; Lok, 1996; Mok & Tam, 2001; Weil, 2000; White & Grenier, 1999). In a review of the literature on the impact of home dialysis, Brunier and McKeever (1993) reported that dialysis-caregivers were required to juggle multiple responsibilities associated with various aspects of the illness and treatment, additional domestic responsibilities, and full-time employment. The stress and demands inherent with providing care to individuals on dialysis has been found to adversely affect the health of the careers (Belasco & Sesso, 2002; Blogg & Hyde, 2008; Quinan, 2005).

The escalation in the numbers of patients diagnosed with ESRD will continue as the 21st century unfolds (Canadian Organ Replacement Registry [CORR], 2011). The predicted growth, coupled with a critical shortage of organs for transplantation, will continue to take its toll on society in terms of costs to the health care system, health care professionals, and most importantly, patients and families who must endure a reduced quality of life and increased stress. With the rapidly growing number of elderly patients with ESRD and those with co-morbid illnesses receiving renal replacement therapy, the need for support from caregivers will likely increase (CORR, 2011). However, Soskolne and Kaplan De-Nour (1989) indicated that family caregivers cannot be expected to provide support without themselves receiving support.

Most studies on family members` experiences of living with someone on dialysis tend to be quantitative, with small samples sizes, and include mostly women, especially wives, as participants. The few researchers that included men either combined them with women in the analysis or made comparisons using very few men. Unfortunately, these studies were unable to discern the unique experiences, concerns, or problems of husbands or partners who live with women on dialysis. Understanding the experiences of men living with women undergoing dialysis for kidney failure is now taking on new importance. Although, there are more men living with ESRD (n = 59.6%) than women (n = 40.4%) (CORR, 2011), the number of women diagnosed with kidney failure has been increasing steadily over the last decade due in part to a higher prevalence of hypertension among women in comparison to their male counterparts (Public Health Agency of Canada, [PHAC], 2010). These trends suggest that women may experience altered physical, emotional, and social functioning and hence, may require assistance. Women who live with a spouse or partner tend to depend on these individuals for support (Kramer & Thompson, 2002).

A large body of literature exists about the experiences of husbands living with spouses with Alzheimer`s disease and cancer. Studies that have investigated the experiences of men living with women with chronic illness have focused on husbands caring for wives with breast cancer (Ciambrone & Allen, 2002; Hilton et al., 2000), diabetes, mental illness (Archer & MacLean, 1993; Mays & Lund, 1999), arthritis or stroke (Harrris & Long, 1999), and heart disease (Kramer & Lambert, 1999). Living with a female partner coping with a chronic illness can bring considerable changes in daily living and may require husbands/partners to assume new roles and responsibilities (Archer & MacLean 1993; Ciambrone & Allen, 2002; Harris & Long, 1999; Hilton, Crawford, & Tarko, 2000; Kramer & Lambert, 1999; Mays & Lund, 1999; Zahlis &

Shands, 1991). However, because these illnesses have unique disease courses and outcomes, it is questionable whether the experiences of husbands living with women affected by these particular illnesses can be generalized to other chronic illness situations such as ESRD.

Despite past recommendations for research that explores the experiences of spouses/partners living with women undergoing dialysis treatment, no such studies were found in the literature. Therefore, nurses' interventions for these men are likely to be based on the experiences of female-caregivers. This may be problematic because nurses' interventions may not be designed to address the unique needs and challenges faced by these men. Therefore, the purpose of my study was to discover a substantive theory, which explains the adjustment process of husbands /partners living with women on dialysis. A better understanding of husbands/partners' experiences of adjusting to living with women on dialysis may provide nurses and other health professionals with an increased awareness of the reality of these men's situations and may contribute to the development of male-gendered interventions to better prepare them to deal with and to adjust to the impact and the demands of this serious chronic illness on their daily lives.

Chapter 2: Literature Review

In this chapter I review the empirical literature in three major areas that are closely related to the population being studied. The first section focuses on family members living with and assisting patients undergoing renal replacement therapies for kidney failure. The second part centers on the experiences of family caregivers of adult individuals dependent on technology in the home. The final section relates to the husbands' perspectives on living with women with various chronic illnesses. The following review of the literature reflects the evidence that was available at the time that the study was designed; more recent and relevant literature will be included in the discussion chapter

Family Members Living with Patients on Renal Replacement Therapy

Kidney failure and renal replacement therapy are associated with illness-induced constraints that challenge patients and family members to accommodate and adapt (Devins et al., 1997). The involvement of the spouse or other family member in providing emotional and physical support to the patient is critical to the patient's quality of life, successful adaptation to dialysis, and adherence to dietary restrictions (Kimmel, 2000). However, family members may find this stressful because the illness and treatment regimen necessitate modifications to lifestyles and daily routines (Horsburgh, Rice, & Matuk, 1998).

Stressful situations associated with renal replacement therapy. In a review of the literature, Brunier and McKeever (1993) concluded that in some situations the demands of kidney failure and renal replacement therapy can be more stressful for family members than for the patients. There are three types of renal replacement therapy available to patients; hemodialysis (hospital or home), peritoneal dialysis, and kidney transplantation.

Home hemodialysis can be associated with the following stressors: dealing with the breakdown of the dialysis machine, inserting needles for dialysis (venipuncture), and the fear that the patient could die while on the machine. In contrast, stressors related to continuous ambulatory peritoneal dialysis (CAPD) or continuous cycler peritoneal dialysis (CCPD) may center on assisting with pharmacologic interventions, doing dialysate exchanges, ordering all the dialysis supplies, as well as getting up many times during the night to troubleshoot (Pelletier-Hibbert & Sohi, 2001). Although the family members of patients receiving hospital-based hemodialysis have no direct dialysis care responsibilities, they also experience challenges and struggles. Commuting to and from the dialysis unit, waiting at the hospital for dialysis treatment to be completed, and rearranging work schedules to drop off and pick up the patient were found to have a significant impact on their time and energy (Atcherson, 1981; Bryan & Evans 1979; Lowry & Atcherson 1984; Pelletier-Hibbert & Sohi, 2001).

In a more recent quantitative study that compared partners of patients on dialysis (n = 988) to those of kidney transplant patients (n = 827), Morelon, Berthoux, Brun-Strang, Fior, and Volle (2005) reported that the quality of life of the latter group was significantly better with respect to their social life and relationships with their spouses and others. In contrast, more than 70% of partners of patients on dialysis revealed being restricted in their travel, leisure activities, and dietary regime. The dialysis group also reported more than 80% curtailment or cessation of sexual relations with their partner compared to 55% in the transplant group. Most partners of transplant patients were found to be more optimistic about the future, which may be why fewer (8%) reported being depressed compared to 14% in the dialysis group. The only gender difference reported in this study pertained to women devoting more time to provide assistance to their dialysis partner; however, the amount of time and nature of assistance provided were not described.

Although kidney transplant recipients are no longer subject to the constraints and stressors imposed by dialysis treatment, their lives and those of their family members are not stress free (Starzomski & Hilton, 2000). The family members of transplant recipients report stressors associated with adjusting to: (a) an intense and lengthy follow-up period; (b) the regimens and side effects associated with immunosuppressant medications; (c) worries about the potential of organ rejection; and (d) uncertainty about how long the transplanted kidney will function (Starzomski & Hilton, 2000; Sutton & Murphy, 1989; White, Ketefian, Starr, & Voepel-Lewis, 1990). In a descriptive correlation study, Starzomski and Hilton (2000) found that partners of kidney transplant recipients and patients on dialysis waiting for a transplant experienced stressors related to: being dissatisfied with their sexual relationship, lack of sufficient time for leisure and recreation, disruptions related to work for themselves and their partners, and changes in their daily routines and household tasks.

There are also stressors commonly experienced by family members regardless of the type of dialysis therapy, for example: (a) accommodating the dietary restrictions imposed by kidney failure (Pelletier-Hibbert & Sohi, 2001), (b) integrating a variety of dietary regimens for co-morbid conditions such as diabetes and/or cardiovascular disease (Pelletier-Hibbert & Sohi, 2001), (c) assisting dialysis patients to comply with dietary and fluid restrictions (Campbell, 1998; Pelletier-Hibbert & Sohi, 2001), (d) living a restricted lifestyle (White & Grenier, 1999), and (e) dealing with the patient's moodiness and loss of emotional closeness with the partner (Campbell, 1998; Lindqvist, Carlsson, & Sjoden, 2000).

Uncertainty has also been found to be a factor contributing to stress in family members of individuals on various types of renal replacement therapy. Brock (1990) studied uncertainty, information needs, and coping effectiveness in family members of individuals on hospital hemodialysis and found that knowledge correlated negatively with uncertainty ($r = -.53$, $p < .001$) and level of education correlated positively with coping effectiveness ($r = .39$, $p < .01$). Sources of uncertainty for family members of patients on CAPD or hemodialysis waiting for a kidney transplant included not knowing (a) when the patient's health would deteriorate, (b) whether dialysis treatment would manage the illness symptoms and/or how the patient would feel after each treatment, (c) how long dialysis treatment would sustain life (Starzomski & Hilton, 2000), and/or (d) if and when the dialyzed individual would get a kidney transplant (Pelletier-Hibbert & Sohi, 2001; Sloan & Gittings, 1998). The impact of these stressors can seriously compromise the family caregiver's psychological and physiological well-being, quality of life, marital relationships, and coping abilities (Devins et al., 1997).

Burden. The negative psychosocial, physical, and financial outcomes of caring for patients on dialysis have been referred to as caregiver burden (George & Gwyther, 1986). There is limited research on caregiver burden among spouses of partners on dialysis. Researchers studying caregiver burden differentiate between objective and subjective kinds of burden. Subjective burden focuses on the extent to which the caregiver perceives care responsibilities to be overly demanding, while objective burden refers to the perceived infringement or disruption of caregiving activities on a caregiver's life, such as social and recreational activities, as well as his/her personal time (Wicks, Milstead, Centingok, & Hathaway, 1997).

Belasco and Sesso (2002) used a predictive model to explain caregiver burden in 101 caregivers of hospital hemodialysis patients in Brazil. The Medical Outcome Survey 36-Item Short Form Health Survey (SF-36) was used to measure QOL and subjective burden was assessed with the Caregiver Burden Scale (CBS). Four significant predictors of caregiver burden were reported. The mental health of the caregiver was the most important variable, followed by patient vitality, type of caregiver (e.g., wife), and the experience of pain. Other psychosocial impacts such as sadness, resentment, guilt and anxiety were reported by wives of dialysis patients (Luk, 2002; White & Grenyer, 1999). In contrast, in a descriptive correlation study, Courts (2000) found low anxiety and depression in 14 home hemodialysis patients and their dialysis partners (n = 9 wives, n = 1 husband, sister or friend, and n = 2 daughters).

Lindqvist et al. (2000) compared the general well-being of spouses of patients on various renal replacement therapies. They studied 21 husbands and 34 wives of patients on CAPD, hospital hemodialysis, and kidney transplant recipients. Spouses of transplant recipients (n = 20) had significantly greater satisfaction with their physical health, emotional well-being, sleep patterns, and sexual functioning than both the CAPD (n = 15) and hemodialysis spouses (n = 20) ($p < .05$). Recipients of transplants may experience relatively stable health conditions, and as a result, their spouses may experience less interference occasioned by daily and long-term problems associated with kidney failure and hence less burden (Molzahn, 1991; Starzomski & Hilton, 2000). Caregiver burden may also impact the QOL of family members of individuals with kidney failure, which I will address in the following section.

Quality of life (QOL). In an exploratory descriptive study of spouses of CAPD patients (n = 16 husbands and n = 22 wives), Dunn et al. (1994) found that perceived QOL varied among the spouses, with 21% rating their QOL high, 55% moderate, and 24% poor. Marital adjustment was the best predictor of QOL, accounting for 54% of the variance. In a more recent study, Lindqvist et al. (2000) were among the few researchers who compared health–related QOL and coping in spouses of patients on various renal replacement therapies. They studied 21 husbands and 34 wives of CAPD patients, hospital hemodialysis patients, and kidney transplant recipients. Spouses of hemodialysis patients (n = 20) rated themselves as less able to manage the demands of the illness, and consequently they experienced poorer QOL than the other spouses of partners on CAPD (n = 15). In contrast, spouses of transplant recipients (n = 20) had significantly greater satisfaction with their physical health, emotional well-being, sleep patterns, and sexual functioning than both the CAPD and hemodialysis spouses ($p < 0.05$). Similarly, two groups of researchers (Harris, Thomas, Wicks, Faulkner, & Hathaway, 2000; Wicks et al., 1997) found that the majority of the caregivers of patients awaiting kidney and pancreas-kidney transplants experienced little to no burden. Recipients and candidates of transplants may experience a relatively stable health condition when compared to those who are not eligible for a transplant. As a result, the spouses of transplant candidates and recipients may have less interference occasioned by daily and long-term problems associated with kidney failure and hence less burden and a more stable QOL (Molzahn, 1991; Starzomski & Hilton, 2000). These researchers asserted that spouses of hemodialysis patients who experience poor QOL may not be in a position to support their partners. In the following section I will address the role of the marital dyad in the adjustment of each partner to the demands of kidney failure and renal replacement therapy.

Adjustment of the marital dyad to dialysis treatment. The significance of the marital and family context has long been recognized in chronic kidney failure. According to Devins et al. (1997), “the condition may affect and be affected by, family life in many ways” (p. 326). Spouses of individuals with kidney failure experience many of the same challenges and constraints encountered by the patient, and kidney failure and renal replacement therapy may affect the couple. A spouse’s adjustment to dialysis can be influenced by the partner’s reaction to kidney failure and dialysis treatment (Chowanec & Binik, 1989; Daneker, Kimmel, Ranich, & Peterson, 2001; Horsburgh et al., 1998), whereas a couple’s adaptation to the demands of the illness and home hemodialysis rests heavily on the physical and psychological well-being and coping abilities of the spouse caregiver (Brackney, 1979).

In one of the few Canadian studies, Chowanec and Binik (1989) examined the relationship among chronic renal failure, marital functioning, and individual psychological well-being in 89 couples (n = 43 husbands as patients and n = 46 wives as patients), sampled from five groups of patients with varying stages of kidney disease: (a) individuals with comparatively minor renal problems (n = 18, absence of ESRD), (b) individuals with progressive renal failure not yet requiring renal replacement (n = 17, pre-dialysis), (c) individuals with ESRD requiring hospital hemodialysis treatment (n = 19), (d) individuals with ESRD on either home hemodialysis or CAPD (n = 18), and (e) post-kidney transplant individuals (n = 17). Surprisingly, these researchers revealed that neither dyadic (marital adjustment, marital role strain) nor individual variables (self-esteem, general psychological distress) differed across these groups. However, the correlation between marital role strain and psychological well-being was significantly higher among couples with a spouse on home dialysis ($r = .90$, $p = < .01$) than in the three non-dialysis groups. This finding may be explained by the fact that people on either home hemodialysis or peritoneal dialysis and their caregivers bear a heavier burden in terms of treatment responsibility and daily conduct of the therapeutic regimen in comparison to hospital hemodialysis and non-dialysis patients.

In another Canadian study, Devins et al. (1997) used the Family Environment Scale (FES) to compare a small sample of 19 couples (10 wives and 9 husbands) where the partner was on hospital hemodialysis (n = 9) or had received a renal transplant (n = 10). Spouses of transplant recipients reported significant enhancement in their personal growth, whereas the spouses of dialysis patients displayed a slight reduction in personal growth. However, personal growth did not change for the patients. Similar results were reported by Kaye, Bray, Gracely, and Levinson (1989) when they found that dialysis family members showed reductions in personal growth on the FES, especially loss of independence and changes in their social lives, while the dialysis patients experienced increased personal growth. Starzomski and Hilton (2000) reported that pre and post kidney transplant patients and their partners depended a great deal on one another for support. However, the partners in both the groups were more affected by issues related to family functioning and were less satisfied with their marriage as were the patients. These two findings were judged to be important areas for further study.

Friesen in a qualitative study (1997) of eight spouses of patients with kidney failure on home hemodialysis, provides some explanations for the observed problems in social and marital functioning. Three levels of spousal caregiving involvement were uncovered: the doers, the minimal assistants, and the joint doers. The doers were all female spouses (n = 3), had no children at home, and most were unemployed. They assumed all the tasks of running home hemodialysis while their partners played a passive role. As a result, the doers expressed moderate levels of resentment about caregiving. In contrast, the minimal assistants were in their early 30s, worked and had young children. They expressed the strongest feelings of resentment toward their partner's disease and the lifestyle changes imposed by dialysis. In contrast, the joint doer-partners shared the responsibilities of dialysis with their ill partner, were older, and most were retired. Unlike the other two groups, the joint doer-partners, maintained activities outside the home, successfully integrated home hemodialysis into their daily lives, and expressed little resentment. They focused more on the normal aspects of their lives. The strong cooperation between the partners appeared to influence their positive experience with dialysis. The joint doer-partners also grew closer as a couple, whereas the doers reported a stable relationship, and the minimal assistants experienced strained relationships. Daneker et al. (2001) note that "chronic illness may have a profound effect on a marriage, often creating new sources of marital tension or amplifying existing marital problems" (p. 840). It is unknown from Friesen's study (1997) whether the dynamics of the relationship and cohesiveness between partners remained the same or changed over time.

Similarly, Brackney (1979) in a study of 12 male home hemodialysis patients and their wife caregivers found that a collaborative relationship between spouses during home dialysis influenced both partners' adjustment to dialysis. The patients' adjustment was positively correlated with the psychological well-being of the wife ($r = .79$; $p < .01$) and negatively correlated with marital conflict ($r = -.86$; $p < .002$). The wives' adjustment was strongly correlated with the physical health of the patients ($r = .79$; $p < .01$). The physical health of the patient was enhanced when a wife positively adjusted to home dialysis ($r = .90$; $p < .001$) and worked co-operatively during dialysis ($r = .83$; $p < .002$). Moreover, wives who could assist with home dialysis care had husband patients who (a) co-operated during dialysis ($r = .87$; $p < .002$), (b) were emotionally adjusted to home dialysis ($r = .84$;

$p < .002$), and (c) were more physically healthy ($r = .82$; $p < .002$). Similarly, the patients' efficacy in performing dialysis tasks was positively correlated with the wives' physical health ($r = .80$; $p < .002$) and emotional adjustment to home dialysis ($r = .81$; $p < .002$). Thus, it appears that greater emotional adjustment and physical health in one spouse increases the efficacy of the other to perform dialysis duties. However, the small sample, the lack of couple interviews, and the inclusion of only male home hemodialysis patients are limitations.

The patient's level of depression is another important factor that may influence the spouse's psychological well-being and marital satisfaction. Daneker et al. (2001) studied depression, perception of social support, and marital satisfaction in 55 spouses ($n = 42$ wives and $n = 13$ husbands) of patients on hospital hemodialysis. They found that more depressed spouses had highly depressed ill-partners, perceived less support from them, and were less happy in their marriages ($p <.05$). These findings suggest that living with a depressed patient can be a significant source of stress for a spouse caregiver. Dealing with a patient's distress may deplete the caregiver's coping resources, particularly when the spouse perceives a lack of support from the ill partner. This in turn may reduce the spouse's ability to support the ill partner and impair his or her ability to provide care (Daneker et al., 2001). Examination of gender differences was not possible in this study due to the small number of husband caregivers.

Factors Influencing Family Members` Experiences

While there may be challenges that are common to all family caregivers regardless of the type of renal replacement therapy, several personal factors have been reported to influence their abilities to integrate the demands and restrictions imposed by kidney failure and dialysis treatment. These factors include the family caregiver's sex, age, length of time spent assisting with dialysis care, as well as the type of coping strategies used to manage the demands of kidney failure and dialysis.

Sex differences. More than three decades ago, Atcherson (1981) argued that it would be "unlikely that men and women adjust in the same ways to the role of dialysis assistant" (p. 34). Friesen (1997) suggested that "spousal perspectives on assisting with dialysis may differ between males and females" (p. 324). The few researchers that have compared gender differences in adjustment to kidney failure and dialysis in family caregivers found mixed results. Some studies have reported that women's experiences as patients or partners were more negative (Blogg et al., 1999; Chowanec & Binik, 1989; Devins et al., 1997; Lindqvist et al., 2000). For example, Blogg et al. (1999) found that wife caregivers (n = 42) were more distressed by the changes in household routines, social life, and standard of living imposed by dialysis compared to husband caregivers (n = 19). They explained that men living with women undergoing dialysis treatment may encounter less disruption in their day-to-day lives "due to the continuance of the female patient's traditional social roles, such as maintaining the household routine and family life," while simultaneously assuming her responsibilities for sustaining home dialysis (Blogg et al., 1999, p. 512).

In contrast, Soskolne and Kaplan De-Nour (1989) found that husband caregivers fared worse in their study of psychological distress and adjustment of spouses and patients on hospital hemodialysis. Husband caregivers (n = 16) reported more psychological distress ($p < .05$) and showed a tendency to worse adjustment in four of the six domains of adjustment compared to wife caregivers (n = 52). Soskolne and Kaplan De-Nour explained that women have traditionally occupied a nurturing role, performed the essential household tasks, and assumed the major responsibility for the care of family members. Therefore, when a woman is sick, her ability to perform these various roles is diminished, causing all family members to be affected, especially the spouses. Men may need to assist or take on additional and nontraditional responsibilities, something that could cause husband caregivers to feel distress (Hilton et al., 2000).

The gender of the patient is also an important consideration in adjustment. Devins et al. (1997) found that couples where the patient was the wife reported a decline in the relationship, whereas couples in which the patient was the husband reported no change in the relationship. Similarly, Chowanec and Binik (1989) reported significant gender differences in psychological well-being, with female patients reporting more distress and more marital role strain ($p < .01$) than male patients. However, no significant differences were reported for the husbands (n = 46) or wives (n = 43) of these patients. In a qualitative study of couples coping with home hemodialysis, Atcherson (1981) found the majority of those who were not able to manage home hemodialysis were women with male caregivers, mainly husbands. In contrast, most patients who dialysed successfully at home were men with female caregivers, usually their wives. Atcherson (1981) postulated that husbands might have greater difficulty adjusting to this caregiving role; however, this has not been determined.

Age of the caregiver. The few studies that examined the family member's age as a predictor of distress and adjustment to kidney failure and dialysis treatment showed mixed results. Harris et al. (2000) found no significant age differences in total burden or role strain between younger and older caregivers of dialysis patients waiting for a kidney transplant. However, in four studies, younger spouses were found to experience more difficulties adjusting to kidney failure and dialysis treatment (Atcherson, 1981; Blogg et al., 1999; Friesen, 1997). For example, Atcherson (1981) compared the adjustment of spouses less than 45 years of age with those over 45 years of age during dialysis training sessions and after three months of caring for their husbands on home hemodialysis. While both age groups reported being worried and nervous about dialysis during training, at three months, the younger spouses reported ongoing difficulty with sleep and anxiety as well as somatic disturbances. Similarly, in an Australian study, Blogg et al. (1999) found that spouses under the age of 45 experienced more distress and life upset than spouses 45 years old and older. Consistent with these studies, Friesen (1997) noted that younger spouses experienced the most resentment towards dialysis, participated the least in dialysis care, and had a particularly difficult time adjusting to the challenges and constraints imposed by ESRD and home dialysis. These investigators postulated that caregivers, especially younger persons, may feel more limited in career and social activities when they assume the caregiving role. Similarly, younger caregivers may experience more secondary role strains, such as work and child rearing, and may have greater financial commitments.

Length of time spent caregiving. In several longitudinal studies, researchers have explored the relationship between length of time caring for someone with kidney failure and caregiver distress. Some investigators reported persistent caregiver distress, whereas others have found that distress dissipated over time. For example, Holcomb and Macdonald (1973) found that 75% of spouses continued to report depression two years after assisting with dialysis, compared to 43% of patients. Similarly, Lowry and Atcherson (1981) found that at six months after starting dialysis, spouses continued to get easily angry with their ill partner. However, depression, insomnia, and diminished cognitive abilities disappeared after six months for most of the caregivers. In a more recent study of family members of hemodialysis patients, Belasco and Sesso (2002) found no relationship between caregiver burden and length of time spent caregiving. According to the researchers, persistent reactions may have been a reflection of feelings of deprivation associated with losses and changes imposed by the illness and dialysis.

In contrast, Bryan and Evan’s (1979) national survey of 198 home hemodialysis caregivers in the U.S. showed that anxiety declined over time, with anxiety highest during the first two years of caregiving. Caution must be applied in interpreting the results of this survey since the authors did not specify how anxiety was measured. Similarly, Courts (2000) observed that the level of stress experienced by 14 spouses of home hemodialysis patients decreased over time; however, it is not clear how stress was measured or how long caregivers had assisted with dialysis.

Coping strategies. Few researchers have investigated coping as a predictor of family members’ adjustment to kidney failure and dialysis. One investigator, Srivastava, (1988) specifically focused on coping, but more researchers have explored the relationship between coping and other variables (Dunn et al., 1994; Lindqvist et al., 2000) or identified themes of coping in qualitative studies (Flaherty & O’Brien, 1992; Pelletier-Hibbert & Sohi, 2000).

Three groups of researchers (Dunn et al., 1994; Lindqvist et al., 2000; Srivastava, 1988) explored coping strategies using the Jalowiec Coping Scale. Dunn et al. (1994) found that spouses of CAPD patients (n= 16 males and n= 22 female) who reported low marital adjustment tended to use more affective coping. Lindqvist et al. (2000) compared coping styles in male and female caregivers. Wife caregivers (n= 34) of hospital hemodialysis, CAPD, and transplant patients tended to use more supportive and palliative coping strategies, whereas husband caregivers (n = 21) tended to use more problem-oriented strategies. Lindqvist et al. (2000) suggested that when caregivers use emotion-oriented styles of coping, this might suggest difficulty in managing their family member’s illness. In contrast, Srivastava (1988) reported that 30 spouses (23 wives and 7 husbands) of individuals on CAPD used similar problem and emotion-focused coping strategies to manage the situation, including accepting it as it was, trying to maintain control, and finding out more. In addition, both men and women reported that they were coping well or very well, despite feeling that dialysis was very demanding and had become the central focus of their lives.

In two qualitative studies, researchers demonstrated that the coping strategies used by family members varied with the type of renal replacement therapy. Flaherty and O'Brien (1992) showed that family members of hospital hemodialysis patients used remote family style most often and distressed family style the least. Remote coping helped individuals to distance themselves from the illness, while distressed coping assisted with managing worries about the ill family member. In contrast, family members of patients on CAPD used altered styles of coping, which focused on accepting the diagnosis and adjusting to lifestyle changes. Family members of patients on home hemodialysis used the enfolded style of coping, which strengthened affection among family members. According to these researchers, the differences in the type of coping strategies used by these family members may be due to the level of involvement required to assist with dialysis. Another group of researchers (Pelletier-Hibbert & Sohi 2001) identified four coping strategies used by 41 family members of individuals on hospital and home hemodialysis or CAPD. All family members reported that living each day as it comes and drawing on God's strength assisted them to deal with uncertainty and the everyday challenges of the illness and its treatment. Finding positive meaning and hoping for a transplant were used mainly by family members of patients waiting for a transplant. According to Lazarus and Folkman (1984), emotion-focused strategies are useful in situations that are appraised as unchangeable and beyond one's control. Although the results of these studies suggest that sex, age, length of time assisting with dialysis, and coping strategies affect adjustment to ESRD and dialysis treatment, the results are not consistent across studies and require further exploration.

Summary

There is a growing body of literature dealing with family members' experiences in living with individuals on various forms of renal replacement therapy. Also, increasing attention has been paid to the various roles and responsibilities of family members in providing emotional and technical support to dialysis patients. It is clear from these findings that the role of the spouse/partner is crucial in the process and outcome of dialysis and transplantation. Considering the severity of kidney failure and the intrusiveness of the treatment regimens, it is not surprising that the lives of most family caregivers are adversely affected. One of the most striking findings had to do with how one spouse's emotional and physical well-being and ability to cooperate in home dialysis can influence the other spouse's adjustment to the demands of kidney failure and dialysis care. In addition, there is evidence to suggest that a caregiver's level of stress, burden, quality of life, and coping abilities vary according to (a) the type of renal replacement treatment, (b) the patient's ability to perform ADL, (c) the patient's level of depression, and (d) the presence of co-morbid illnesses such as diabetes in the patient.

My review of the literature pertaining to family members of individuals on various types of renal replacement therapy also revealed a number of shortcomings. In the majority of the studies, a wide range of variables and measures were used, making it difficult to compare and generalize findings. As well, most of the studies were guided by theoretical frameworks that pre-determined the way that caregiving outcomes could be explained. Such frameworks constrained the range of variables studied and largely ignored contextual issues (e.g., home milieu) that might have an impact on the experiences of family members. Of particular concern is the fact that the sample size in most of the studies was not only small, but most of our understanding about living with someone with kidney failure has been studied from the perspective of women, especially wives. This focus is understandable given that women generally predominate in the caregiving role and the prevalence of kidney failure is greater in men. However, the few researchers who recruited husband caregivers either included them in the analysis with wives or conducted separate comparisons with very few men. Consequently, these investigators were unable to discern the unique concerns, issues, and experiences of husbands/partners who live with women on dialysis. Thus, there is limited information about these men; and as a result, researchers are calling for studies about this cohort (Atcherson, 1981; Blogg et al., 1999; Brunier & McKeever, 1993; Daneker et al., 2001; Friesen, 1997). Therefore, to address some of these shortcomings, I propose a qualitative study to learn about the adjustment process of husbands/partners living with women undergoing dialysis treatment. In the following section, I will highlight the challenges faced by family members who live with and assist adults using other types of technology in the home. Their experiences will be compared and contrasted with those of dialysis-caregivers.

Health-Related or Medical Technology at Home

Haemodialysis was the first technological treatment to be transferred into the home in the 1960s (Brunier & McKeever, 1993; Smith, 1994). Since then, the number of patients on home technology has increased due to advances in treatments, the development of reliable technology, the expansion of home care, and the healthcare reforms aimed at reducing the length of hospital stays (Smith, 1995; Smith, et al., 2002). Smith et al. (2002) asserted that assisting with medical technology in the home is stressful and disruptive to usual family activities. My review of the literature revealed that the most common types of medical technology in the home are infusion therapy, oxygen therapy from a ventilator, and external defibrillators.

Caregiving and infusion therapies. The use of infusion therapy in the home emerged in the mid-eighties. Since then, researchers have explored family caregiving with respect to the use of infusion therapies for total parenteral nutrition (Smith, 1994; 1999; Smith, Gieffer, & Bieker, 1991; Smith, Moushey, Marien, & Weber, 1993; Smith, Moushey, Ross, & Giefer, 1993) and inotropic infusion therapy for end-stage heart failure (Scott, 2001).

Total parenteral nutrition. Smith, Gieffer et al. (1991) interviewed five caregivers of TPN recipients about their reactions to caregiving, family adaptation, and preparation for caregiving. The caregivers expressed pride in managing technological care and found caregiving to be enjoyable and gratifying. However, they also reported a financial burden, anxiety, and deterioration in their own health. The caregivers stressed the importance of being prepared for the caring role and knowing how to manage emergencies.

Smith, Moushey, Marien et al. (1993) and Smith, Moushey, Ross et al. (1993) studied the same group of 20 family caregivers of TPN partners (n = 16 were spouses). Nine of the patients received TPN 24 hours continuously, whereas 11 had only nighttime infusion. In the first study, Smith, Moushey et al. (1993) used a 60-itemTPN checklist with caregivers to rate the importance of specific content in managing TPN at home. Caregivers rated aseptic technique, emergency procedures, supply for infusion, and administration of TPN as being of highest importance. Although items on emotional-social content were also rated as important, the caregivers reported that health professionals had addressed only one item. The researchers explained that the caregivers probably received the information but were too overwhelmed to absorb it. The small sample and absence of psychometrics on the TPN checklist limit the generalizability of the findings. In the second study with this sample, Smith, Moushey, Ross et al. (1993) used a semi-structured interview to explore caregiving responsibilities and psychological reactions of these 20 family caregivers. The majority described their health as good since initiating TPN. However, 80% reported adverse psychological and emotional effects. Six reported feeling tired and exhausted initially. Changes in family responsibilities also decreased their time to pursue personal interests. The caregivers were frustrated with the lack of assistance from other family members and social isolation. On a positive note, they expressed a sense of accomplishment and confidence with their caregiving.

Smith (1994) went on to develop an explanatory model of caregiving effectiveness based on work with 111 caregivers of adult TPN patients with non-malignant bowel disease. The final model included economic stability, family coping, depression, age, mutuality, years of caregiving, and reaction to caregiving and it accounted for 33% of the variance in caregivers' QOL ($p <.05$). In a second study with 31 caregivers of patients on TPN, the model explained 56% of the caregiver's QOL ($p = .03$); however, this was largely due to situational depression and social support (Smith, 1999). The small sample and the different patient population in the later study may explain the differences in findings between the two studies.

Inotropic infusion. Inotropic medications are potent pharmacological agents that can be administered either as an intermittent or a continuous infusion for palliative measures or as a bridge to cardiac transplantation (Boger, DeLuca, Watkins,Vershave, & Thomley, 1997). Scott (2001) explored the experiences of four spouse caregivers of patients who were receiving inotropic infusions in an ambulatory setting or at home. Caregiving was perceived as both a positive and gratifying experience and was made easier by having access to community-based inotropic therapy. Each day that the care recipient survived was perceived to be a positive benefit of caregiving. The caregivers also expressed anxiety, fear, and apprehensiveness, which were a result of administering medication, lifestyle changes, and confinement. The technical aspect of care and constant vigilance resulted in overwhelming responsibilities, social isolation, and depression. This finding is consistent with what has been reported by some family members of dialysis patients.

Caregiving and ventilator therapy. Caring for family members receiving mechanical ventilation has been studied in adult and pediatric populations. However, I have included only studies pertaining to ventilator-dependent adults in this review (Findeis, Larson, Gallo, & Shekleton, 1994; Sevick et al., 1994; Smith, Mayer, Metsker et al., 1998; Smith, Mayer, Parkurst et al., 1998; Thomas, Ellison, Howell, & Winters, 1992). Two groups of researchers (Findeis et al., 1994; Sevick et al., 1994) examined caregiving appraisal in this situation using the Caregiver Appraisal Scale (CAS) (Lawton, Kleban, Moss, Rovine, & Glicksman, 1989). Findeis et al. (1994) investigated caregiving burden, impact, satisfaction, and mastery in 12 family caregivers. Caregivers' burden and mastery scores indicated that they perceived their experiences in a positive light. The negotiation and coordination of professional services was reported to be more difficult than physical care. In contrast, the results from the interviews indicated that most of the caregivers' personal, social, and financial lives were negatively affected, but they were unable to articulate specific satisfying aspects of caregiving. Sevick et al. (1994) in their study of 26 caregivers of ventilator-dependent recipients also reported positive appraisals for all of the subscales of the CAS.

Smith, Mayer et al. (1991) explored responses to caregiving in 20 family members caring for patients receiving ventilation at home. Caregivers' responses on the Family Crisis Oriented Personal Evaluation Scales (F-COPES) indicated that the caregivers coped adequately with the situation. No significant differences were found in coping between male and female caregivers ($p = .53$). Over time, caregivers reported decreasing satisfaction with family functioning on the Family APGAR ($r = -.59$, $p = .05$). A moderate association between the F-COPES and Family APGAR ($r = .506$, $p = .038$) suggested that caregivers who coped well, tended to experience more satisfaction with family functioning. Although caregivers spoke positively about their ability to bring their relative home and master the skills, they reported an overwhelming sense of responsibility and feeling hopeless and resentful about the care recipient's dependence.

Several other investigators have addressed the needs of family caregivers managing home ventilation. Thomas et al. (1992) in their study of caregivers' needs, identified five priority areas: continuity of care, caregiver/recipient communication, emergency provisions, financial concerns, and family dynamics. New caregivers wanted to know how to handle emergencies, whereas experienced caregivers were more concerned about finances. The learning needs and quality of life of 21 family caregivers managing continuous positive airway (CPAP) ventilation regimens were examined in a study by Smith, Mayer, Metsker et al. (1998). Caregivers' scores on the Quality of life Index were below the norm for healthy adults. On a positive note, the average score of caregivers on the preparedness scale indicated confidence in providing home CPAP care. Caregivers preparedness scores were negatively correlated with depression ($r = -.61$, $p = .009$), suggesting that being well prepared for the caregiving role is associated with less distress. Conversely, the researchers indicated that being distressed may interfere with one's ability to learn the role. Interviews with family members indicated that their information needs centered on understanding the effects of sleep apnea on the patient. Caregivers were able to sleep better once the patient had started CPAP.

In a similar study, Scott and Arslanian-Engoren (2002) investigated caregiver preparedness, responses, and mental health while caring for family members with tracheotomies on prolonged mechanical ventilation. The caregivers felt well prepared with respect to accessing information, engaging in diversion activities, and dealing with emergencies. They felt less prepared to co-ordinate healthcare services and manage the emotional and physical needs of the patient and least prepared for the stress associated with caregiving. Consistent with previous findings, these results showed that caregivers were experiencing distress. More than half of the caregivers were anxious, 40% were depressed, and 73% were despondent at times. Although caregivers reported enjoyment and gratification from caregiving, they suffered from reduced family and social interactions, financial hardships, and physical exhaustion, similar to the experience of dialysis-caregivers.

Caregiving and external defibrillator. When compared to other types of medical technologies in the home, external defibrillators are used the least frequently due in part to the availability of interventions which can be used to sustain the function of the heart

(Cummins, Eisenberg, Bergner et al., 1984; Cummins, Eisenberg, Moore et al., 1985; Moore et al., 1987). Only two cohorts of researchers have examined external defibrillator (ED) skill acquisition and retention among family caregivers (Cummins et al., 1985; Moore et al., 1987). Moore et al. trained 34 spouses and significant others of cardiac arrest survivors in cardiopulmonary resuscitation (CPR) and ED procedures. Although most of the caregivers (94%) were able to learn the necessary skills to perform external defibrillation, 30% failed to perform ED successfully after six weeks. Despite retraining, 48% failed to perform adequately at the three-month follow-up. Similarly, Cummins et al. (1985) found that caregivers had difficulty remembering how to perform the ED procedure. Although some family members felt more secure having the ED device in their home, others reported that having the device in a prominent place in the home caused considerable distress. The investigators noted that families tended to deny the recipient's health risk and needed to reduce the stress associated with the potential of another cardiac arrest.

Summary

The dearth of studies on caregivers of individuals requiring technological home care, coupled with the varied research designs, posed challenges to interpreting the findings. However, several patterns did emerge. Family caregivers needed to be well informed about managing the technology, including dealing with emergencies and preparing to assume their caregiving roles and responsibilities which surfaced as important in almost every study. Caregivers also needed to understand the psychosocial implications of providing care. Although caregivers reported a sense of satisfaction and fulfillment from assisting, they experienced changes in family responsibilities, a decline in physical and emotional well-being, and social isolation. Consistent with the studies of family members of dialysis patients, a large percentage of the caregivers were women, particularly wives. Less is known about what it is like for men to live with someone dependent on technology for survival and the nature of their roles and responsibilities in this situation.

There is mounting evidence from the literature that husbands/partners are affected by their wives' illness. Indeed, husbands/partners are the first to be called upon to meet their wives' need for care (Kramer & Thompson, 2002). Because research on husbands living with a spouse with ESRD or assisting with medical technology at home is lacking, in the next section I will describe the experiences of husbands living with spouses who have a chronic illness.

The Experiences of Husbands Living with a Chronically Ill Spouse

When a wife experiences a serious chronic illness, it also affects the lives of the husband and family. Living with a wife with a chronic illness can bring considerable changes in daily living and may require substantial physical and emotional commitment on the part of the husband (Archer & MacLean 1993; Ciambrone & Allen, 2002; Harris & Long, 1999; Hilton et al., 2000; Kramer & Lambert, 1999; Mays & Lund, 1999; Zahlis & Shands, 1991). Some husbands may become burdened by caregiving and/or non-traditional responsibilities, with resultant consequences for their psychological and physical well-being (Boeije, Duijnstee, & Grypdonck, 2003; Parsons, 1997). On the other hand, efforts to cope with these changes and personal growth may buffer some of the stressors arising from their wives' illness (Hilton et al., 2000; Wilson & Morse, 1991).

Men as caregivers. In a National Survey on Canadian caregivers (Health Canada, 2002) it was found that the majority of caregivers were wives or daughters while 24% were men. Although the percentage of male caregivers was small, it represented a 14% increase since 1996 (Health Canada, 2002). Traditionally, men's contribution to care has included instrumental tasks such as yard repair and maintenance, transportation, and/or financial management (Kaye & Applegate, 1990) or supporting the caregiving efforts of their wives or sisters (Stoller, 2002).

Gilligan in her theory (1982) proposed that women act out of an ethic of care and men act out of an ethic of right or duty. Thus, male caregivers may commit and attach in a manner different from that of women. However, not all researchers have supported this theory. For example, Motenko (1988) and Siriopoulos, Brown, and Wright (1999) found that love and commitment were the motivating principles among husband-caregivers of women with dementia. Kaye and Applegate (1990) found older husbands caring for women with dementia used both instrumental and affective terms on the Bem Sex Role Inventory (BSRI) to describe themselves. Some researchers have found that men derive rewards from providing personal care and emotional support. These included: (a) a sense of continuity by managing and controlling their wives' needs (Thompson, 2002), (b) gratifications and intrinsic rewards formerly found in work (Archer & MacLean, 1993), (c) an opportunity to extend their authority within family structure and their work (Harris 1993; Kaye & Applegate, 1990), (d) the experience of nurturing (Kay & Applegate, 1990), and (e) interpersonal commitment and ongoing reciprocity between spouses (Neufeld & Harrison, 1998).

There are also external pressures that are gradually bringing changes to men's involvement in caregiving. These include smaller families, the dispersion of the nuclear family, and changing family roles (Harris, 1998). The increasing numbers of women entering the work force and increased life expectancy, combined with the increased prevalence of chronic illness, are also likely to make male caregiving more of an expectation and even a necessity. Among married women with a chronic illness, the husband is commonly identified as the most important source of support and assistance (Ciambrone & Allen, 2002). As well, husbands, like wives, provide the most consistent and dependable care for longer periods of time than any other kind of caregiver (Harris, 1993). In the following section, I will summarize the implications and impact of living with and assisting a wife with a chronic illness.

Husband caregivers of women with Alzheimer's disease (AD). The roles and responsibilities assumed by husbands to assist their spouses cope with the demands of AD have included providing (a) personal care such as bathing; feeding, or toileting; (b) instrumental care such as home maintenance, yard work, transportation; (c) emotional support; and (d) household assistance. The nature of the marital relationship, the illness situation, the needs and physical and cognitive limitations experienced by the care recipient have influenced the types of roles that husbands may need to assume. When Kramer and Lambert (1999), inquired about the type of assistance husbands provided to their wives, only five of the 26 husbands indicated that they helped with bathing and dressing, while most assumed more household responsibilities. Two other group of researchers reported that caregiver husbands assumed more household tasks compared to non-caregiver husbands who continued to function along traditional gender lines (Chang & White-Means, 1991; Kaye & Applegate, 1993). Caregiving men increased the amount of time per week they spent on domestic chores (Kramer & Lambert, 1999; Mathew, Mattocks, & Slatt, 1990). In fact, Chang and White-Means (1991) observed that some caregiving husbands spent an average of 65 hours a week assisting their wives, while non-caregiving men spent approximately one hour per week assisting with household chores. Assuming unfamiliar household duties has been found to be stressful. Both Ciambrone and Allen (2002) and Siriopoulos et al. (1999) reported that husbands caring for their wives with AD felt inadequately prepared to take on domestic roles. However, other investigators found that men felt least competent and most stressed when providing personal care to their wives (Kaye & Applegate, 1990; Parson, 1997).

Regardless of the discomfort experienced, most husbands assumed caregiving responsibilities out of love, concern, marital vows, duty, and/or lack of alternatives. For some of the husbands, reciprocity motivated them to become caregivers. Neufeld and Harrison (1998) explored the concept of reciprocity in 22 male caregivers and care recipients with AD. The men (n = 10) who gave care on the basis of reciprocity expressed positive feelings towards the care recipient, whereas those who gave care on the basis of duty (n = 10) experienced negative emotions towards the recipient. Similarly, other researchers found that a desire to reciprocate the care they had received from their wives was a final act of gratitude that symbolized a balanced exchange between them and their loved one at the end of a long-standing relationship (Harris, 1993; Kramer & Lambert, 1999; Parson, 1997; Siriopoulos et al., 1999).

Husband caregivers of women with breast cancer. Women with breast cancer may require assistance from their husbands due to the disease process and the potential side effects of the treatments (Northhouse, 1990). As the men caring for women with AD, these husbands assumed unfamiliar responsibilities such as household chores, personal care, medication management, and transportation or mobility (Hilton et al., 2000; Lloyd & Coggles, 1990; Sabo, Brown, & Smith 1986; Samms, 1999; Wilson & Morse, 1991; Zahlis & Shands, 1991). Some men felt unprepared and uncomfortable assuming some of these responsibilities (Ciambrone & Allen, 2002; Hilton et al., 2000). Despite their distress, they assumed these duties in order to make life easier for their wives (Hilton et al., 2000; Samms 1999; Zahlis & Shands, 1991). When Sabo et al. (1986) interviewed 24 husbands of mastectomy patients, they found that the husbands described their primary role as that of protective guardian of their wives' physical and emotional well-being. Similarly, in Samms`s (1999) qualitative study of nine husbands of women with breast cancer, two themes emerged: being there, which entailed providing emotional support to their wives; and doing my duty, which involved domestic chores. Being there was also a theme in Hilton et al.'s study (2000) of 10 husbands of women with breast cancer. In addition to providing emotional support, the husbands acquired and interpreted information, accompanied their wives to appointments, and assisted with decision-making about treatment options. The commitment shown by husbands caring for their ill wives with cancer was consistent with the literature on husbands of women with AD. They did not resent caregiving; however, some husbands found that assuming extra responsibilities while trying to cope with the illness became emotionally and physically exhausting.

Living with and assisting a chronically ill wife. The husbands of women with chronic illnesses may find themselves thrust into an unfamiliar role because the traditional socialization of males does not place emphasis on the direct provision of physical care. Therefore, living with and assisting a wife may have negative consequences, such as imposition of what is felt as a burden and alterations in physical and emotional well-being (Thompson, 2002).

Burden. Kramer (1997) developed a 25-item Screen for Caregiver Burden (SCB) to assess both objective and subjective burden in 74 retired husbands of women with AD. Husbands who scored the highest burden were managing more memory and behaviour problems ($r = .42, p < .001$), were less satisfied with their social lives ($r = -.27, p < .05$), reported greater use of emotion-focused coping ($r = .57, p > .001$), and were in poorer health ($r = -.26, p < .05$). Kramer (1997) found the strongest predictors of strain in husband-caregivers had to do with the strategies used to regulate emotional responses to stress. These strategies included wishful thinking, denial, suppressed feelings, self-blame, and avoidance. Kaye and Applegate (1990) found that men who were employed reported the greatest burden.

Husbands of women with breast cancer also found that balancing increased home responsibilities with their work responsibilities was stressful. Zahlis and Shands (1991) reported that husbands found it difficult to make changes in their work schedules to accommodate child-care and household management. However, burden was more a function of social role disruption and financial strain for male caregivers of mentally ill relatives (Mays & Lund, 1999).

Physical and emotional well-being. Caregiving burden may lead to problems in caregivers' physical and mental health. A few researchers have evaluated the physical and psychosocial well-being of male caregivers. Fuller-Jonap and Haley (1995) compared the mental and physical health of caregiver-husbands (n = 52) of wives with AD to non-caregiver men (n = 53). Caregiver husbands had poorer mental and physical health. They reported greater difficulty getting sleep and rest, higher levels of respiratory symptoms, and fewer opportunities for exercise. In a national study of male caregivers of women with AD, Kaye and Applegate (1990) found that most men perceived themselves to be in relatively good health; however, approximately 40% indicated that poor health limited their ability to provide care.

Men have also described the psychosocial repercussions of caregiving. These include living a restricted social life and feeling captive in their home (Parsons, 1997) or tied down (Siriopoulos et al., 1999). Other caregivers described feeling lonely, powerless, or out of control as the disease progressed (Harris, 1998; Parson, 1997). Many men expressed profound grief and loss in watching the steady deterioration of a loved one with cognitive impairment (Harris; 1993; 1998; Kaye & Applegate; 1990; Parson, 1997; Siriopoulos et al., 1999). For the husbands of wives with AD, feelings of aloneness and loneliness were intimately linked with loss of connectedness with the spouse due to their wives' disruptive behaviors and memory problems (Harris; 1993; Siriopoulos et al., 1999). Orsi's (1994) study of husbands of women with cancer found that the more involved men were in assisting with ADL the lower their self-esteem ($r = -.32$, $p < .05$). Mannee and Zautra (1990) found that husbands of women with rheumatoid arthritis did not complain about feeling burdened in assisting their wives with personal care and household chores; however, they found the limitations imposed by the illness on their social, recreation, and sexual lives difficult to endure.

In studies of husbands caring for wives with breast cancer, Lewis, Woods, Hough, and Bensely (1989) reported that more illness demands were associated with increased depression in husbands. Zahlis and Shands (1993) found that husbands who had to deal with their partners' emotions and changes in the quality of the couple's intimate relationship had the most difficulty. They were uncertain how to help alleviate their partners' suffering and questioned the effectiveness of their approaches. Similarly, Sabo et al. (1990) found that husbands questioned whether they had the ability to support and reassure their wives. These husbands felt unprepared to deal with their partners' anxiety and depression. Husbands also worried about the extent of the disease at the time of diagnosis, whether the cancer would spread or recur at a later time, and, ultimately, whether their partner would survive (Northhouse & Peters-Golden, 1993). Northouse (1989) reported that husbands were more concerned about their partner's survival than with the body changes associated with mastectomy. Although there is no doubt that living with and assisting a wife with a chronic illness may have negative consequences for husbands, there are also positive aspects of the experience.

Rewards from caregiving. Positive feelings about caregiving may mitigate stress and buffer burden or strain (Archbold, Stewart, Greenlick, & Harvath, 1990; Given & Given, 1991; Picot, 1995). Positive growth from caregiving involves the extent to which the caregiving role is appraised as enriching. Kramer (1997) suggested that caregiving may enhance men's sense of worth as it provides them with an opportunity to keep the marriage and family intact through their caring efforts.

Husbands caring for their wives with dementia appraised the caregiving role as emotionally gratifying and satisfying (Archer & MacLean, 1993; Harris, 1998; Kaye & Applegate, 1990; Lazarus & Folkman, 1994; Sidwell-Sipes, 2002), derived personal esteem rewards and closer relationships with their wives (Kramer, 1997), and gained pleasure in becoming more compassionate and thoughtful and experienced personal growth (Harris, 1993). Men caring for wives with a mental illness were proud of their ability to care for a loved one (Mays & Lund, 1999). The majority of researchers have focused on the benefits for husband caregivers of women with AD. It is not known whether these results can be generalized to younger, working husbands of women with other chronic illnesses (Ciambrone & Allen, 2002).

Coping strategies. Coping is defined by Lazarus and Folkman (1984) as a "constantly changing cognitive and behavioral effort to master, reduce, or tolerate demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Kramer (1997) indicated that the way in which the caregiver copes is likely to influence his/her appraisal of caregiving as strain or gain. A number of researchers reported that husbands living with and assisting wives with AD coped by: (a) establishing a routine, maintaining normal function in their respective roles and responsibilities, holding on to the memories of their wives, and using humor to keep their spirits up (Siriopoulos et al., 1999); (b) participating in social activities (Archer & MacLean, 1993); (c) recognizing their limitations or making time for themselves (Archer & MacLean, 1993; Harris, 1993; Mays & Lund, 1999); and (d) pursuing hobbies, friendships, or physical activities (Archer & Maclean, 1993). These strategies were found to assist husbands to sustain their energy and prevent them from becoming overwhelmed or resentful of their circumstances.

Kramer (1997) explored coping in male caregivers using the Ways of Coping Checklist in 74 husbands caring for wives with dementia. Satisfaction with social participation ($p <.01$) and problem-focused coping ($p < .001$) predicted caregiver gain. Husbands who appraised high levels of gain in caregiving were more satisfied with their social lives and reported greater use of problem-focused coping. Similarly, Harris (1993) reported that a problem-solving approach coupled with taking control of the caregiving situation helped elderly husbands cope with their wives' AD. Kramer explained that taking action and control of the caregiving situation might be a natural extension of men's work roles and thereby allow them to feel accomplished and less helpless.

Informal and formal support and resources. Whether motivated by male stoicism, a desire to retain control, or the gratification realized from sustaining a meaningful relationship with the care recipient, male caregivers are often observed to forge ahead alone with minimal help from others. For example, a number of men in the Harris (1993) study were reluctant to relinquish any aspect of their caregiving role and echoed the sentiment no one takes better care of her than I do. Similarly, husband caregivers in Kay and Applegate's study (1994) resisted offers of help and resources. However, researchers (Archer & MacLean, 1993; Harris, 1993; Parson, 1997) also described a sense of abandonment and social isolation expressed by men when friends and family did not help out. This created conflicts with family members (Parson, 1997) or increased men's feelings of isolation (Harris, 1993; Kramer, 1997). In contrast, caregivers who received positive feedback from family members found this to be critical to their on-going caregiving (Siriopoulos et al., 1999).

The use of formal support by family caregivers has resulted in lower levels of caregiver depression, deterioration in health, and social isolation (Coe & Neufeld, 1999).

Coe and Neufeld explored the experiences of 24 male caregivers of cognitively impaired older adults in using formal support. The majority of the participants were husbands (n = 17), while others included sons, a son-in-law, a brother, a grandson, or a friend. The most common reasons for resisting assistance were "a desire to maintain independence, a sense of personal responsibility for caregiving, and pride" (p. 574). Acknowledging the need for formal help occurred following a crisis or when caregiving demands exceeded the caregiver's emotional or physical abilities. Formal support included hiring help to supplement care at home or relinquishing care to a long-term care facility. A few investigators reported that husbands caring for wives with AD readily used respite care services, such as in-home care, day care, or vacation care services (Harris, 1993), and a senior's day care center, home care workers, and/or family members (Siriopoulos et al., 1999). Unfortunately, formal respite services were not always available or long wait lists made such services less accessible (Harris, 1993; Harris & Long, 1999). Husbands of wives with breast cancer found that attending a men's support group helped them to cope with fear and loneliness (Hilton et al., 2000).

Summary

The caregiving roles and responsibilities assumed by men have been studied mainly from the perspective of husbands/partners caring for women with AD or breast cancer. Male caregivers may be fewer in number, but they are committed to their caregiving responsibilities. Based on this research, men appear willing to perform most, if not all caregiving tasks, to be very involved emotionally, to use formal services only when absolutely necessary, and to be affected by the strain of caregiving. Being able to find positive meaning, having access to resources, and using energizing strategies seemed to make their situations more bearable.

Chapter 3: Research Design and Methodology

The adjustment of family members of individuals on dialysis has been studied primarily from the perspective of women, particularly wives. Researchers suggest that these wives need to adjust to myriad stressors in their lives that result from multiple demands imposed by kidney failure and its associated treatments. It is not known whether husbands or partners experience a similar reality when their wives are on dialysis. Given that no studies have previously identified the unique experiences of husbands living with women undergoing dialysis, a grounded theory approach was deemed appropriate to investigate from the perspective of men, the process of adjustment to living with women on dialysis. According to Glaser (1978), grounded theory is a useful method to research situations that have not been previously studied, where the existing research has major gaps, or where a new perspective might be desirable to identify areas for nursing intervention. It is particularly useful when researchers want to learn about the ways that individuals understand and manage what is happening to them within the context of existing or potential health challenges (Morse, 2001; Schreiber, 2001). In this chapter, I will outline the present study's purpose, the philosophical underpinnings of grounded theory, the recruitment procedure, data collection and the data analysis process as well as, ethical considerations.

Study Purpose

The overall research question for this study was "what is the process of adjusting to living with a wife/partner undergoing dialysis treatment for kidney failure?" The study's purpose was twofold: (1) to identify the main concern of husbands/partners adapting to living with women on dialysis, and (2) to explore how husbands/partners adjust to this main concern.

Philosophical Underpinnings of Grounded Theory

Grounded theory, an emergent research design within the naturalistic paradigm, was developed by Glaser and Strauss in 1967. It allows researchers to discover what is going on in the data and to uncover the basic social psychological process to explain the phenomena (Glaser, 1973). Glaser stated that "the goal of grounded theory is to generate a theory that accounts for patterns of behavior which is relevant and problematic for those involved" (p. 93). This design is congruent with the description of inquiry within the naturalist worldview by Lincoln and Guba (1985): namely, that inquiry within the naturalist worldview is complex, constructed, and ultimately subjective.

Several researchers have identified symbolic interactionism as the basic underpinning of grounded theory (Beck, 2004; Chenitz & Swanson, 1986; Milliken & Schreiber, 2001). Symbolic interaction is a social-psychological theory that focuses on human behavior and the meanings that people give to the situations or events they experience (Glaser 1994). Symbolic interactionism, as a theoretical perspective, was derived from the philosophy of pragmatism (MacDonald, 2001), which emphasizes the practical and gives primacy to usefulness over theoretical knowledge (Seigfried, 1998). From a pragmatist perspective, truth cannot be arrived at through deductive reasoning from an a priori theory but rather must be developed inductively with constant empirical verification. Truth is modified in the light of new discoveries and is relative to time and place. “Pragmatic reflection begins with experience as an interactive process involving individuals and their social and natural environment” (Seigfried, 1998, p. 51). Symbolic interaction can be traced back to George Herbert Mead and Herbert Blumer (Beck, 2004). Mead`s contribution relates to his description of the process whereby a person develops a sense of self and society through social interaction with others and his or her natural environment (MacDonalds, 2001). Blumer (1969) further elaborated the theory by identifying three premises (a) humans act towards things or people on the basis of the meanings they assign to those people or things, (b) these meanings are derived from social interactions with others, and (c) these meanings are managed and altered through an interpretive process used by individuals to make sense of and handle the things or people they encounter. It is this kind of meaning created by individuals in a particular, concrete situation that guides their behavior, action, and the consequences of that action (Chenitz & Swanson, 1986). Thus, if individuals base their actions on the interpretations of meanings, it is essential to discover the actor’s meanings in order to understand and explain the behavior (Milliken & Schreiber, 2001). Both verbal and nonverbal communications supply the mechanism for the meaning of an event or situation to be shared (Chenitz & Swanson, 1986; Gillis & Jackson, 2002). The underpinnings of pragmatism and symbolic interactionism drive both what grounded theorists do (method) and how they do it (methodology), both of which I will address in the research design section.

Research Design

Within grounded theory, method, data collection, and analysis occur concurrently through a dialogue between the participants and the researcher (Baker, Wuest, & Stern, 1992). The direction of the discussion is decided as much by the participants as by broad interview questions developed by the researcher. There are four distinguishing characteristics of grounded theory: (a) it focuses on process and trajectory, resulting in identifiable stages and phases; (b) it uses gerunds (labels ending in "ing") indicating action and change; (c) it has a core variable or category that ties the stages and phases of the theory together; and (d) it makes the synthesis of descriptive data readily apparent though its concepts and relational statements aimed at procuring mid-range theories (Glaser, 1978; 1998; Morse, 2001). According to Glaser (1978) the research question raised by grounded theory is "what is going on here?" Furthermore, because grounded theory is problem-focused (Morse, 2001), grounded theorists begin with an assumption that participants share a problematic situation, which they may or may not be able to articulate (Schreiber, 2002). Therefore, there are two further questions that guide the grounded theory researcher's entry into the field: what is the main problem for people under study, and how do participants address or resolve the identified problem? (Glaser, 1978). The process of grounded theory is both inductive and deductive in nature, which means that the theory is grounded in the data rather than developed from an existing framework (Morse, 2001). The outcome is identification of a basic social process that explains the salient issues in the scenario under study (Stern, 1980).

Grounded theory research begins with the broad purpose of determining what is going on within an inquiry into a particular area of interest rather than with a narrow research question (Beck, 2004; Glaser 1978). The data are analyzed by the researcher for the common themes which emerge to explain what is happening in the lives of the participants. As data collection and analysis proceed, the researcher continuously reflects on the meaning of the words, phrases, and actions of the participants and compares them with one another. This constant comparison is aimed at revealing significant meaning not at a substantive descriptive level but rather at a more theoretical level in the form of a framework to explain what is most significant. Identification of factors that influence variations in the emerging categories is vital in theory development. However, it is important to let the issues emerge before deciding that certain participant characteristics are significant. For example, factors such as age, social class, income, or location may only become part of the analysis if they influence theory development (Glaser, 1978). Sources of data are selected on the basis of what they can contribute to the emerging theory, a process called theoretical sampling (Glaser & Strauss, 1967). Using theoretical sampling, the researcher intentionally decides what type and source of data to collect next in order to try to revise or confirm hypotheses and address issues, gaps, questions, or relevant concepts arising from previous data analysis (Strauss & Corbin, 1990). Through the process of data collection and analysis, a core category representing a pattern of behavior that is relevant to and/or problematic for persons involved in the study emerges (Beck, 2004). This core variable has three essential characteristics: it recurs frequently in the data, it links the various data together, and it explains much of the variation in the data (Glaser, 1978). Once the core variable is identified, extant theory and literature are sampled for what they can contribute to the developing theory. Data collection and analysis proceed until no new concepts are identified, that is, until data saturation has been reached (Morse, 1995). I will further elaborate on the research method when I describe the sample, the recruitment procedure, as well as the data collection and data analysis process.

Characteristics of the Participants

Eighteen husbands, who spoke French and/or English, met the inclusion criteria of living with women on dialysis. They expressed an interest in participating in the study by mailing in a request, calling a toll free number, or sending an email to an address specific for the study. I contacted them by phone to further explain the study and respond to their questions. Once their verbal consent was received, a convenient date and time were confirmed for a face-to-face or phone interview. While the sample size may be considered small in comparison to Morse's (1994) standard of 25 to 40 interviews in a grounded theory for a doctoral level study, the data collected were deemed sufficiently rich to saturate categories and discern variations in experiences. According to Morse (1995), "it is not the quantity as much as the richness of data derived from detailed description that is important in the saturation process" (p. 148).

A demographic data sheet was completed by all husbands after informed consent was obtained from them (see Appendix B). The mean age of the husbands was 63.5 years, while their wives average age was slightly younger at 61.3 years (Table 1). Fifteen of the husbands spoke English only, two were unilingual Francophone, and one who was bilingual chose to be interviewed in English. Most lived in rural areas (n = 13) and their level of education ranged from elementary to doctoral preparation. The average length of time they had been married was 39 years (SD 13.2) with a range of 17 to 56 years. Slightly over half of the men were retired, while others worked full-time or part-time. The length of time women had been on dialysis ranged from 3 months to 26 years with a mean of 7.1 years. Most women were receiving hospital hemodialysis, while the others were either on CAPD, CCPD, or home hemodialysis.

Seven of the women had previously received a kidney transplant and six were waiting for their second transplant, while a larger portion of the women (n = 11) were not eligible for a transplant. All but one couple had children; however, only three had children between the ages of 8 and 17 still living at home. Four husbands were experiencing health concerns such as diabetes, cancer (prostate or leukemia in remission), or cataracts. Only one woman had received assistance from community health nurses for peritoneal catheter dressing change twice a week for a short period of time.

Recruitment Process

Husbands or partners 19 years of age or older, English and/or French speaking, and willing to share their experiences of living with a spouse on dialysis were invited to take part in the study. Recruitment of potential participants took place in three hospitals in two Maritime Provinces and through the media over a period of two years. While multiple media recruitment strategies were implemented simultaneously, recruitment from the hospitals took place one hospital at a time.

Table 1

Demographic Characteristics of the Participants and their Spouses (N = 18)

Characteristics	Descriptive Statistics
Age of Husbands (years)	
Mean	63.5
Range	41-82
Age of Wives (years)	
Mean	61.2
Range	40-80
Employment Status	
Retired	10 (55.5%)
Full-time	5 (27.7%)
Part-time	3 (16.6%)
Length of Time Married (years)	
Mean	39
Range	17-56
Type of Dialysis	
Hospital Hemodialysis	12 (66.6%)
CCPD	3 (16.5%)
CAPD	2 (11.1%)
Home Hemodialysis	1 (5.5%)

Hospital recruitment. The number of nurses involved in the recruitment at the three hospitals varied from one to five depending on the number of dialysis patients. They all took part in an information session about the study's purpose, research design, recruitment approaches, and inclusion criteria. Recruitment nurses collaborated with a nephrologist to identify potential participants. In one of the hospitals the recruitment nurse requested to be paid an hourly fee for recruiting, while nurses in two other hospitals preferred to have a donation made to their education fund.

Nurses involved in the recruitment had the option of using three strategies to approach potential participants. However, all the nurses used the same two approaches, which consisted of mailing information to women if they were on dialysis at home or approaching them during a hospital hemodialysis session. The nurses were unable to use the third option which involved directly approaching husbands on the unit or in clinic due to infrequent contact with them. When women were approached during one of their dialysis sessions, the nurses explained the study, provided them with written information about the study's purpose (see Appendix C), and asked them if they would consider giving their husband/partner information about the study (see Appendix D). Women on home dialysis were mailed a package of information about the study. Two weeks after the wives agreed to share information about the study with their husbands or were mailed a package of information, the recruitment nurses followed up with a reminder note to inform the husbands/partners about the study and to thank those who had already shared the information (see Appendix E).

A total of 104 women on dialysis who lived with a husband/partner who met the eligibility criteria were identified and of those, 96 were approached either in person (n = 86) or my mail (n = 10) by the recruitment nurses. Slightly over half of these women (n = 58; 60.4%) agreed to relay information to their husband/partner about the study, however, only 14 husbands were recruited. Recruitment was extended to two satellite renal units without success. Given the low response rate from the hospital settings, no other renal units were considered for recruitment after December 2006. Among the women (n = 38; 39.6%) who had refused to give a package of information to their husband/partner, the following reasons were provided: the husband did not feel well, he is too shy or too busy, or would not be interested. In one of the hospitals, the recruitment nurses discovered that approximately 14 information packages had been thrown into bins either inside or outside the hospital dialysis unit, suggesting that some of the women may have agreed to provide information to their husbands to please the recruitment nurses or had changed their minds before going home.

Recruitment through advertisements. While hospital recruitment was taking place, I simultaneously recruited over a 21 month period potential participants through a variety of media venues, such as posting paid ads in both French and English newspapers in three Maritime provinces (Prince Edward Island (PEI), Nova Scotia (NS), and New Brunswick (NB); doing free Public Service Announcements (PSAs) throughout NB; on web-sites; advertising in dialysis patients' newsletters in the Ontario and British Columbia branches of the Kidney Foundation of Canada; featuring the study in a French newspaper and in an interview on CBC Radio; and presenting a poster at the provincial annual meeting of the NB branch of the Kidney Foundation of Canada. These approaches resulted in the recruitment of two participants, while an additional two were recruited by word of mouth, for a total of 18 participants.

Data Collection

Data were collected using semi-structured face-to-face or telephone tape-recorded interviews at a convenient time and date for the participants and the researcher. Although telephone interviews tend to be used less often than face-to-face interviews in qualitative research, they are considered to be a “versatile” and “effective” means of collecting data (Opdenakker, 2006; Sweet, 2002). Researchers (Chapple, 1999; Kavanaugh & Ayres, 1998; Sturges & Hanrahan, 2004) have reported that data from telephone interviews are as rich, vivid, detailed, and of as high a quality as data collected from face-to-face interviews. Using telephone interviews with this group of men was beneficial in allowing them to remain home with their wives and to schedule the interview at a time that was convenient with their work or while their wives rested.

Prior to beginning each interview, the study was explained, questions were answered, and consent was obtained from all participants. For telephone interviews, a copy of the consent form was mailed to the participants prior to doing the interview and reviewed before tape recording their verbal consent on a separate cassette. Once consent was received, all interviews were tape recorded with the permission of the participants and subsequently transcribed. For those who were interviewed by phone, a device called a can-corder was used to tape record their interview. I conducted all the interviews.

The initial interviews were facilitated by an interview guide that consisted of broad open-ended questions designed to elicit participants’ responses about their adjustment to living with a wife on dialysis (see Appendix F). During each interview, I listened attentively to what the men had to tell me and encouraged them to expand or talk more when they were having difficulty findings words. The interview questions changed as data collection and analysis proceeded and emerging categories were developed. However, I did ask one consistent question of all husbands about how they had discovered that their wives’ kidneys had failed; I did this in order to situate when and how the adjustment process began for each participant and determine the factors that influenced their adjustment. Although I did not necessarily begin each interview with that question, it was woven into the other questions. All questions in the original interview guide were translated into French and back-translated into English by a professional translator in order to ensure congruence. However, as data collection and analysis unfolded, I developed and translated additional questions to investigate new and emerging ideas. As well, as the interviews proceeded, I began to focus the discussion to gather comparative data, to clarify, and to check my hypotheses.

Ten husbands chose a face-to-face interview (55.5%) and eight selected a telephone interview (44.4 %). Face-to-face interviews took place at locations preferred by the husbands, such as their home (n = 3), a quiet room at the hospital while their wife dialyzed (n = 6), or in my work office (n = 1). Husbands participated in telephone interviews while at work (n = 3) or at home (n = 5) when their wives were on dialysis or resting. In two situations, the women were at home during a face-to-face and a telephone interview. Husbands talked freely, shared their feelings, and disclosed intimate information during their interviews. However, differences emerged between husbands who were interviewed in-person versus those who were interviewed by phone. During face-to-face interviews, three husbands became very emotional when they spoke about their wives' suffering and their fear of losing them which required me to stop their interviews for them to take a break. None of the interviews had to be rescheduled. Husbands who were interviewed by phone expressed their feelings: however, none became emotional. As well, face-to face interviews were longer in duration, with an average of 107 minutes (range 75 to 240 minutes) versus 68 minutes for telephone interviews (range 55 to 90 minutes). The shortest interview took place by phone with a husband whose wife was present in the same room during the interview. Her presence may have been a factor that influenced the length of the interview.

A disadvantage of doing telephone interviews was the absence of visual cues from the participants. However, the advantages included decreased cost and time associated with traveling and increased access to geographically dispersed participants. The shortest travel distance for in-person interviews was 26.6 km each way (30 minutes), whereas the longest distance was 243.1 km each way (4 hour drive each way). Traveling provided opportunities to experience the weather conditions husbands endured to bring their wives to the hospital for dialysis. After completing each interview, I made notes of particular facial expressions, body language, tone of voice, and thoughts to capture any impression that would enrich the recorded interviews, the transcripts, and data analysis.

Data Analysis

The purpose of grounded theory analysis is to discover the core variable central to the social process present in the data (Glaser, 1978). This research method requires that the data be analyzed as they are collected through a process of coding, categorizing, constant comparison, integration and reduction, in what is a back-and-forth endeavor (Glaser; 1978; Stern, 1980). In the present study, data collection and analysis occurred concurrently. Data were coded in the language of the interview with the husband. The goal of the analysis was to generate a theory that would explain the adjustment process of husbands living with wives on dialysis. In the following section, I will outline the process of data analysis.

Substantive coding (first and second level coding). Once an interview was completed, it was transcribed by a transcriptionist. I reviewed all the transcribed interviews while listening to the tape-recorded interviews to establish the accuracy of the transcription and to document nuances or non-verbal responses observed, such as pauses, silences, hesitancies, and to ensure that the husbands' emotions were not lost. I corrected inaccuracies and formatted the transcripts to accommodate coding and note-taking alongside each line. I began data analysis at the first interview, using open coding (first-level coding), which consisted of examining the data line by line to determine the action present in the data (Glaser, 1978). I generated in vivo codes from all interviews in their original language (French and English in vivo codes) to remain grounded in the data (Glaser, 1978). The 18 transcribed interviews provided a total of 612 pages of data for analysis from which 1593 in vivo codes were generated (see Appendix G).

As the number of first-level codes proliferated and codes recurred, I compared them with each other to identify similarities and differences and I gradually collapsed them to create clusters or categories of substantive codes that seemed to fit together (second-level coding). This level of coding resulted in 64 categories which were given provisional labels that best fit the clustered in vivo codes (see Appendix H for examples). Simultaneous to the second-level coding, I wrote theoretical memos which consisted of ideas, thoughts, leads, and hunches about relationships of codes and categories, which I continued to develop and to memo until the end of the study. The memos written throughout the entire research process of grounded theory assisted me with the development of the theory and the writing of the research report (Glaser, 1978) (see Appendix I). I kept the memos in a notebook or a computer data file.

In addition to the emergence of a large number of categories, sorting through large amounts of transcribed data from 18 interviews was overwhelming at times, making it difficult for me to discern relationships between concepts and their properties and dimensions. I continued to memo, review transcripts, compare and recode data, as well as use diagrams which were invaluable from three perspectives (see Appendix J). First, they provided me with a way of visualizing, reflecting on, and understanding the relationships between categories; secondly, they were useful for identifying areas where additional data were needed; and finally, they were a useful communication tool with the participants to validate and expand categories (Schreiber & Stern, 2001). Collectively, these strategies facilitated the analysis to progress from a descriptive level to a more theoretical level of understanding the phenomenon (third-level coding).

Theoretical coding (third level coding). "Theoretical coding conceptualizes how the substantive codes may relate to each other as hypotheses to be integrated into a theory" (Glaser 1978, p. 72). Theoretical coding enabled me to transform the descriptive data conceptually into codes that evolved into the theory that would account for the data. At this stage, using a constant comparative method, I compared category to category to ensure they were mutually exclusive (Streubert & Carpenter, 1995). I used theoretical coding to tease out properties and dimension of categories. I referred to Glaser's (1978) 18 families of theoretical codes which are not mutually exclusive and overlap considerably (see Glaser, 1978, pp. 74-82) for a full description and overview in Appendix K to analyze the data. However, I relied mostly on the general coding family of "the 6 C's, Causes, Contexts, Contingencies, Consequences, Covariances, and Conditions" because they are considered "the bread and butter theoretical codes" and "the first general codes to consider when coding data" (Glaser, 1978, p. 74). These codes assisted me to link categories and raise them to a more conceptual level which resulted in collapsing and developing other categories generated from the first 10 interviews. These preliminary categories were used to generate further hypotheses and to guide subsequent interviews. I frequently revisited the data to make sure the categories were grounded in the data and to provide opportunities for the development of new hypotheses and additional memos. Using constant comparisons, I questioned whether a category was a cause or a consequence of another category, and I expanded the use of other theoretical codes, such as strategies, dimensions, and degrees which represent some of Glaser's (1978) 18 families of theoretical codes. The memos became part of the data and as such were coded and sorted, contributing to the integration and density of the theory (Glaser, 1978). Diagrams were used to visually represent the relationships among the categories, to rearrange the categories using the theoretical codes, and to identify where the categories needed further development (Chenitz & Swanson, 1986). I shared the diagrams and the outline of the major categories with some of the last participants with whom I did face-to-face interviews and I sought their input to expand and validate the categories. While immersed in the comparison of the categories, I searched for a main theme or "story line" that explained the main problem husbands were experiencing. According to Glaser (1978), the core variable must be central, stable, and pervasive: it must make sense to the people in the study setting and incorporate as much of the descriptive variation in the data as feasible.

Categories were further sorted, collapsed, and some were renamed as a result of multiple re-writes, submissions, and feedback from my two advisors that brought the analysis to a theoretical level. Once a tentative conceptual framework explaining the major patterns in the data was generated, I restricted coding to those categories that related only to this core variable and its properties. In my study, the core variable, embracing a transformed life, served to explain "the substance of what is going on in the data" (Glaser, 1978, p. 94). Because the core variable emerged as a process with four stages changing over time and with discrete turning points, it was referred to as a basic social process.

Theoretical sampling. As data analysis and collection proceeded, additional data collection was guided by theoretical sampling which is used to "round out thin areas" in an emerging framework (Glaser, 1978, p. 101). Theoretical sampling is "the process of data collection for generating theory whereby the analysis jointly collects, codes, and analyzes … data and decides what data to collect next and where to find them, in order to develop … theory as it emerges" (Glaser & Strauss, 1967, p. 45). As the study progressed, the decisions for data collection were guided by considering from whom I might find the answers to some emerging questions and hypotheses. For example, the first seven interviews were done with husbands who were retired and they expressed difficulties with assuming and juggling new roles and responsibilities, as well as with coordinating these around the dialysis schedule. Their responses made me question whether husbands who worked full-time or part-time might experience similar or different issues in regard to assuming and juggling multiple roles and responsibilities. In order to capture variations in the experiences of the men, I decided that it was necessary to collect data from participants who could provide answers to these questions. Therefore, I guided the recruitment nurses from the third hospital to recruit husbands who were employed to compare their experience and uncover variations in emerging categories. Theoretical sampling took several forms, such as choosing new participants on the basis of what they could contribute, looking for comparisons in the data already collected, and asking new participants to clarify, comment on, and elaborate on data previously collected by asking, "How does this explain or fit with your experience?" (Wuest, 2007). Glaser (1978) suggested that theoretical sampling should continue until saturation occurs; that is, no further variation in a concept is emerging from the data being collected.

Saturation occurs in categories where there are no new data to add to existing codes and no new codes under which the data fit (Glaser, 1978; 1994). Although Glaser (1978) recommends that theoretical sampling not stop until codes are "saturated, elaborated, and integrated into the emerging theory" (p. 37), I stopped the sample size at 18 husbands when most of the concepts had been well defined and minimal new variations were being discovered. Furthermore, my decision to cease data collection was related to the challenges in recruiting potential participants in three hospitals and through various media resources over a period of two years.

Methodological Rigor

Several authors (Lincoln & Guba, 1985; Munhall & Oiler, 1986; Sandelowski, 1993) have reported that there are different criteria for assessing the merits of research done within the naturalistic paradigm. The value of qualitative research results rests on the trustworthiness of the entire research process, and this is determined by the criteria of

(a) *credibility*, which refers to the trust in or believability of the data, its final analysis and the final report (Lincoln & Guba, 1985); (b) *dependability*, which is about the stability of the data over time and whether repeating the study with the same or similar participants would generate transferable similar results; (c) *transferability*, which means providing a comprehensive descriptions to enable others to believe they understand the event as if it were happening to them (Burns & Groves, 1997); and (d) *confirmability*, which involves examining the data, findings, interpretations, and recommendations to ensure that they are supported by the data and are internally coherent (Lincoln & Guba, 1985).

Credibility of the data was achieved through member-checking during each interview. Incoming participants were asked to comment on and elaborate on emerging categories and hypotheses generated in previous interviews. Peer debriefing sessions took place with colleagues and my two advisors, who have considerable experience in the research design and/or the population under study. Written or oral summaries of data analysis were discussed with my advisors to determine if the emerging categories and interpretation of the data accurately reflected the experiences of the participants and to check for any bias in data collection and analysis.

Transferability was accomplished by providing a rich, saturated, and comprehensive description of the data so that readers can make their own judgments as to the applicability of the data in other contexts (Polit & Hungler, 1995). Whether the findings are transferable will be determined by individuals who use the theory to guide their practice. Sufficient details and examples of verbatim comments have been inserted in the findings chapter for others to assess the possible transferability of the findings (Guba & Lincoln, 1989). Obtaining demographic data also provided additional information to evaluate the applicability of the data to other contexts.

Keeping a journal about the decisions regarding recruitment, data collection, and data analysis was one of the strategies used to establish the dependability of the data. It was challenging to keep a journal because data collection and analysis in grounded theory are an iterative process of developing, checking, and keeping or discarding hypotheses. Journaling assisted me to reflect on my thoughts, to record leads and hunches, and to uncover potential biases in interpretation (Lincoln & Guba, 1985). In addition, my two advisors independently analyzed selected transcripts, which were then compared to my analysis, and revisions were made based on consensus. Data collection and analysis were discussed on a regular basis with my supervisors by phone or during face-to-face meetings.

Confirmability was achieved by sharing with my two advisors copies of a few coded interview transcripts, some memos, minutes of meetings, and schematic diagrams of the evolving categories and the evolving theory. Confirmability was further established by checking with some of the participants if the theory had fit, worked, grabbed their attention, and could be modified to reflect changes to the underlying data (Glaser, 1978).

Fit in a grounded theory study "means that the categories that are generated must be indicated by the data and applied readily to the data" instead of forcing the data into pre-conceived categories (Chenitz & Swanson, 1986, p. 13). During the analysis, categories were modified as new data were generated. An example of this is the evolution of the concept of protective support, which originally included the properties of being there, protecting the other, and watching. As additional data were collected and transcripts were revisited, it became clear that there was much more to this concept than was originally identified. Hence, some of these properties were collapsed or renamed while new ones were generated to reflect the purpose of the husbands' support, which consisted of actions to protect and relieve their wives from undue stress, make them comfortable, preserve their sense of self, and provide a buffer to their physical and emotional suffering. This type of support was captured in the sub-process of <u>engaging in protective support</u>, which was achieved using the three strategies of <u>watching over her</u>, <u>advocating and confronting incompetence/insensitivity</u>, and <u>shielding</u>.

Whether a theory *works* means that it "should be able to explain what happened, predict what will happen and interpret what was happening in an area of substantive or formal inquiry" (Glaser, 1978, p. 4). Evidence that the substantive theory developed in this study works has been affirmed with the study participants and colleagues who reviewed the schema. The evidence of whether the framework will be useful for nurses and for guiding health policy remains to be seen.

To *grab* attention means that the theory is relevant, interesting, useful, and comprehensible to the participants and within the context of the study (Fain, 2004). Until this theory has been made available to more husbands, it is difficult for me to determine its grab. Glaser (1978) discussed the need for grounded theory to be *modifiable* in order to continue to be useful in changing social conditions. When a researcher writes a grounded theory, she or he is freezing it for that instance only; the variation in the basic social processes can continue to be modified as circumstances change. I modified the emerging theory to fit the data as I collected new information and engaged in ongoing data analysis. Therefore, the modifiability of this theory was tested in the process of its development and will be further tested when others attempt to use it.

Difficulties encountered with the recruitment of potential participants and the time lag between data collection and the completion of data analysis, as well as the distance to travel to revisit some of the earlier participants, made it impossible to do member validation to check the accuracy of my interpretation of their experiences after the analysis was completed. However, member-checking and validation were built into the research process and were an integral part of the constant comparative analysis and theoretical sampling, so subsequent participants were involved in validating, clarifying, and/or adding to the information provided by previous participants.

Ethical Considerations

Participation in this study was voluntary. Approval to conduct the study was first obtained from the Ethics Committee of McGill University in July 2005. Subsequent ethical approvals were obtained from the three participating health regions: the Acadie-Bathurst Health Authority, South-East Regional Health Authority, and Capital Health in Nova Scotia. Changes to the recruitment process had to be made to increase access to a larger pool of potential participants. Two separate submissions to amend the initial proposal were made to the McGill University Ethics Committee before proceeding with further recruitment. The amendments included deleting informal visits with couples, providing husbands/partners with the option to do a person-to-person or telephone interview, and extending the newspaper advertisements to include bilingual public service announcements (PSA) on the radio and television. Applications for continuing reviews at each of the ethics committees of the three participating hospitals and McGill University were sought on a yearly basis from the inception of the study. Key ethical considerations for this project were informed consent, beneficence, confidentiality, and anonymity (Polit & Tatano-Beck, 2004).

Informed consent. For study participants, informed consent involves issues of self-determination and full disclosure (Polit & Tatano-Beck, 2004). Participants were recruited voluntarily. It was their choice to respond to advertisements or letter by using a toll-free 1-800 number, an e-mail address, or by mailing their response to me directly. I was the only person who had access to all of these response options. Upon receiving a response from a potential participant, I contacted the individual by phone at a time convenient to them. Before being asked to participate, each participant was made aware of the study's purpose, risks, the benefits of participating in the study, and the method I would use to collect data. I also answered their questions and informed them that their participation was voluntary, and that they were free to withdraw or to refuse to discuss specific questions at any time. I also informed the participants that the findings would be presented to lay and professional groups but with personal identifying data removed.

Prior to any interviews, I reviewed the consent form with all the participants (see Appendix L & M). I asked if they understood the consent form and if they had any questions or concerns about the process. Those who took part in face-to-face interviews were asked to sign a consent form at the start of the interview, and I gave the participants a signed copy of the consent form for future reference and kept a copy for my files. The husbands who were interviewed by phone were mailed a copy of the consent form prior to being interviewed. I reviewed the consent form with them over the phone prior to starting the interview, and I captured their verbal consent on a tape separate from the recorded interview.

Given the extended period of time to recruit participants and to complete data collection and analysis, I believed that it was important for the participants to be kept informed about the study's status so they would not feel that I had forgotten them. Hence, I communicated with each of them at least once a year by mail while data collection and analysis were taking place to update them about the progress of the study. Contacting each participant provided unexpected responses from some of them by mail, e-mail, or phone about their own update about their wives, such as her death, getting a kidney transplant, surgeries, and general well-being. A summary of the findings will be mailed to those who expressed an interest.

Beneficence. The two main principles of beneficence include: to do no harm or to prevent harm, and to do good or promote good (Polit & Tatano-Beck, 2004). Although there were no anticipated risks to participating in this study, a few of the participants who took part in a face-to-face interview became emotional when they discussed witnessing their wives' suffering and t heir fear of losing them. When that occurred, I stopped the tape recorder and the interview and offered them the options to take a break, discontinue the interview, or reschedule the interview to another time. Some husbands shared that they had not expected to become tearful during the interview. I reassured them that their reaction was very normal considering all they had experienced, and all the interviews were resumed after a break. In a few situations, when financial difficulties were discussed, I offered a few of the participants the name of the hospital renal social worker with whom I had made prior arrangements for participants to contact if needed. After each interview I took time for debriefing to check out how they were feeling and to confirm their sources of support. During these debriefing moments, some participants verbally expressed an appreciation for the opportunity to tell their story.

Confidentiality and anonymity. Patton (2002) differentiates between confidentiality and anonymity: confidentially refers to what will be told to others about a project, while anonymity refers to what one does or does not know about details of a participant's involvement in a study. Issues of confidentiality and anonymity were addressed in a number of ways. First, all personal identifying information was removed from the transcripts, tapes, and interviews; and they were subsequently referred to by a code number. I was the only person able to link tapes and transcribed copies to specific participants. The names of the participants have not been used throughout this report, nor will they appear in any presentations or publications arising from this study. Second, one set of transcripts, consent forms, demographic sheets, and the tapes from the interviews were kept separately at all times in a secure locked cabinet accessible only to me. Third, all field notes, memos, and diagrams avoided use of identifying information. Fourth, the two transcribers who were hired to type the English or French audio-taped interviews were instructed to maintain confidentiality of the material and asked to sign a confidentially agreement (see Appendix N). Finally, all data from the transcripts, field notes, memos, diagrams, and tapes will be kept for a period of five years as indicated in the consent form or until the study is completed, after which they will be destroyed. None of the participants requested that I return the copy of their taped interview.

Chapter 4: Substantive Theory

My purpose in this grounded theory study was to explore and describe the adjustment process of husbands who live with wives on dialysis. I have identified as the most central issue for these husbands having to deal with multiple changes imposed by the demands and impact of kidney failure and its treatment regimens on various dimensions of their lives. In this chapter, I provide an overview of the Basic Social Process (BSP) of <u>embracing a transformed life</u> of living with wives on dialysis, highlight the four conditions influencing the BSP, and describe the four stages of the BSP. The changes that permeated their lives are described in the corresponding sections of the BSP. I have included descriptive statements or exemplars of the data in italics to support the theory.

Central Issue

The impact of kidney failure and its treatment regimens created permanent, temporary, and/or sporadic limitations, changes, and disruptions in the lives of husbands, couples, and families. One husband summarized the changes by stating that: “We had to change our lifestyle, we had to change our thinking, we had to change our diets, it affected everything” (17). The changes impacted roles and responsibilities at home and work, social and recreational activities, finances, relationships with their spouses and others, home environment, daily routines, and future plans, as well as health and/or sleep patterns. These changes required that husbands make significant and often difficult sacrifices, concessions, and compromises in their lives.

Although the impact of these changes created many hardships for husbands, witnessing their wives’ suffering was more distressing: “To see someone you love suffer that’s really hard” (09). Husbands appreciated the availability of dialysis to sustain their wives’ lives and were grateful for its benefits; however, they were also concerned about the adverse impact this technology inflicted on their wives’ well-being and their own lives. There were no simple means of reconciling this dilemma because without dialysis a man’s wife would die and life without her would be inconceivable: “The thought of losing [wife’s name] isn’t very good…. It isn’t a nice feeling at all [puts a lot of emphasis on at all]” (05). These men became resigned to the fact that kidney failure and its treatment regimens were now part of their lives, although they disliked the limitations, changes, and restrictions that resulted. However, rather than resent their new reality or accept a life constrained by the illness, they chose to rise to the challenge and embrace their transformed life.

Overview of the Basic Social Process

Embracing a transformed life of living with wives on dialysis is a process of responding to changes imposed by the illness and its treatment regimens on their daily lives by both appraising and tackling these changes as challenges to be addressed and managed. One husband illustrated: “You got to face this illness with an open mind. It’s what you make it. I made up my mind that I was going to look after her and do it to the best of my abilities” (18). In so doing, husbands witnessed and experienced unexpected positive outcomes for their wives and themselves.

The basic social process of embracing a transformed life is situated at the center of the diagram in Figure 1to illustrate that it is fundamental to what caregiving husbands were experiencing. The theory is characterized by four interrelated stages. The first stage of becoming aware involved the discovery of progressive or sudden changes in their wives’ health, which prompted all husbands to engage in the other stages of, involving oneself, centering life on their wives, and striving to achieve balance. The overlapping stages/circles and shadows reflect that although each stage was demarcated by specific events, the husbands described their experiences of adjusting to living with women on dialysis in overlapping and recurring stages. In addition, the different levels of the stages/circles represent variations in the extent to which the husbands’ lives were changed and the magnitude of adjustment they had to make to accommodate the demands of the illness and treatments. The lower the circle is positioned, the greater the adjustment. The last circle is situated slightly lower than the first circle to denote that the husbands did not return to their pre-dialysis way of life but rather, were adapting to a different way of living. In the diagram, the bi-directional arrows between circles/stages represent husbands’ occasional return to earlier stages while still being involved in later stages. When interviewed, some husbands had already returned to the first two stages while others anticipated having to revisit them when and if their wives experienced an unexpected acute health crisis, new complications, symptoms, or medical problems that required them to seek information and care or wait for appointments, test results, a diagnosis, and/or treatments. Four influencing conditions (marital relationship, women's health status, informal support, and formal support) facilitated and/or restricted husbands' efforts to embrace their transformed life. Their marital relationship and their wives' health influenced all stages. The bi-directional arrows between the four influencing conditions and the BSP indicate that an interdependent relationship exists.

The initial stage of becoming aware involves the discovery and reaction to the insidious or sudden changes in their wives' health. This stage marked the beginning of the disruptions the husbands experienced in their lives. The amount of time spent in this first stage varied according to the progressive or sudden onset of symptoms. However, in both instances, becoming aware was the catalyst or trigger that compelled husbands to move into the second stage of involving oneself to seek information and care in order to make sense of the symptoms and ease suffering and to prepare themselves to assist their wives with illness-related care. During this stage, both the diagnosis of kidney failure and need for dialysis treatment were confirmed.

The onset of dialysis treatment for the wives was the next event that prompted all the husbands to shift their focus to centering life on their wives, which is the third stage of the BSP. By the time the women started dialysis they were very ill and needed their husbands' support, assistance, and care. Without hesitation, all the husbands responded by devoting their time and energies to addressing their wives' needs and fitting the changes imposed by the illness and its treatment regimens into their daily lives. Centering life on their wives was achieved through five interrelated and simultaneously occurring sub-processes: providing illness-related care, engaging in protective support, attending to their wives' voice, concentrating on daily goals, and simplifying life. During this stage, they confronted the greatest number and types of changes, which had significant impact on both their daily and future lives. When women regained some stability in their health, husbands and couples transitioned into the final stage of striving to achieve balance to regain some normalcy and quality of life for themselves and their wives and families, while continuing to center life on their wives. During this stage, husbands engaged in a combination of five sub-processes: creating routines, replenishing, bringing others on board, hoping for a kidney transplant, and finding positive meaning.

Some of these sub-processes were difficult to realize and sustain, others such as hoping for a kidney transplant and replenishing were not carried out by all.

Influencing Conditions

Throughout the four stages of embracing a transformed life of living with wives on dialysis, the husband's efforts to adjust were influenced by one or a combination of four conditions: (a) the marital relationship, (b) the women's health status, (c) informal support, and (d) formal support, which I will describe in the next section.

Marital relationship. Within the context of this study, the nature of the marital relationship, namely strong bonds of affection, as well as profound respect, devotion, and love for their wives, influenced the husbands' commitment to embrace a transformed life of living with wives on dialysis. Husbands perceived it to be "[their] responsibility to do things for [wives]" (01) and to provide support to address their needs. The nature of the marital relationship was revealed as the husbands described the onset of their wives' illness and the resulting changes in their own and the couples' daily lives. When discussing their experiences of living with a wife on dialysis, most husbands referred to themselves using "we", rather than "I" or "me", which reflected the bond and connection with their wives. The couples had been married between 17 and 56 years. Marital beliefs, marital history, and reciprocity defined these relationships.

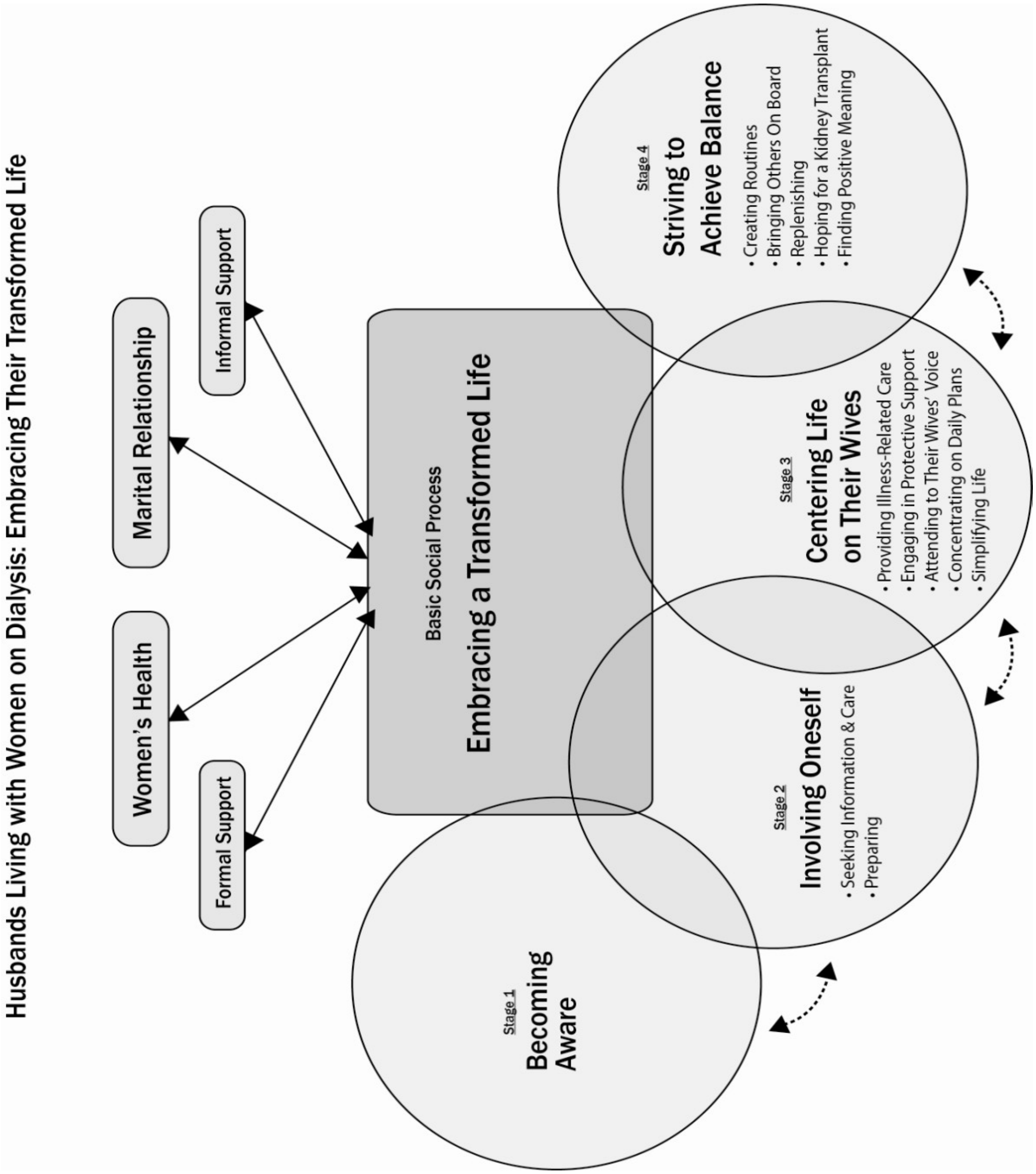
Marital beliefs. Marital beliefs pertain to the beliefs husbands held about marriage. These beliefs were initially voiced when their wedding vows were exchanged decades ago, at which time promises were made to each other that "for better" or "worse", they would remain together. Marital beliefs also included expectations that they would likely experience both prosperous and difficult times in their marriages. Marriage vows to be there for each other "in sickness" and "in health" were being fulfilled, although it was easier for some husbands than others.

For other men, their efforts to embrace their transformed life were influenced by strong bonds of affection and devotion the couple had experienced throughout their years of marriage that provided a solid foundation to deal with the illness and its treatment regimens. As one husband explained:

> My commitment is much deeper than the vows of marriage, there has to be a bond... a large bond that… helps a person to adapt. If there is no bond, then one

> just turns his back and could say ‘I don’t need this’, but if you had a good bond in the first place then everything just carries through from there. (18)

Figure 1


Husbands Living with Women on Dialysis: Embracing Their Transformed Life
Formal Support
Women's Health
Marital Relationship
Informal Support
Basic Social Process
Embracing a Transformed Life
Stage 1
Becoming Aware
Stage 2
Involving Oneself
• Seeking Information & Care
• Preparing
Stage 3
Centering Life on Their Wives
• Providing Illness-Related Care
• Engaging in Protective Support
• Attending to Their Wives' Voice
• Concentrating on Daily Plans
• Simplifying Life
Stage 4
Striving to Achieve Balance
• Creating Routines
• Bringing Others On Board
• Replenishing
• Hoping for a Kidney Transplant
• Finding Positive Meaning

Although husbands were not specifically questioned on the strength of their pre-diagnosis relationship with their wife, changes in the marital relationships did occur and were described by husbands as positive, negligible, and/or negative. Some husbands, especially those who had been married for more than 20 years and/or it was their first marriage, openly shared that their marital relationships had always been strong; however, they believed that the illness had enhanced their closeness: “If anything it’s just deepened my commitment to her” (09). Husbands attributed the enhanced emotional closeness to the uncertainty about the long-term ability of dialysis to sustain their wives’ lives. This situation prompted a few husbands to do the extras and spend as much time as they could doing things for and with their wives rather than by themselves or with others.

In contrast, three husbands (04, 06, 13) reported growing apart in their relationships due to frequently occurring illness and treatment-related effects such as fatigue, lack of energy, and decreased sexual libido. The emotional and physical distance in their relationship was expressed in statements of missing the companionship, sexual intimacy, and expressions of affection. Although they addressed their wives’ needs, it was more difficult for them. These husbands (04, 06, 13) thought about leaving their wives during the course of the illness; however, financial and structural investments in the relationship and their beliefs in honoring their marriage vows were provided as reasons for sustaining their commitment.

For all husbands, the emotional connection with their wives was not the only aspect of their relationship that had changed. Regardless of age, all husbands openly discussed disruptions or cessations of sexual intimacy since their wives’ illness. Most husbands shared that they were able to maintain emotional closeness even in the absence of sexual intimacy. They continued to experience affection, gratitude, and love for their wives and came to value “just sitting together” or “holding hands” as important ways to show that they were there for each other. In contrast, the same three husbands (04, 06, 13) whose relationship with their wives had negatively changed indicated that when sexual intimacy was less easy or was not possible, other forms of affection were absent. Sleeping in separate rooms contributed to the lack of intimacy and generated feelings of loneliness for some (04, 06, 13).

Marital history. Marital history refers to husbands' efforts to build their relationship/partnership and to overcome challenges throughout their married lives. The couples' beliefs about marriage as an institution had been tested over several decades of married life. Individual marital histories varied considerably; but collectively, couples had overcome a variety of situational and developmental challenges, such as poverty, family feuds, death of family members, retirement, cancer experiences and/or multiple health challenges. Most husbands described having had a long-standing loving relationship with their wives: "We've been married for 49 years and we always get along. We have a good rapport, a good relationship" (09). Embracing a transformed life provided a way to demonstrate their continued support to their wives. They expressed pride in what they had accomplished with their wives in the past, including raising their families, traveling, socializing, and/or community or church involvement. Within this marital context, changes imposed by illness and treatment regimens were perceived as simply another challenge, perhaps equally or more demanding and imposing than any others, but nonetheless one that most were working on as a team. Some husbands perceived their wives to be pillars of strength from whom they drew courage to sustain their efforts to deal with these changes, limitations, and disruptions.

Reciprocity. The husbands did not use the word caregiver when they referred to themselves nor did they associate any or all of the responsibilities required of them to be caregiving activities. It wasn't until they were specifically asked if they considered themselves to be caregivers that some reluctantly agreed with the concept, while others argued that they were "just doing what a husband should do" or "it was their turn to provide care". While the demands and impact of the illness and its treatment regimens created many hardships for husbands, it was also perceived as an opportunity to give back the support, assistance, and care wives previously had provided to them and their families. Reciprocating provided husbands with the opportunity to affirm their indebtedness and appreciation and to reaffirm their love of their wives. At the same time, they reaped personal satisfaction and fulfillment from their involvement: "By helping her it helps me too" (09).

Women's health status. A second condition identified to influence variations in the extent of changes the husbands experienced and their commitment towards embracing a transformed life was the wives' health status, more specifically the illness trajectory of chronic kidney disease (CKD). Similar to other chronic illnesses, CKD is characterized by properties of insidiousness, precariousness, and uncertainty. In addition, the type of dialysis women were receiving influenced how well they felt, with some being as debilitated by dialysis treatment as they were from kidney failure. The length of time women had been on dialysis was not a determining factor in their responses to dialysis treatment or decline in health. Rather, the women's age and presence of co-morbidities such as diabetes and/or vascular diseases impacted more negatively on their physical and/or cognitive health. In these situations, husbands had to provide more assistance and assumed more roles and responsibilities.

Insidiousness. There was considerable variation in the health histories of women and the onset of this chronic illness. Some wives had been experiencing other chronic health problems prior to being diagnosed. The presence of past and/or on-going health difficulties did not facilitate husbands' adjustment. For most husbands, however, the presence of CKD was the first chronic illness their wives had experienced.

Three distinct patterns of chronic kidney disease were identified. One group of women was diagnosed in childhood or early adulthood with kidney problems such as polycystic kidney disease. A second group discovered that their kidneys had failed after experiencing progressive symptoms and deterioration in health. In both groups, reaching a final diagnosis of kidney failure was a prolonged process involving numerous tests, treatments, and consultations with different health specialists. Husbands had some time to anticipate and prepare for dialysis. The last group consisted of women who were diagnosed with kidney failure and started dialysis after experiencing a sudden and unexpected health crisis. Hence, some women experienced progressive deterioration in their health over periods of months or years, whereas for others, the diagnosis occurred suddenly and unexpectedly over a period of hours or a few days.

Precariousness. By the time the women were ready to start dialysis treatment, their health had deteriorated significantly. They experienced shortness of breath, swelling of the extremities, and fatigue. These symptoms impacted negatively on their functioning and self-care abilities, which in turn affected their ability to assume daily roles and responsibilities, and to participate in decisions previously taken as a couple.

The extent to which women were debilitated varied. The more debilitated women were the more dependent on their husbands for assistance and care they became. This was the case for women who were physically and/or cognitively incapacitated. The women's health fluctuated from day to day between periods of relative stability and instability, which husbands referred to as good days versus bad days. There were variations in the types of adverse effects women experienced and the extent to which they were affected. Many husbands referred to the erratic nature of symptoms as being on a roller coaster: "A lot of ups and downs. You think things are getting better then you get a down swing. I don't get my hopes [up?] because you know things aren't going to get better" (02). Consequently, the husbands' roles and responsibilities within the home and future plans were constantly shifting in concert with changes in their wives' health and functional abilities.

Uncertainty. Husbands experienced uncertainty associated with: (a) their wives' on-going deterioration in health, unpredictable responses after each dialysis session, and the decision to stop dialysis; (b) the long-term ability of dialysis to minimize symptoms and sustain lives; and (c) the availability of a kidney transplant. They were well aware that kidney failure is a chronic, lifelong illness for which there is no cure or recovery barring a transplant. Uncertainty also revolved around potential complications such as congestive health failure, pulmonary edema, infected fistula and/or excessive infiltration. Their daily or future lives were uncertain because they were contingent on their wives' well-being. The fluctuation in their wives' health raised questions and fears about how the illness would unfold and the impact it might have on their own health. It also impacted on their ability to make plans and to socialize alone or as a couple.

Dialysis treatment. The type of dialysis treatment women were receiving influenced their health and the nature and extent of limitations, changes and disruptions in daily activities. Most of the women were receiving hospital hemodialysis (66.6%), while others were either on CAPD or CCPD, and one was on home hemodialysis. Some women, particularly those receiving hemodialysis, experienced more acute adverse effects from the treatment. Witnessing their wives suffer from dialysis treatment was one of the biggest challenges for husbands. When dialysis was first initiated, some husbands lived in fear that a medical emergency would arise that would exceed their ability to render assistance to their wives. Dialysis treatment had to be a priority, otherwise their wives would die. Regardless of the type of treatment the women received, the dialysis schedule structured their daily lives. In one case, the husband hired a caregiver to assist with hemodialysis at home so he could work.

Informal support. Support and resources are the third condition influencing the process of embracing a transformed life. While the preference of most husbands was to personally assist their wives, over time they came to realize that others also wanted to help out and, moreover, they needed help. Most husbands were surrounded by a network of individuals who provided instrumental, emotional, financial, and/or spiritual support. The most common source of informal support came from adult children, grandchildren, and/or parents or in-laws. However, among these individuals, adult daughters were the most consistent source of support. Employers and working colleagues were also accessible and available, allowing husbands to fulfill other obligations. Some husbands readily accepted, received, and/or recruited support from these individuals, whereas others were more reluctant to do so.

Willingness of others to assist. The perceived willingness of others to assist determined whether husbands could request and/or accept assistance. A common barrier to requesting assistance was the fear of imposing on others. As well, if husbands believed a person was unwilling to help, they were not likely to request help from that individual. Although, unsolicited support was appreciated, husbands did not always feel comfortable being the recipients. Their level of comfort was dependent on (a) the nature of their relationship with the provider, (b) the type of assistance provided, and more importantly (c) the provision of past assistance and the potential to reciprocate in the future.

Accessibility. Proximity of support determined whether and how often men could access the support. Accessibility to informal support was facilitated by two factors: geographical proximity and the nature of the relationship.

Geographical proximity ranged from living under the same roof to being a long distance away. Although some husbands lived near their adult children, not all enjoyed positive relationships with them. In these cases, the husbands were reluctant to seek support from them. In a few situations, husbands were alienated from their children prior to the illness. Consequently, these husbands did not keep their adult children informed, thus lessening available support even in times of crisis. In contrast, close parent-child relationships provided husbands with emotional support even when these children lived far away. In these situations, children remained accessible through daily phone calls, frequent e-mails, or summer visits. In the absence of family support, neighbors and friends stepped in to fill the void. Support providers affected the husbands' levels of comfort in recruiting and accepting assistance, particularly when they perceived that they might be imposing on their time. Some of the husbands added that the presence of grandchildren in their lives was a wonderful emotional uplift. Having family members in their lives communicated caring to the husbands. Having adequate supportive people and financial resources facilitated the husbands' ability to embrace their transformed life. Conversely, husbands who did not have much support shouldered all the responsibilities for dealing with the illness and treatment regimens, and this made it more difficult to adapt to their transformed lives.

Supportive interactions with healthcare professionals. Support from healthcare providers refers to the provision of appropriate and competent interventions delivered in a caring and professional manner to the wives and to the husbands. Formal support came from various professionals, including family physicians, nephrologists, dieticians, and nurses working in an outpatient renal clinic, home dialysis program, hospital dialysis unit, and/or the community. The types of support these professionals provided were emotional, instrumental, and informational in nature. When healthcare professionals provided helpful interventions, husbands were able to more effectively channel their energies and time towards assisting their wives. Conversely, when the interventions provided were unhelpful, the husbands' workload and sense of isolation increased.

Healthcare professionals conveyed helpful support to the husbands and their wives when they provided information, engaged with them, created a welcoming environment, and provided follow-up care.

Providing information. Before their wives started dialysis, the husbands needed to understand the meaning and implications of kidney failure and treatment regimens. They obtained information and directed their questions to the nephrologists or renal nurses who in turn welcomed their questions and provided them with helpful information. Nephrologists were reported to be the most helpful professionals to provide information about kidney failure and renal replacement treatment options. Renal nurses were identified as being most helpful and patient when teaching skills about illness-related care.

Engaging with them. The ability of renal healthcare professionals to acknowledge that husbands were a significant support to their wives was important. Nephrologists acknowledged husbands when they invited them to take part in discussions, responded to their questions, and inquired about how [they were doing] today? Referring to husbands by their first names while attending appointments with their wives or when they met them inside or outside the hospital environment personalized the encounters. Nurses engaged husbands by inviting them to take part in their wives' care, and some nurses demonstrated empathy when they acknowledged the challenges of living with someone on dialysis. They showed compassion when they were attentive to the husbands' needs for food and rest. Husbands who assisted women on peritoneal dialysis, dropped them off or waited outside the hemodialysis dialysis unit had few opportunities to interact with the renal professionals.

Creating a welcoming environment. Renal nurses were perceived to be pivotal to everything that goes on in the dialysis unit (15) and to be key individuals with whom the husbands had the closest and most frequent contact (01, 03, 05, 07, 16). They created a welcoming environment by allowing husbands to sit with their wives while they dialyzed and by using humor to create an environment that was uplifting for their wives.

Providing follow-up care. Home visits or follow-up phone calls from renal nurses working in the home dialysis unit when dialysis was first initiated provided husbands with opportunities to ask questions and receive feedback about peritoneal dialysis. Unfortunately, such follow-ups were short-lived and focused only on dialysis related tasks. Community health nurses were also important contacts for husbands after their wives had been discharged from the hospital post-operatively or for post-peritoneal dialysis training (04, 06, 08, 09, 10). These nurses were also instrumental in assessing the need for home assistance, providing some assistance with peritoneal dialysis, doing blood work, and monitoring vitals. The care provided by community nurses was described as being superb (06), excellent (15). For some husbands who assisted their wives with peritoneal dialysis at home, follow-up was the only contact they had. While some accounts illustrate excellence in communication, respect, and concern on the part of most health professionals, other instances reveal unhelpful approaches.

Unsupportive interactions with health care professional. Unhelpful interactions occurred when healthcare professionals (a) provided inappropriate assistance or interventions, (b) discounted their wives' and/or husbands' input, queries, or concerns, (c) failed to provide compassionate care, and (d) interacted unprofessionally.

Inappropriate assistance or interventions. Husbands experienced a lack of trust/faith in their family physicians' judgments when their wives' health continued to deteriorate. Some physicians provided no interventions or follow-up care or prescribed interventions that were either ineffective or unsuitable to address the health problems. As a result, husbands believed that their wives suffered unnecessarily. It took months, and in some cases years, before their wives were finally referred to a nephrologist; and in some cases, husbands had to request a transfer of care**.**

Discounting the wives' and husbands' input, queries, or concerns. When healthcare professionals disregarded or discounted husbands' or wives' questions or concerns, they conveyed a lack of respect. In some situations, the women and their husbands were fearful of negative repercussions if they questioned or made suggestions to healthcare professionals, so they remained silent. They were cautious about the type of questions they might ask and whom they should approach and when. Waiting for the right time and the right people to express their concerns improved their chances of getting their wives' needs addressed. Humoring the staff prior to making a request guaranteed success. Husbands believed that they had no recourse but to resort to such tactics to ensure that their wives received care.

Lack of compassionate care. When professionals focused their care solely on doing dialysis, and overlooked the patients' and husbands' needs for emotional support, they demonstrated a lack of compassion. If a need was recognized, appropriate counsel or support was not forthcoming. Husbands of women who had been on dialysis for extended periods of time noticed changes in the nature of care over time and were adamant that health professionals needed to remain attentive to their wives' emotional well-being. In such situations, these husbands were often alone in shouldering the responsibility for addressing their wives' emotional needs.

Unprofessional behaviors. Husbands appreciated nurses who were willing to reveal some relevant personal information about themselves, such as facts about their families, because it helped husbands to connect with their human qualities. However, husbands did not appreciate conversations such as gossip about the other nurses or personal information about nurses' social lives. Other characteristics of unprofessional approaches included behaviors that conveyed lack of compassion or consideration, such as being nasty (08) or rough (08) with their wives or themselves.

Despite these negative experiences, most husbands recognized the overall competence of the healthcare professionals. They recognized their imperfections as examples of human limitations and acknowledged that nurses and physicians were often overworked while attempting to address the needs of a growing population of dialysis patients. As a result, most husbands continued to have faith in the care that renal health professionals provided to their wives.

The nature of the marital relationship, the women's health status, and both informal and formal support influenced participants' responses throughout the four stages of the BSP. In the following section, I will provide in-depth descriptions of each stage, and their sub-processes as well as, the strategies the husbands carried out to embrace a transformed life of living with wives on dialysis.

Stage 1- Becoming Aware

Becoming aware is a process of discovering that something was wrong with their wives' health which prompted the husbands to become involved. Husbands became aware of their wives' failing health when they were informed by their wives or by recognizing changes in their wives' health through observations and interactions.

Some women (03, 07, 13, 15, 16) had lived with chronic kidney disease (CKD) since early in their childhood or adult life. They continued to experience deterioration in their kidney functions for years or decades before their kidneys finally failed. Other women had already experienced kidney failure, but they had received a kidney transplant prior to dating their husbands and, when they met, these women were in stable health. Some women either informed their husbands about having CKD prior to marriage or they discovered that they had CKD early in their marriage.

When the women openly confided about the possibility that their kidneys could fail in the future when they first met their husband, it helped the men to make an informed decision about committing to the relationship. Becoming aware that dialysis treatment and/or a kidney transplant could be needed in the future did not discourage these men from pursuing their relationship. Choosing to stay in the relationship marked the beginning of their devotion towards embracing a life that would ultimately be transformed.

Eight husbands (01, 02, 04, 05, 06, 08, 12, 18) became aware that their wives were experiencing changes in their health when they noticed or were told of shortness of breath, fatigue, and lethargy. In most cases, these symptoms progressed over a period of months and years, as one husband explained: “In the two years prior to starting dialysis she was very tired. She could sleep on a tack in no time. We didn’t know that it was because her kidneys were failing” (04). Some women in this group had been treated for chronic illnesses such as diabetes and/or heart problems. Although these husbands were concerned about the changes in their wives’ health, none of the men attributed these symptoms to a potentially life-threatening chronic illness. For these two groups of men, persistent distressing symptoms and their wives’ on-going decrease in functional abilities made it clear that these symptoms could no longer be ignored, and the husbands were prompted to seek information and care. As kidney functions continued to decline, so did the women’s functional abilities, which made it difficult or impossible for them to continue assuming certain roles and responsibilities in the home, and their husbands began taking over or chipping in with chores and cooking to make things easier for their wives. Hence, changes in their wives health generated changes in aspects of their lives.

In contrast, five men (09, 10, 11, 14, 17) talked about their wives’ sudden distressing symptoms that ranged from flu-like symptoms to being unresponsive: “It was hard [started to cry] to find her flat like a rag doll… I called 9-1-1. She had a stroke in the middle of the night and I didn’t know it” (09). These husbands experienced unexpected crises as their wives' lives hovered between life and death. Information and care were sought from emergency health professionals to relieve their wives' distressing symptoms.

From the time husbands became aware that their wives' health was deteriorating, they committed themselves to placing their wives' needs before all other needs and wants because their wives' well-being was most important: "I know what she needs and I know that she's is going to get it if I can. I certainly have to focus on [wife's name] and her dialysis" (05). Regardless of how husbands became aware that their wives were experiencing health problems, they responded by becoming involved to ease their wives' suffering.

Stage 2- Involving Oneself

Involving oneself occurred prior to the initiation of dialysis and in response to becoming aware of the changes in their wife's health. This stage consisted of a process of taking action to address her progressive or sudden change in health by seeking information and care and by preparing themselves.

Seeking information and care. Seeking information and care refers to finding answers to uncover and understand the meaning of symptoms and to obtain effective treatments to ease their wives' suffering. The extent to which husbands were involved in seeking information and care was influenced by their wives' progressive or sudden changes in health. Women with long-standing CKD had independently attended follow-up visits with a nephrologist for most of their lives. As their health worsened, and the need for dialysis became more imminent, husbands accompanied their wives during follow-up visits. For these couples, seeking information and care was uncomplicated because nephrologists provided pertinent information, responded to their concerns, and included them in decisions. Such helpful support assisted husbands to make sense of their wives' changing health and increased their confidence that they were receiving competent care. Prior to attending these follow-up visits, some couples used problem-solving approaches that they had employed previously during their marriage: "It's always worked when both of us put our both heads together. So before going to these appointments we'd come up with some questions so we wouldn't miss something" (07).

When women were unaware that their kidneys were failing, the husbands' involvement with seeking information and care changed in tandem with their wives' deteriorating health. When symptoms first appeared, husbands did not attend doctors' visits with their wives or they waited in the waiting room. However, husbands became more involved when their wives became too debilitated to attend alone or when the symptoms persisted despite repeated visits:

> She'd been going on her own for some time. Whatever he was giving her wasn't working. So I figured that I'd better start going with her to see what was going on. It's a good thing I did, but even then it was too late, it had progressed into something irreversible, the cancer was too advanced. I just wish I had gone with her sooner, the outcome might have been different. (04)

Husbands feared that their wives would die if they did not receive timely and appropriate care. However, obtaining a medical diagnosis was not a quick process. It took repeated visits over a period of several months and, in some cases, years before uncovering the cause of their wives' symptoms and/or being referred to a nephrologist.

During this process, there were no variations in the husbands' commitment of being there because none wanted their wives "to go through this alone" (09). A few also perceived that their wives would do the same for them if the roles were reversed, which seemed to reinforce their efforts to seek treatment for their wives. Seeking care for their wives provided an opportunity to demonstrate their indebtedness and appreciation for the support their wives had provided to them when they were dealing with illness.

Husbands' efforts to seek information and care were hampered by healthcare professionals, particularly family physicians, when they: (a) failed to investigate the underlying causes of their wives' symptoms, do follow-ups, prescribe diagnostic tests, and/or make referrals to renal specialists and (b) ignored their concerns. One husband seemed to speak for all the others when he shared: "Quite frankly I was somewhat disturbed at the attitude, just the misjudgment of our family physician... and the lack of follow through. So in my opinion, when he found something that was abnormal, he should have kept an eye on it" (03).

Four husbands became dissatisfied with the lack of interventions from their family physicians and mistrusted their abilities to deliver competent care (01, 04, 01, 18), which prompted one couple to switch doctors: "We had a doctor for 25 years. I don't think she was interested. Now we have a good one. She ordered tests and that's how we found out that [wife's name] had kidney problems. We're happy with her" (01). After repeated visits to the family physician one husband took his wife to the emergency department "where we found that her kidneys were not working" (008). Some husbands wondered whether their wives' kidney failure could have been prevented if diagnosed earlier. The diagnosis of kidney failure was a "shock" to seven husbands (01, 04, 06, 08, 11, 12, 18), whereas for others it was a "relief" because now "something could be done" to ease their wives' suffering.

For both groups of men, the on-going monitoring of kidney function by nephrologists through diagnostic tests, such as glomerular filtration rate (GFR), provided tangible evidence about the progression of the CKD and some predictability about when dialysis might be initiated: "Dr. [name] kept watching her until she got down to about fifteen percent for her kidneys and then he said, 'another six months before you have to go on dialysis.' Well, low and behold, at 6 months he put her on dialysis" (01). Being kept informed and prepared by the nephrologists may have buffered some of the shock since "I knew it [dialysis] was going to happen, so it wasn't a shock as it would be for a lot of other people that suddenly have to go on dialysis" (07).

In contrast, husbands of women who had to seek emergency care by either ordering an ambulance or driving their wives to the hospital because "she was fighting for her life" (09) were informed of their wives' diagnosis of kidney failure and need for dialysis within hours or days of their admission to the hospital. Some also discovered that their wives were experiencing multiple health problems that required stabilizing interventions before dialysis could be initiated. Husbands praised the helpful support provided by emergency health professionals when they gave them information and included them in all the decisions. Such support assisted them to make sense of the severity of their wives' health. They were shocked by the suddenness with which their lives were changed and the rapidity with which they had to assimilate the diagnosis of a life-threatening disease. Their life situation was fraught with uncertainty about how everything would turn out, and for some husbands their own health was affected: "Je pouvais plus souffler comment j'étais 'stresser' de la voir toute branchée" (08) [translation:"I couldn't breathe, I was too stressed from seeing her hooked up to the machines"] or "I had great difficulty sleeping" (10). Some women in this group had to be transferred to other hospitals in another city or province to access dialysis treatment and specialized care. Without hesitation, husbands accompanied their wives to seek such care and to provide them with emotional support and assistance: "I didn't want to be away [crying]. I figured she wanted me there. I was worried that she might not live through all of that" (09).

During this time, some husbands put their job on hold, decreased their working hours, and/or relocated temporarily for weeks or months to be with their wives. While away from home, husbands rented apartments, hotel rooms, or stayed in bed-and-breakfast accommodations until their wives could either be transferred to their local hospital or discharged home. These were added expenses they had not anticipated. One husband, who could not get time off work or relocate to be with his wife, managed to visit his wife every day by traveling long distances:

> It's 800 kilometers, round-trip, and I did that four times a week at least for a period of about 6 months. I was pretty much worn out, but knowing how happy it made her feel when I walked in her room kept me going. (14)

Unique to this group of men was the support provided by family members, especially their adult children whose presence helped them deal with this health crisis. One husband was grateful that his daughter lived close by; he wondered how he would have otherwise managed on his own: "Ma fille m'a aidé à la transporter à l'hôpital, sans elle j'aurais pas pu, j'étais trop en 'shock' [translation: "It's a good thing that my daughter lived close by. She helped me to bring her to the hospital. Without her I don't think I could have done it myself. I was in shock"] (08). In contrast, for husbands who were geographically distant from their adult children, support was relayed by phone during this time of crisis. Regardless of how and when husbands learned about their wives' need for dialysis, all husbands continued to gather information and meet with healthcare professionals to prepare themselves to assist their wives with illness-related care.

Preparing themselves. Preparing themselves is a process whereby husbands actively acquired the necessary knowledge and skills to assist their wives with illness-related care. While certain elements of preparation were part of the standardized protocol that all patients and family members received from renal care professionals prior to starting dialysis, some of the preparatory work was self-initiated by the husbands. All participants had contact with numerous renal professionals before the start of dialysis to learn about dialysis treatment, diet, and the technical skills of peritoneal dialysis. The extent to which women were debilitated by kidney failure influenced whether the men had to prepare on their own or as a couple: “I spent six weeks in [name of city] learning how to do peritoneal dialysis for my wife so I could do it for her at home because she wasn’t in any shape to learn any of it” (06).

In situations where women were more stable, teaching sessions were attended by both partners, which made learning about illness-related care less daunting. Support from nephrologists included being encouraged to attend pre-dialysis care with their wives and to ask questions. Such support assisted them to make sense of the situation, particularly when simple language and visual materials were used. As well, when information was relayed calmly and in small doses, husbands indicated that “we didn’t feel rushed” (03). In addition, tailoring the information according to the patients’ and husbands’ educational backgrounds demonstrated respect.

Support received from the renal nurses was also helpful in assisting husbands to acquire knowledge and skills about dialysis. Renal nurses working in the home dialysis unit provided information and hands-on training sessions about peritoneal dialysis that was invaluable and enabled husbands to develop a “sense of connection [with these nurses].... So not only are they excellent nurses, but they’re like friends because you’re with them every day for 10 weeks” (06). The extent of the training husbands received tended to vary according to dialysis units within the same province and across different provinces. In a few cases (02, 11) the opportunities for hands-on practice for peritoneal dialysis were limited and considered inadequate. Orientation to the hemodialysis unit, routines, and visiting protocols, as well as to general services such as parking, waiting area, and/or food access before starting dialysis was a “huge benefit to help a person understand what’s happening... what to expect” (15) and provided an opportunity to become familiar with the treatment environment, ask questions, and provide exposure to the noise and smells of the unit.

Some husbands also used their own approaches for preparing themselves for the onset of dialysis. They supplemented their understanding by seeking information from books or the internet about kidney failure, dialysis treatment, and dietary regime. Some contacted their local branch of the Kidney Foundation of Canada when “they gave me pamphlets, recipe book, and the name of a person in charge of a support group for the patient and family” (05). Their need for a greater understanding stemmed from both a desire to assist their wives and their need to make sense of the illness and dialysis.

Summary of Stage 2: Involving Oneself

The process of involving oneself was contingent on the husbands becoming aware that their wives’ health had changed. This recognition prompted all the husbands to involve themselves in seeking information/care and preparing themselves to assist their wives. This stage was stressful and a time of tremendous uncertainty that created a difficult context in which changes began to take place in household responsibilities, work schedule, and living arrangements. The extent to which husbands were involved in seeking information/care and preparing varied according to women’s health status and the helpful/unhelpful support of healthcare professionals. Once dialysis was initiated, the husbands moved into the third stage of centering life on their wives. It was not until they entered this stage that they discovered the extent to which their lives would be disrupted, changed, and limited by the illness and treatment regimens and how their commitment to embracing a transformed life would be both strengthened and challenged.

Stage 3- Centering Life on Their Wives

The third stage, centering life on their wives, is the process of husbands dedicating their time and energies towards addressing their wives’ needs and fitting the demands of the illness into their daily and future lives. By the time dialysis treatment was initiated, the women had experienced considerable emotional turmoil brought on by the diagnosis and reduced functional abilities. In some cases, they were hovering between life and death. Their husbands were well aware that without dialysis treatment their wives would die. As one husband explained: “It has to get done... otherwise she will die, so that pretty well says it all right there” (04). Their wives’ needs and the dialysis schedule dictated when other activities, responsibilities, and plans could occur. Life centered on managing the implications of the illness and treatment regimens. According to one husband: “Everything had to stop for this. Life revolves around her needs now and dialysis” (06).

Although most husbands had successfully coped with and adapted to previous challenges in their lives, none of these had prepared them for the implications of living with a spouse dependent on technology for survival. Some husbands adopted a mind-over-matter attitude to do their best, as expressed by one husband: “I made up my mind that I was going to look after her to the best of my abilities” (18). Centering life on their wives involved five sub-processes of providing illness-related care, engaging in protective support, attending to their wives’ voice, concentrating on daily goals, and simplifying life.

Providing illness-related care. Accommodating illness-related treatments required a radical modification of lifestyle. By the time dialysis was initiated, the women were too debilitated to participate in their roles and responsibilities. They had to relinquish most of their household responsibilities to their husbands and accept being cared for by them. Providing illness-related care consisted of a process of juggling a cluster of specialized responsibilities to assist with dialysis treatment, prepare and administer medications, and provide optimal nutrition. Activities associated with illness-related care needed to be coordinated, sequenced, and/or implemented at a prescribed time. Maintaining any kind of normal lifestyle in the face of these commitments was difficult and demanded a profound rearranging or relinquishing of usual activities.

Specific activities needed to be carried out to make sure that their wives received and followed the prescribed treatment regimens for peritoneal dialysis at home or hemodialysis at the hospital. The responsibilities associated with peritoneal dialysis at home versus in-hospital hemodialysis differed. Assisting with peritoneal dialysis required husbands to assume a variety of responsibilities such as: (a) monitoring vital signs and weight, (b) assisting with peritoneal dialysis, (c) troubleshooting, (d) keeping track of and storing dialysis supplies, and (e) revamping their living space.

Monitoring vital signs and weight. One of the first tasks of assisting their wives with peritoneal dialysis included taking and monitoring their vital signs and weight every day before and/or after each dialysis session to guide treatment: “The nurse calls and they tell me what strength of solution to use on her” (11). Once they had completed this task, they focused on carrying out the dialysis treatment.

Doing peritoneal dialysis. When peritoneal dialysis was initiated, all the women required assistance from their husbands. Over time most women were able to assume responsibility with minimal help. The more women were physically and/or cognitively debilitated by kidney failure and co-morbid illnesses, the more husbands had to assist with dialysis. At the time of the interviews, a few women had switched from hospital hemodialysis to either CAPD which consisted of four exchanges per day, seven days per week or CCPD seven times a week. In most cases, both partners had received training from the renal nurses prior to switching. In contrast, one husband trained alone and carried out peritoneal dialysis for his wife (06) on a full-time basis because she was bedridden. It was not uncommon for most husbands to take over dialysis when their wives experienced a "bad day".

For some couples, both partners collaborated to manage dialysis-related tasks that were mutually agreed on based on the women's self-care abilities and health status. For the most part, the women tended to do lighter tasks such as connecting, infiltrating, and draining the dialysate solution, while the husbands did the heavier tasks,"[getting] her bags out for her... put a new bag in the machine in the coolatron to heat it up. And when she's finished I have to empty the bag and put it in the garbage can" (11). The level of involvement fluctuated according to their wives' health. On "good days" women fully took part in their dialysis activities. On "bad days" they had to relinquish all responsibilities to their husbands. Over time, one husband became totally responsible for his wife's dialysis care because "[she] couldn`t do it anymore, she couldn't remember how" (02). It was not uncommon for the division of labor to change between partners during the course of the day or from day-to-day. As explained by one husband: "As you can see she cannot walk, she's panting there now ... her shortness of breath, it's a little bit worse this afternoon so I'll have to do it [CAPD] for her the rest of the day" (11). Taking over for their wives was non-negotiable because it had to be done and they could not delegate these tasks to others because of the specialized skills required. Husbands had to be on stand-by and flexible with their time so they could take over dialysis for their wives when they were unable to manage.

The negative outcomes of assisting their wives with dialysis included being tied down, restricted, and isolated. One husband whose wife was bedridden described his involvement as confinement: "It's like being on house arrest. I`m at her beck and call twenty-four hours seven. It's hard. All of a sudden you're grounded" (06). Husbands needed to be close by to keep track of the next dialysis exchange since most of the women tended to sleep a lot. A major concern for husbands while assisting their wives with peritoneal dialysis was fear of making mistakes such as improperly connecting and disconnecting tubing or not finding a solution while troubleshooting a problem.

The positive benefits of assisting their wives with peritoneal dialysis included: (a) not having to travel to and from the hospital hemodialysis unit three times per week, especially in treacherous weather conditions; (b) not having to spend long hours waiting for hemodialysis to be completed; and (c) having some free time to replenish during the day, especially with CCPD if their wives' health was relatively stable or they could recruit someone to watch over them during their absence. Although assisting with dialysis-related activities involved completely new responsibilities for husbands, they spoke with confidence about their ability to perform the procedures and demonstrated the details involved in setting up a CCPD machine:

> There's a cassette and I have to set all the hoses up and I put the bags in, it takes three bags and I put one on top, there's a heater on top of the machine. And I put one bag there and two or three below, and she has a tube, and after the machine is not running for about ten minutes I have to give it time enough to heat the first bag and then I hook up. The machine will tell me to hook up and it runs all night. (02)

Troubleshooting. Husbands were also involved in troubleshooting solutions to solve problems associated with peritoneal dialysis. Husbands used three different strategies to troubleshoot. First, they checked the cycler machine to get directions about the nature of the problem and how to fix it. As one husband pointed out: "The machine beeps and it will usually say 'slow drain' and then I get her to move off the tube, press a button to restart the machine and go back to bed. Those are easy problems to solve" (02). When this approach didn't work they relied on written protocols provided by healthcare professionals. As a last resort, they enlisted the assistance of others by either calling "an 800 number if anything that goes wrong with the machine itself that I can't fix" (06) or calling the renal nurses via a 24-hour pager system. Some men commented that their workplace skills were helpful in troubleshooting: "Perhaps, my working career… a lot of it was design and startup of new plants when things go wrong and so I'm used to coping with things going wrong" (12). There were times when husbands would get up "two or three times" (02) during the night to troubleshoot "because their wives did not hear the machine. So [they] wake up automatically" (02). When that happened, their sleep patterns were interrupted, leaving them tired.

Keeping track of and storing dialysis supplies. Both CAPD and CCPD required supplies that needed to be ordered, delivered, and stored monthly. Therefore, husbands were also responsible for maintaining and replenishing dialysis related supplies. Keeping a log detailing items used and discarded as well as a calendar to mark "when things [supplies] need to be ordered and get delivered" (11) was helpful. The calendar was also used to keep track of medical appointments, phone conversations with renal nurses, patient status indicators, and test results. Some husbands (06, 12) did not mind doing this kind of work, but one found it very cumbersome because he was "never good at book work, so now keeping a record of everything and knowing when to order the stuff and what to order is a real pain in the butt. I find that kind of hard" (11). They appreciated that all the supplies were free of charge and that they were delivered, unloaded, and stored monthly for them by the delivery personnel. The heavy boxes of dialysate solutions were a concern for older men who wondered about their long-term ability to carry supplies up the stairs (02, 12). Storing supplies was problematic for a few couples and required them to reorganize their living space.

Reorganizing their living space. In order to have space to accommodate dialysis supplies, a few of the couples had to reorganize parts of their home, such as transforming a bedroom, an office, or a basement into a dialysis/supply room (06, 13, 17). One couple moved to a larger apartment (02). Husbands made changes to their home environment to provide a clean and clutter-free room for their wives to do peritoneal dialysis or store dialysis supplies. One man whose wife was in the process of switching over from hospital hemodialysis to CAPD anticipated having to "tear a wall out so we have more space for the equipment or whatever is required" (04). One husband reminisced about the prior usage of one of their bedrooms which he had transformed into a storage room:

> I used to have a train set up in that bedroom which was fun to see it up and I really enjoyed it. But now, the bedroom is a warehouse... with sixty-nine boxes of solution. So there's just room to walk to the edge of the bed and then grab whatever bag she needs. (06)

In contrast, a few husbands decided to not reorganize any rooms in their homes. They kept all the dialysis supplies/machine out of sight, away from their main living areas and stored supplies in their basements (12) or behind closed doors (11, 13). Keeping things separate served two purposes. First, it kept a sense of normality in the home "because you don't need to have all this medical paraphernalia all over the place. I try to keep a sense of normality as much as I can" (13); and secondly, it allowed them to have "some control over where we put the stuff. Where there are other things about this disease that we can't control, you hang on to the things you can control like where to put the boxes for dialysis" (12). Such control was important when considering that reorganizing their homes represented one of the many compromises, sacrifices, and concessions they had to make in their lives. In contrast to peritoneal dialysis, hemodialysis treatment required less direct involvement. Husbands ensured that their wives had transportation to the dialysis center three times per week.

Assisting with hospital hemodialysis. All of the husbands assumed primary responsibility for driving their wives to in-center dialysis at the initiation of treatment. The extent of the husbands' involvement in providing transportation was influenced by their wives and the availability of informal support. Some husbands drove 30 minutes or less, while others drove for more than one hour each way three times per week. For some husbands, being the sole and principal driver for their wives meant that they had to resume highway driving after stopping such practice due to their age (05, 11) and/or health:

> I am 81 so, you start to feel that maybe you could be a bit of a hazard, so I didn't really want to drive on the highway but I knew I had to. I am not sure how long I'll be able to drive her. At my age I should be cutting down driving instead of increasing. Boy, we are putting the miles on. (05)

Those who lived less than 30 minutes away from a hospital tended to leave their wives at the dialysis unit and return "home and do the dishes, the laundry, groceries" while she dialyzed (18). Those who lived further away had to wait four to five hours for their wives to complete their dialysis. In some situations husbands took advantage of such time to resume pre-dialysis activities such as walking, reading, or doing work. More importantly, waiting provided the opportunity to be readily available and accessible to support their wives when they experienced adverse effects from dialysis.

There were drawbacks associated with traveling to dialysis. These included experiencing personal and financial costs associated with traveling, driving in treacherous weather and dealing with an unpredictable dialysis schedule. The personal costs were related to being tired and stressed from driving long distances (03, 05, 12, 18), as one man shared: “I get tense when I drive, especially when there are a lot of trucks, so I find if all goes well I sleep very well that night that I drive [laughs]” (05). For men who had been driving at least three years, the accumulated tiredness and stressfulness from driving eventually took its toll on their health: “I got drawn down pretty low and was getting sick a lot, which wasn’t good for both of us” (15). For couples with children, being away from home three nights a week for dialysis treatment negatively affected their children: “We saw changes in our youngest child who was missing his mother and father because we were always on the road. We couldn’t help him with homework or deal with certain issues” (15).

Financial costs associated with weekly travel expenses such as gas, meals, and parking tickets (03, 04, 05, 07, 08, 09, 10, 13, 14, 15, 16, 18) were also difficult. The expenses were proportionate to the amount of travelling, and for some that meant spending about 150 dollars per week on gas and other expenditures: “Je fais le plein d’essence le mardi, jeudi et encore le samedi… puis il faut que je passe au restaurant souper trois jours par semaine” [translation: “I need to put gas in the car Tuesday, Thursday and Saturday and then stop at a restaurant three times per week for supper”] (10). In addition, there were sporadic costs associated with maintaining the car, such as purchasing good tires (18) and in some cases buying a more reliable car. None of the husbands expected to deal with these extra illness-related costs during their working and retirement years. Although the negative implications of these expenses were experienced by all the men, it was not as difficult for those who had an adequate retirement income (04, 05, 07, 09, 15, 18) compared to those living on a limited income (01, 02, 03, 08, 10, 16). One husband divulged: “The problem is financially. We’re in a situation where I am going to have to go bankrupt” (01). Some husbands could apply for a rebate on their income tax for traveling expenses if they lived beyond a 40 km radius from the dialysis unit. However, husbands who were not eligible for a refund thought they were being penalized (03, 04, 16, 07, 13, 18). Most, reported that none of the health professionals had ever explored their financial situations with them and that they did not know who they could talk to about their finances (05, 08, 09, 10, 18).

The amount of traveling also influenced when husbands could carry out their other responsibilities at home and/or work or socialize. Regardless of the distance, husbands were less worried about driving or waiting but were more distressed when their wives experienced adverse effects on the way home after dialysis treatment:

> I guess the best word is concerned to take her home. She's sometimes dizzy and experiences difficulty walking into the house. I feel pretty helpless because I have no idea what I can do to help her. It's rough that part. I find it scary. (05)

There were also positive outcomes resulting from traveling, which included being present to provide their wives with emotional support after dialysis, monitoring for negative effects of dialysis, and/or spending uninterrupted time together as a couple during their commute.

Preparing and administering medications. Husbands prepared and administered oral and/or subcutaneous medications to their wives when they were too physically and/or cognitively incapacitated to do it themselves. While most men had prior experiences with oral self-medication, administering daily subcutaneous insulin or monthly injections of Eprex (02, 06, 11) was new. They referred to this task as "doing nursing care" (02, 06). Even when women were able to independently prepare and take their medications, husbands tended to be on stand-by to assist and monitor intake. When the women were not compliant with taking their prescribed medications, conflict sometimes resulted. In addition to these on-going responsibilities, husbands also <u>provided optimal nutrition</u> to their wives either on a temporary or permanent basis, depending on their wives' state of health.

Providing optimal nutrition. Husbands prepared meals in order to ensure that their wives received and adhered to their prescribed diet. The extent of husbands' involvement varied according to the severity of their wives' health condition; the more incapacitated she was, the more involved husbands had to be in <u>providing optimal nutrition</u>. All husbands assumed full responsibility for cooking when their wives started dialysis (02, 03, 05, 06, 08, 09, 10, 12, 14, 18) however, over time, if the women's health improved, the men shared the responsibility with their wives (01, 11, 15) by "chipping in" when needed (04, 07, 13, 16, 17). In situations where the women's health continued to decline, their husbands took total responsibility for meal preparation (02, 03, 06, 08, 09, 12, 18), because: "She gets very tired, plus she forgets some things. So she can't do it no more" (04).

Preparing and planning meals for the family had been the primary responsibility of women in most families, especially the older generation. One of the challenges of providing optimal nutrition was to find ways to be involved without overstepping role boundaries. Most of the older men had never cooked or baked before (01, 02, 05, 09, 11) or had only done so occasionally (03, 04, 06, 08, 10, 18) because working full-time had always been their primary responsibility: "I wasn't in the kitchen much. [Wife's name] did the cooking. So now I cook and grocery shop. These are new responsibilities for me" (01). In contrast, most of the younger husbands had prior experiences with meal preparation (06, 14). Regardless of the extent of their previous experiences, most husbands willingly took on this role to assist their wives. In some cases, engaging in meal preparation was seen as an opportunity to reciprocate for the care received from their wives in the past:

> She's looked after me for 46 years. She always cooked beautiful meals, cleaned the house for me and the kids when I was working steady but now she can't do anything anymore, so I said, "It's my turn now. You relax and I'll do my share. (03)

For a few husbands, meal preparation was a chore because no one else was available (04, 06, 13) and they had never enjoyed cooking. Strategies for <u>providing optimal nutrition</u> consisted of <u>learning how to cook</u>, <u>adopting their wives' diet</u>, and <u>enforcing the dietary regime</u>.

Learning how to cook. The process of acquiring the necessary knowledge and skills to prepare appropriate meals for their wives required that the husbands learn how to grocery shop, follow recipes, and decipher food labels (04, 05, 08, 09, 11, 12, 17). They sought information from the dietician, the internet, and/or recipe books. Support from the renal dietician was invaluable for assisting them to learn about the renal diet and how to incorporate other diets for diabetes and/or cardiac disease (01, 03, 05, 06, 11). Information about substituting prohibited food with permitted ingredients allowed husbands to cook some of their favorite and familiar recipes to maintain normalcy in their lives.

Husbands did not receive any information for helping their wives deal with loss of appetite, nausea, and distaste for certain foods. A few husbands (08, 09, 10) who did not have access to a renal dietician accessed information and recipes on the internet (08) or purchased a cookbook which "has all kinds of information about dialysis and about nutrition related to dialysis. So it's invaluable" (09). A recipe book provided by the Kidney Foundation also assisted them to make appropriate food choices and meals. Men's responses to preparing meals were mixed. Husbands with previous experience believed they had an advantage over those who had never cooked before: "I would hate to be somebody that didn't know how to cook. In the situation that I'm in, what in the devil would you do?" (06). However, husbands with no prior experience saw this as an asset: "I think it must be a lot tougher for somebody who has been cooking because I am a new cook [laughs], so I take the recipe and it's not a problem to adjust it because I'm learning the recipe anyway" (05). A few of the older participants (01, 03, 05, 18) took pride in their ability to learn a new skill late in life: "I had never cooked a full meal until the age of 82, so I think the fact that I can do it now is quite an accomplishment. I think, frankly, I am thriving on it" (05). Husbands who never liked to cook did not change their attitude; however, their involvement was made somewhat more tolerable by witnessing positive improvement in their wives' health and being complimented by their wives: "I hate cooking with a passion but [wife's name] insists that I am the best cook that she's had for a long time… so it makes it a bit easier for me" (13). In addition to preparing nourishing meals, husbands adopted their wives' diet to demonstrate their support and encourage them to adhere to the regime.

Adopting their wives' diet. Making a conscious decision and choice to eat whatever their wives were prescribed to eat and drink was deemed to be important even if it meant giving up certain ingredients, which made their food taste "more bland, but it has not been a big adjustment" (04). The benefits to their wives sustained their determination to conform to the regime. In situations in which the women regained some level of involvement in meal preparation, adopting their wives' diet was a strategy to make things easier for them. When children were living at home, it was more difficult to adopt the women's regime, and different meals were prepared. Most husbands perceived that simply <u>providing optimal nutrition</u> was insufficient to prevent heath crises, and some also <u>enforced the prescribed dietary regime</u> to minimize illness-related complications.

Enforcing the prescribed dietary regime. Husbands took measures such as curtailing, limiting, and/or exerting control over their wives' prescribed dietary and fluid intake. They portioned food and fluid intake, limited the type of food and fluids they purchased to reduce temptation, and/or hid forbidden food and fluids in an effort to "keep her blood within acceptable limits the best I can and so far we're successful" (05). The extent to which husbands could enforce the dietary regime varied according to their level of involvement in meal preparation. The more they were involved, the more control they could exert over the type and quantity of food/fluid their wives consumed. Although the husbands did not enjoy enforcing the dietary regime, they believed that by assisting their wives to regulate their intake, they could enhance their quality of life and positively influence the course of the illness trajectory. Husbands who did not prepare meals enforced the regime by reminding, encouraging, and/or suggesting to their wives to limit food/fluid intake. Positive feedback from renal nurses and dieticians sustained husbands' efforts to exert control over their wives' diet. Unfortunately, their efforts were sometimes insufficient to prevent their wives from experiencing health crises.

Most husbands had no previous experience providing assistance with illness-related care. Juggling multiple competing responsibilities associated with dialysis and meal preparation was difficult. However, they rose to the challenge by obtaining the necessary knowledge and developing essential skills to fulfill these responsibilities. In addition, the husbands were also sensitive to the emotional impact kidney failure and its treatments could have on their wives.

Engaging in protective support. <u>Engaging in protective support</u> consisted of guarding, promoting, and enhancing their wives' physical and emotional well-being because "to see somebody you love suffer is hard" (09). It was role that the husbands had fulfilled prior to their wives being unwell. The husbands <u>engaged in protective support</u> when there was a risk or perceived threat to their wives' physical and emotional well-being. Risks came from the impact of the illness and dialysis itself and from healthcare providers or services. All the husbands were fiercely protective of their wives in these situations because the risks were perceived as imposing unnecessary suffering as well as having the potential to threaten life. Being able to access informal and formal support were conditions that influenced the husbands' efforts to carry out the following three strategies: watching over her, advocating and confronting incompetence/insensitivity, and shielding.

Watching over her. Watching over their wives occurred daily and consisted of observing and listening attentively to their wives for signs and symptoms of distress and complications. One husband explained: "I`m at her beck and call twenty-four hours seven. I mean I`m always on guard" (06). Watching over her also included an evaluative component when a husband decided whether or not to take action or simply continue monitoring. Husbands used the information gleaned while being on guard to assess perceived or actual threats and the action required to re-establish the health stability of their wives. Fear that a wife might die was often the impetus for watching over her: "I kind of sleep with one ear open and one eye open to make sure she doesn't get in a crisis. If I don't catch it, she might pass away" (11).

Husbands used various approaches for watching over her, such as periodically checking up on their wives (08, 09), using walkie-talkies (06), or making impromptu phone calls at home (15, 16, 17). If women experienced adverse effects from dialysis, the intensity of monitoring increased: "I take her pulse and watch her breathing and then I know she's going to be OK" (09). Even when their wives' health was stable, husbands continued to remain alert. Drawing from previous experiences assisted husbands in discerning the seriousness of the distress: "I can tell when she's good and when she's not. When she's feeling good she's around and she's trying to help and everything but when she's not feeling good I know it because she don't move" (09).

Watching over her had the potential to create conflict between partners when the perception of symptom severity differed between spouses and/or when the women resisted their husbands' attempts to seek assistance from healthcare professionals. When women were opposed to seeking assistance, the need to watch over her was heightened. It was mostly during times of a health crisis or when the women experienced adverse effects of dialysis that their husbands imagined the possibility of losing their wives. Although watching over their wives could have a negative impact on the husbands' sleep patterns and social lives, they insisted that it was an important responsibility.

If personal appointments or work responsibilities could not be postponed, cancelled, or rescheduled, husbands brought others on board by recruiting family members or neighbors to watch over their wives during their absence, especially when a wife was experiencing a bad day. Having someone present reassured them that someone would intervene in their absence. Although <u>recruiting others</u> freed up time to attend to personal and work related matters, they experienced little respite or relief. The husbands indicated that their wives were "always on [their] mind" (07, 08, 09, 13, 14, 16). Therefore, they tended not to <u>recruit others</u> to perform certain functions unless they believed it was absolutely necessary.

A few husbands also wanted to <u>watch over</u> their wives while they dialyzed at the hospital (01, 03, 05, 07, 08, 09, 10, 11, 12, 15, 16). This was possible when health professionals created a welcoming environment for husbands to sit with their wives, a practice that was not endorsed by all renal units. Some care professionals involved husbands by allowing them to take their wives' temperature (15, 16), insert the needle if they had prior experience with this task (07), and/or apply pressure on the fistula post-dialysis (15, 16). Being welcomed in the dialysis unit and being able to engage in their wives' care depended on the nurses' time, experience, personality, and/or attitude. Being able to <u>watch over</u> their wives while they dialyzed diminished husbands feelings of helplessness and provided opportunities to: (a) partake in some pre-dialysis activities as a couple, such as watching television, reading, or playing cards; (b) offer emotional support when their wives experienced adverse effects from dialysis; and (c) reassure their wives they were receiving competent care. Reasons cited by the renal staff for not allowing husbands to sit with their wives included limited space on the dialysis unit, privacy issues, and increased risk of infection. While most husbands understood and respected the explanations, two (08, 10) had great difficulty understanding why hospital volunteers were allowed to spend time with their wives. Husbands who spent time with their wives inside or waited outside the hospital hemodialysis unit had more contact with the renal staff and felt valued when staff: (a) acknowledged their presence, (b) engaged them in formal and informal discussions, (c) took the time to respond to their questions, (d) inquired about “how they [were] doing?” and/or (e) referred to them by their “first name”. Regardless of the husbands’ presence or absence during dialysis, all engaged in protective care by advocating or confronting incompetence/insensitivity through interactions with healthcare providers to positively influence circumstances or care provision.

Advocating and confronting incompetence/insensitivity. The husbands advocated and confronted incompetent/insensitive healthcare professionals when they perceived that their wives needed to receive services, treatments, and care. Husbands were likely to engage in this strategy when healthcare professionals: (a) upset their wives, (b) discounted matters that were important to their wives and themselves, and/or (c) compromised their wives’ care. Some husbands explained that once dialysis was initiated, it became obvious that the treatment would not necessarily be provided in ways that were most beneficial to their wives, but rather in ways that worked best for the renal staff (07, 08, 11, 13, 15, 16). This was particularly evident in situations when women who had been on dialysis for long periods of time made suggestions about certain clamping techniques that worked for them. Their suggestions were often ignored by nurses; and consequently, some women felt intimidated to make further suggestions because they feared being mistreated if they made said anything. Hence, husbands had to advocate and in some cases confront healthcare professionals to defend their wives’ right to be heard and treated fairly, but receptivity varied among healthcare professionals. One husband noted: “I live with her 24 hours a day…I’m very familiar with her… sometimes I make comments about something and they do not listen” (15). When husbands felt unheard, they enlisted the support of the renal dialysis unit managers. They found that although doctors or staff nurses did not listen to them or their wives, they would listen to the unit manager.

Pushing for action to make the healthcare system move was another approach to advocating and confronting. In one case, the husband had to fight for a particular course of action for his wife to continue with home hemodialysis care: “I called the minister of health after he sent a letter indicating that they would be taking dialysis from our home after [wife's name] has been on it for 20 years. I just wished they would work more with the patient" (14).

Follow-up care and communication of important information between family physicians and nephrologists within the same or across various dialysis units was sometimes fragmented, inconsistent, and/or lacked coordination. These situations tended to occur mostly to women who were receiving dialysis care at two different units during the week, had been transferred to another dialysis unit, and/or were receiving care from several physicians for multiple health problems. Husbands had to push for action when they observed a lack of continuity and coordination of care:

> She was being dealt by half a dozen different doctors and it didn't look like they were talking to each other. Doctor A would give her something. Doctor B, C, or D would give her something else…. To me it was like an assembly line. Get the patient in, give her a pill and get her out. (13)

They perceived potential risks and benefits to advocating or confronting. Confrontation could result in husbands being shut out of the dialysis unit and therefore prevent them from being able to watch over their wives. They were also fearful of repercussions to their wives' care if they alienated healthcare professionals by questioning them too much or by making too many suggestions. Husbands' good behavior, on the other hand, might be rewarded with more compassionate care for their wives and access to information. In order to minimize the risk of alienating the staff, husbands of women who had started dialysis tended to "remain silent" or "walk on egg shells," whereas husbands of women who had been on dialysis for longer periods learned through experience to create a humorous ambience with the nurses before approaching them. As one husband explained: "Sometimes they [nurses] are not in the greatest moods so I'll joke around and they seem to be a little bit better and they may treat [name of wife] a little bit better" (07). Husbands of women who had been on dialysis for at least five years had learned through experience to "navigate the system" (07) in order to avoid confrontations with healthcare professionals. This entailed being courteous, accommodating, and diplomatic regarding "when to ask questions, when not to, and the proper questions also to ask" (07).

Three husbands (07, 08, 11) perceived that they were "disturbing" or were a "hindrance" to health professionals when they advocated for care. Husbands viewed themselves as indispensable to their wives' care team. Yet, some husbands, especially those who assisted their wives with peritoneal dialysis at home or dropped their wives off at the dialysis unit, thought that their participation remained invisible to others. Some renal professionals had seldom or never inquired about how husbands were doing or managing at home despite having made periodic follow-up calls or visits to the home. One husband whose wife had been on hospital hemodialysis for six years stated: "J'ai jamais eu un 86elephone ici. Jamais. Jamais pour dire, 'Comment ça va, monsieur?' (08) [translation: "I have never received a phone call to inquire how I am managing]." This may explain why a number of husbands were quick to respond "no one" when questioned, "Who looks after you emotionally?" (01, 02, 05, 06, 07, 08, 11, 13, 18). Support from health professionals seemed more vital to receive when informal support was unavailable and/or when husbands were more isolated.

While concerns for their wives' well-being and anger about incompetent care forced husbands to advocate and confront healthcare professionals, husbands believed that sharing these emotions could impact their wives' abilities to fight and keep going. They were convinced that they needed to be strong themselves; otherwise, "if you are not strong, it's hard for them to stay strong too" (14). Husbands protected their wives from their feelings by shielding them.

Shielding. The strategy of shielding was used to conceal their fears and feelings from their wives in order to emotionally protect them and to avoid marital conflict. Witnessing their wives' deteriorating health and decreasing functional abilities was emotionally difficult for husbands; however, they did not want to share these feelings with their wives. They used a combination of approaches to shield their emotions from their wives, such as: (a) disguising their true feelings: "I don't want her to see me sad because then it's going to make her sad. So you kind of gotta keep a smile on your face most of the time" (14); (b) counteracting their wives' feelings so that when their wives were "frustrated,…[they] tried not to be frustrated" themselves (15); and/or (c) treading lightly to avoid unpleasantness, saying the wrong thing, or expressing their feelings the wrong way.

Shielding their emotions was also achieved by being tactful, calm, and patient when discussing emotionally laden issues such as death or the uncertainty of getting a kidney transplant. Issues related to death and dying were openly discussed by nine of the couples (01, 03, 05, 06, 07, 12, 16, 17, 18), whereas, in three couples the wives remained silent (08, 09, 10). In these situations, it may have been that the wives were shielding their own emotions from their husbands in order to protect them. When death was discussed by wives, husbands empathized with their partners' thoughts, sometimes thinking about how they might react if the situation was reversed. However, thoughts, beliefs and fears about death and dying were rarely voiced to their wives, to protect them from more suffering.

Shielding their emotions was not always easy or possible especially in situations where husbands experienced frustration and resentment about the impact of the illness and treatment regimens on their social lives and sexual intimacy. In these situations, feelings were not verbally expressed to wives, but rather conveyed by using an escape-avoidance type of behavior such as "walking away" (06), "doing hobbies" (13), or "I kind of put one ear out and the other one just goes deaf. I really don't concentrate on what she has to say. I do my crossword puzzles. I've tuned out. I don't want to hear about it" (13). Although husbands worked hard to protect their wives from their feelings, they did show how much their wives were valued as wife, mother, and someone whose opinion and involvement still mattered. Husbands engaged in attending to their wives' voice to make them still feel appreciated and important in their lives and homes.

Attending to their wives' voice. Attending to their wives' voice involved listening and consideration of their wives' wishes, input, and preferences before the husbands responded or decided on a course of action. They achieved this by using two strategies: maintaining her cherished identity and accommodating her wishes.

Maintaining cherished identity. Husbands maintained their wives identity in the family by making a conscious effort and decision to bolster their wives' sense of self, to validate that their input mattered, and to keep them involved in family decisions, child discipline, meal preparations and/or chores when the wives wanted or in ways that were still possible for them to engage in. For husbands, the two most important goals in maintaining cherished identity were to protect their wives from feeling useless, invisible, or diminished and to let them know that they still had important contributions to make to the family and their relationship. One husband explained:

> I always ask her what she would like to eat, "Do you like to have a chocolate cake or all bran muffins?" I'll get the recipe book out and she'll come over and tell me "Put this and put this in that tray." You know? That's important. I let her do that to make her feel she's helping. I don't go and tell her to sit down, you know, knowing I can do it myself. That would not be right. (09)

In the case of three couples who were experiencing marital difficulties (04, 06, 13), the women's opinions were sometimes ignored: "I've gone to see my relatives… I just do it. [Wife's name] doesn't like it but, hey, it doesn't matter" (13). However, these husbands would readily cancel or postpone their plans if their wives were unwell.

Cherished identity was also maintained when husbands stepped back and reduced their involvement, particularly in activities which their wives had held responsibility for previously. Stepping back required husbands to be attuned to their wives' verbal and nonverbal cues. Husbands were concerned that if they persisted in offering assistance or doing for their wives when their help was not needed or wanted, they risked irritating their wives by interfering and making them feel inadequate. Rather than completely take over, the husbands assisted as needed as one husband stated "She does the wash and folds the clothes, so that's her job, but I carry the basket of clothes upstairs because it's too heavy for her" (03). Decisions about who would carry out certain responsibilities in the home were mutually agreed upon through discussion. When women were not feeling well, their husbands readily took over until their wives could resume the activity. In situations (04, 13) in which the marital relationship was strained, the husbands tended to make independent decisions regarding their wives' readiness to resume pre-illness roles:

> She had stopped driving so I said, 'You either start driving again, or I get rid of the car.… It was kind of like 'Get off your buns and get going. Stop feeling sorry for yourself.' So I kind of had to force the issue. (13)

Maintaining their wives' cherished identity provided opportunities for couples to preserve normalcy and familiarity when some of the pre-illness roles were resumed that had existed over the course of their marriage. When the women could participate, it reassured the husbands that their wives' health was improving or at least was being maintained. A second strategy to attend to wife's voice involved <u>accommodating her wishes.</u>

Accommodating her wishes. Husbands made an effort to accommodate their wives after starting dialysis; they seldom refused any of their requests. Accommodating her wishes provided husbands with a way to buffer a wife's suffering and enrich her life with joy, and it also benefitted husbands by allowing them to build memories and minimize regrets:

> I know that anything could happen to her at any time. I feel that I've done everything I can to make her happy. I've seen a lot of people say 'What if I would have done this? Why did I do this?' I don't want to do that. I want no regrets. (07)

Women's requests varied in nature from being simple to complex, free of charge to costly, and/or requiring little to extensive planning. Ways in which husbands accommodated their wives' wishes included: (a) taking part in activities that mattered to their wives but that they didn't particularly enjoy, such as playing bingo (03); (b) doing things around the house when the wives wanted them done instead of when it was convenient to them (06, 07); and/or (c) spending time with their wives (01, 05, 14, 15, 16, 17). For some husbands granting their wives' wishes had financial and/or personal implications. One retired husband had to resume work on a part-time basis to purchase a cottage his wife requested: "My wife said, 'We don't know how long we're gonna have as far as the time of life goes. So I would like to have a cottage…. It was just something that I had to make happen" (01). Despite the extra income, he was contemplating filing for bankruptcy, something he was desperately trying to avoid so he could hold on to the cottage. Another husband (07) referred to "going overboard to accommodate her wishes" because he was cognizant of the fact that dialysis treatment would not sustain life forever and he wanted to make her life as pleasant as possible. There were also simpler ways that husbands accommodated a wife's wishes, such as getting her a snack in the middle of the night; taking her for a drive when there were more pressing issues to address and lifting the ban on forbidden food so she could enjoy a treat. One husband set limits on the type of wishes he was prepared to grant, especially if it meant more responsibilities for him: "She asked for a dog but she doesn't do much around the house so how is she going to look after a dog. I sure don't need that added responsibility" (13). Some husbands' reluctance to accommodate their wives wishes was due in part to their lack of time or energy. In order to free up some time and streamline their energies to focus on their wives, the husbands engaged in concentrating on daily goals and simplifying life.

Concentrating on daily goals. Husbands concentrated on daily goals by pacing themselves to manage the demands of the illness and treatments. The extent to which husbands concentrated on daily goals varied according to their wives’ health. Husbands of women who had recently started dialysis and/or who were debilitated were more likely to concentrate on daily goals and hold future plans in abeyance: “There is a lot of uncertainty that I’ m dealing with on a day-to-day basis too...She can be feeling well one day but you don’t know what the next day’s going to be” (06). Concentrating on daily goals was not easy and the men often wished to return to more predictable and stable lives. Three strategies assisted them to concentrate on daily goals: taking it step-by-step, bit-by-bit, refraining from looking at the big picture, and/or living each day fully.

Taking it step-by-step, bit-by-bit. Because of the unpredictable nature of their wives’ health, the husbands tended to go with the flow to deal with uncertainty. It required flexibility in timing of tasks or activities, as well as spontaneity to make changes in the type and extent of involvement in roles/responsibilities or pursuit of plans or activities: “You have to adapt to circumstances as they come. Concentrate on one thing at a time and wish for the best and go from there” (18) and “take things as they come, bit-by-bit, otherwise it’s too overwhelming” (04).

Refraining from looking at the big picture. Husbands avoided thinking about what the future might hold because it was too overwhelming or frightening. This strategy was used by husbands who were aware that other dialysis patients had experienced further disability or death. Most were unsure about how they would manage without their wives’ presence in their lives; and for husbands with young children, thinking about life without their wives was devastating. In contrast, five husbands (04, 06, 12, 13, 18) had accepted death as an inevitable and natural part of life and perceived that there was nothing to be achieved by discussing, thinking, or worrying about something that was out of their control. Spiritual beliefs facilitated their acceptance of death and they derived comfort from their belief that their wives would no longer suffer (01, 15, 16). One husband shared: “I don’t worry about her dying, because the faith that we have, we believe she’ll be in a better place where there’s no suffering” (01). Although, fear of losing their wives weighed heavily on their minds, predeceasing their wives was more distressing because they were worried about leaving their wives and children alone to cope both emotionally and financially.

Living each day fully. Five husbands said that they lived each day fully by making the most of each day, savoring the present with their wives, and being inspired to find meaning and fulfillment in what each today had to bring. Uncertainty regarding their wives' health and the long-term ability of dialysis to sustain life prompted these men to live each day fully: "I know that tomorrow [wife] may not be around. So you know I want to share what I can with her now, today" (07). Living each day fully and refraining from looking at the big picture provided husbands with some control over and emotional protection from a possible shortened future with their wives. Concentrating on daily goals required that husbands make "sacrifices… in order to do that" (07), which they accomplished by simplifying their lives to accommodate the limitations, restrictions, and changes imposed by the illness.

Simplifying life. Simplifying life is a process of scaling down or giving up activities, events, and cherished pursuits that had once mattered to the husbands in order to maximize their availability to address their wives' needs and accommodate changes imposed by the illness. They gave up, set aside, or cut back on activities out of necessity to simplify life. The extent to which they needed to simplify their lives varied from occasionally or temporarily to permanently, and they used three strategies to do so relinquishing, putting on hold, and/or curtailing activities.

Relinquishing. This strategy entailed giving up past activities husbands had done alone or with others before dialysis was initiated. They gave up activities that required them to be absent from their homes for hours to days at a time, such as traveling for vacations or work and some social events (01, 03, 05, 06, 07, 11, 12, 13, 16). Eventually 10 husbands discontinued traveling on both short and long trips due to the progressive deterioration in the women's health (01, 02, 03, 04, 05, 06, 08, 11, 12, 18): "We have traveled all over the world and we biked for nine days in Holland, which means that … she had energy in her day. She doesn't anymore, so we can't travel" (05). Moreover, they gave up doing what they had done annually with friends for years, such as skiing trips and curling.

Although two women on peritoneal dialysis (12, 17) were in stable health, they were reluctant to travel because the quantity of supplies they needed to prepare and transport took too much space in the car. In some situations giving up traveling also meant abandoning social activities they had enjoyed for years as a couple. They refused to schedule social activities in advance because it was too disappointing when they couldn't attend the event. In addition, the rigid dialysis schedule severely limited their contact with friends, thus further contributing to their social isolation. The wives' fluctuating health status restricted their husbands' ability to travel. One husband discovered how unpredictable the illness can be: "It was supposed to be a two-day trip to Ottawa, but I ended up coming back in the evening because [wife's name] had been sick" (15).

Putting on hold. Being uncertain about how their wives would respond to dialysis treatment and wanting to be there for them in times of need, five husbands temporarily put on hold their work-related responsibilities for varying periods of time that ranged from six weeks to three months, depending on their wives' health and the support from employers (07, 13, 14, 15, 16, 17). Husbands could not afford to leave their employment for extended periods of time because their financial contributions were necessary to pay the bills and provide for their families. Putting on hold was achieved by negotiating a leave of absence from work for varying periods of time prior to or shortly after their wives started dialysis: "When she did go for her dialysis, I stayed at home for the first five or six months ... in case she needed me" (13).

Curtailing. Husbands restricted the length and frequency of time spent doing pleasurable activities alone or with others. They cut back on hobbies, exercise, volunteering, rest, reading, private time alone, and socializing when their wives started dialysis and when their health deteriorated. Husbands restricted their own activities outside the home because they did not feel comfortable leaving their wives alone for fear that something bad would happen while they were away. In other cases, a sense of guilt or neglect prevented husbands from leaving their wives alone. During times when their wives' health was relatively stable, some husbands (05, 07, 09, 12, 13, 14, 15, 18) would take advantage of these moments to resume certain types of activities to replenish themselves; albeit they only did so for short periods of time and if someone else could watch over her during their absence. With the exception of a few husbands (01, 02, 06) whose wives were severely debilitated by kidney failure and other co-morbidities, most activities had to be simplified only temporarily.

One major negative outcome of simplifying life was isolation from friends: “Our friends don’t come up to us and say ‘We’re going someplace, would you guys like to come with us?...’We kind of miss out” (13). In addition, those who were retired could no longer dream of being free to travel, socialize, and pursue interests: “Not quite what I expected retirement to be, not at all, no. If this what the golden years are all about, then there’s not much gold there, that’s for sure” (18). With the exception of three husbands (01, 02, 06) whose wives were severely debilitated by end-stage renal disease and other co-morbidities, most husbands were able to resume some pre-illness activities. Simplifying their social, recreational, and work-related activities freed up the husbands’ to focus on their wives, but it was insufficient to accommodate all the changes imposed by the illness. They also needed to create routines to establish order in their lives.

Summary Stage 3: Centering Life on Their Wives

Following the second stage of involving oneself, husbands shifted their efforts towards centering life on their wives to address their wives’ needs and accommodate changes in their daily lives. The wives’ physical and emotional well-being and needs took precedence. During this stage, husbands discovered the magnitude and types of changes, disruptions, and limitations the illness could impose on their lives. Husbands were overwhelmed by the multiple roles and responsibilities they had to assume and manage. Centering life on their wives required husbands to provide illness related care, engage in protective support, attend to her voice, concentrate on daily goals, and simplify their lives. Their commitment to center life on their wives was motivated by strong bonds of affection and their desire to be supportive in sickness and in health. Providing illness-related care including dialysis, medications, and attending to the dietary regime were duties for which husbands had limited to no skills. However, their desire to support, assist, and care for their wives inspired them to acquire the essential knowledge and skills to take on these responsibilities. Husbands intimate knowledge of their wives and understanding of their wives’ responses to kidney failure and dialysis positioned them well to provide <u>protective support</u> and <u>attend to their wives' voices</u> with competence and confidence.

The illness and its treatment demands required husbands to re-structure their daily lives. They were overwhelmed by the many changes that permeated their lives and in response, <u>concentrated on daily goals</u> to pace and focus themselves on the tasks at hand. Strategies to <u>simplify their lives</u>, such as relinquishing, putting on hold, or curtailing activities, events, and/or interests, allowed husbands to protect their time and energy so they could <u>center life on their wives</u>. Regardless of the type of dialysis, centering life on their wives came at a price. Husbands experienced exhaustion, isolation, sleep deprivation, and/or financial difficulties and more so when their wives were more debilitated. In situations in which the marital relationship appeared more strained, <u>simplifying life</u> and <u>attending to her voice</u> were more difficult. Older husbands seemed to be least affected by the changes because they had already modified their lifestyle, but they had to learn most of the skills associated with <u>providing optimum nutrition</u>. While the majority of illness-related responsibilities were new to husbands, other roles were extensions of their involvement. The husbands all demonstrated the abilities and determination to learn technical and troubleshooting skills and developed their problem-solving, advocating, coordinating, and decision-making skills in innovative ways. Over time, dialysis treatment did improve the health of most women sufficiently for their husbands to <u>strive to achieve balance</u> in their daily lives while continuing to some extent to center life on their wives.

Stage 4 – Striving to Achieve Balance

Moving from the third stage of <u>centering life on their wives</u> to the final stage, <u>striving to achieve balance</u>, was a subtle transition. This stage represented a shift in focus from mainly addressing their wives' needs to regaining some semblance of normalcy and quality of life for themselves, their wives, and their families. <u>Striving to achieve balance</u> was contingent on the women's experiencing some stability in their health and was inspired by a need to regain some control over their lives. One husband whose wife had been on dialysis for about eight years explained:

> It [illness/dialysis] may dictate, but it's important that it doesn't control you.... Then you lose so much of your life because all of a sudden everything revolves totally

> around the illness. We've tried not to do that. It is important to our family because if you let it control you, then not only does it control you physically, but then it also controls you emotionally as well. (15)

A complete state of balance was impossible because the women experienced good days and bad days. They described balance as living as well as possible within the constraints imposed by end-stage renal disease and its treatments. Therefore, achieving balance was described as a state of mind: "That's a huge challenge that we have to create that balance. Balance family, balance work, balance the illness. And you come to that balance then you have a whole different attitude towards it [illness and dialysis]" (15). <u>Striving to achieve balance</u> was an on-going process. While husbands engaged in all or some of the following five sub-processes of <u>creating routines</u>, <u>bringing others on board</u>, <u>replenishing</u>, <u>hoping for a kidney transplant</u>, and <u>finding positive meaning</u>, they sometimes returned temporarily to earlier stages to address unfamiliar or recurring health problems.

Creating routines. <u>Creating routines</u> assisted husbands to bring order, structure, and predictability into their chaotic life. Any previous routines they may have had in their lives no longer fit with their new reality. In some situations where a routine had never been part of their lives, a routine was now a necessity: "Before we were pretty impulsive… That was kind of the lifestyle that we always had but we can't do that anymore. So needing to have a routine was a big adjustment (17).

They created two routines, one to manage the demands of dialysis and the other to accomplish activities of daily living. While the dialysis routine had to remain constant, their daily routine could be modified to add an unplanned activity or postpone or cancel planned activities. Developing both routines was a trial-and-error process that occurred over time and required patience and flexibility. The longer women had been on dialysis and/or the more stable their health, the easier it was to create and sustain both routines.

Dialysis routine. Regardless of the type of dialysis women were receiving, nine husbands had to develop a <u>dialysis routine</u> to ensure that their wives received dialysis at the prescribed time (02, 03, 05. 06, 08, 09, 12, 14, 18). Husbands needed to plan, sequence, and coordinate various activities that needed to be done before leaving home for hospital hemodialysis or doing peritoneal dialysis at home. The routine included a combination of the following activities: preparing and consuming meals before and after dialysis, getting the car ready, and/or assessing vitals/weight and setting up the equipment for peritoneal dialysis. Many of these tasks needed to be completed simultaneously or in close succession; therefore, it was necessary to coordinate these activities.

The extent of husbands' involvement in the dialysis routine varied according to the women's health and type of dialysis treatment. Six husbands were totally responsible for the dialysis routine (03, 08, 09, 11, 12, 18), while five collaborated as a couple, which was more consistent with their marital style of each partner having specific duties (01, 05, 10, 15, 16). One husband described the situation: "My wife makes a picnic supper to eat in the car on our way home and I get the car ready before leaving for dialysis" (05). A timeframe for waking up and going to bed was dictated by the type and schedule of dialysis. Hospital hemodialysis sessions took place on the same days three times per week for each woman; however, the time slot for these sessions could either be at a fixed time or at an irregular time in the morning, afternoon, or evening. In contrast, husbands of women on peritoneal dialysis referred to the ritual of putting their wives on and taking them off dialysis. Regardless of the type of dialysis, the schedule could mean an early rise and lunch, while supper and bedtime could occur much later than their previous pattern. A few husbands got up at least one hour before their wives to get themselves ready first so they could be available to provide assistance to their wives (03, 08, 09, 10, 11).

Having to organize their routines around the dialysis schedule had implications for the planning and preparation of meals: "We're due here [dialysis unit] around one o'clock so we're talking about what we are having for lunch around ten o'clock. We have to prepare lunch easily an hour before takeoff time. So we're thinking about meals ahead of time" (05). Various approaches to develop a routine for preparing meals were used, such as cooking extra food to have as leftovers the following day or for freezing for a later date, purchasing a slow-cooker (05, 08, 09), and/or using pre-packaged frozen meals, all intended to lessen their load of preparing meals after a long and tiring day of traveling or following peritoneal dialysis.

For husbands of women on hospital hemodialysis, the routine also included getting their car ready in the morning or the evening prior to leaving for dialysis. In addition, for those who traveled long distances, they had to keep a close watch on the weather to guide their decisions about whether to return home or stay overnight after dialysis as this husband explained: “Twice we packed our suitcases in case we had to do an overnight … So we always have to plan in anticipation of whatever might happen” (05). The dialysis schedule provided a framework around which other activities or events needed to be inserted: and therefore, they also had to create an everyday routine.

Everyday routine. Carrying out a routine for everyday activities consisted of assigning priorities and coordinating home and work responsibilities, errands, and/or appointments around the dialysis schedule. When dialysis was initiated, women were unable to continue their household responsibilities as a result of recuperating from surgery, experiencing debilitating symptoms, and/or being unable to lift due to the presence of a fistula or peritoneal catheter. Husbands took over all household responsibilities until their wives regained some stability in their health. Some of the older men (01, 05, 06, 11, 12, 18) either had never done housework before or had occasionally assisted their wives. They had to learn how to carry out new household responsibilities. In some cases, taking over all household chores was a complete reversal of roles for husbands.

Husbands who traveled short distances to access a hospital dialysis unit completed housework, errands, or appointments while their wives dialyzed or slept (01, 03, 05, 08, 18). In contrast, husbands who traveled longer distances or whose wives were on peritoneal dialysis had to get everyday activities done between dialysis sessions. Some men designated specific mornings for doing housework, whereas laundry or grocery shopping activities took place on alternate days to make their workloads more manageable. Husbands with young children were responsible for getting their children ready for school, especially if their wives’ hemodialysis sessions were in the early mornings.

Husbands who were employed altered their work schedule to fit the dialysis and everyday routines. Support from their employers and working colleagues was instrumental in allowing them to: (a) leave work early or mid-shift to accompany their wives to doctors’ appointments, follow-up visits, or when “issues come up with [children]” (15, 16, 17); (b) work on weekends to drive their wives to dialysis during the week; (c) complete their “work at home” rather than at the office (15, 17); and/or work in the evenings or on days off “I would take time off during the day and then I would come into the office in the evening or else I would work at home" (15). A few (07, 17) described reorganizing their work days to include frequent calls home to check up on their wives after hemodialysis. Work colleagues also provided emotional support when they inquired "about [them] about [their] wife, then you know that they care. Now that's big" (15) or when they offered to take over some of the husbands' work to ease their load (07, 15, 16, 17). A few husbands (07, 13) did not want to discuss their life situation with colleagues because they didn't want to bother them: "They don't want to hear my woes and toes and all that good stuff. I don't want to be a burden to them, so I don't talk about it" (13). Altering their work was not without consequences. It impacted on opportunities to further their education (07), get advancements or promotions, and/or further develop their skills (07, 13, 15, 16).

Although retired husbands did not have to coordinate a full time job, they nonetheless considered "being concerned about dialysis and about my wife's health [to be] a full-time job" (05). Retired husbands tended to be as busy as those who worked full or part-time because their wives were more physically and/or cognitively debilitated. They needed to provide more assistance with illness-related care and routines. Other significant differences emerged between employed and retired husbands. Most husbands who held full or part-time jobs commented that the opportunity to work outside the home had important social and personal benefits. For example, in some cases (01, 07, 13) work provided them with "diversion so I don't have to dwell so much on my wife's health. It's a source of distraction to a certain extent, gets me out of the house" (01), and a venue to socialize (01) as well as an opportunity to have time for themselves (13, 15, 17) and receive support from colleagues (01, 03, 07, 13, 15, 16, 17). In contrast, although retired husbands might have had more time on their hands, they thought "that it's almost a full-time job being concerned about dialysis and about my wife's health" (15). Most retired husbands wondered how they would ever manage to juggle multiple roles and responsibilities if they also "had a steady job. It would be difficult" (03).

It was not uncommon for husbands to experience disruptions to their everyday routines due to their wives' fluctuating health and responses to dialysis treatment. When women felt well post-dialysis or between dialysis sessions, this resulted in the husbands and/or couples engaging in pleasant and unplanned activities: "Sometimes after dialysis she'll say 'I don't feel like going home.' So we'll go to Walmart, look around…and come home at almost eight o'clock. We're tired but that has been a good day for us" (01). In contrast, when women felt unwell or experienced a health crisis, their everyday routines got disrupted and any planned activities had to be cancelled, suspended, or delayed. Therefore, flexibility was important in order to deal with this "unpredictable disease" (010) and to minimize disappointments from not being able to pursue an event they had looked forward to for weeks or months. Some husbands resisted planning activities ahead of time and instead <u>concentrated on daily goals</u> because "You don't know what the next day is going to bring" (02).

The husbands invested a significant amount of time and effort to organize both dialysis and everyday routines which they believed contributed to improving their wives' overall health. Positive outcomes of developing routines were associated with the repetitive nature of various activities which created stability and predictability in their lives because "We know what is going to happen on dialysis days now. There is not as many unknowns but more predictability" (15). Their newly developed routines made some husbands slow down and pace themselves to do things they had never done before, such as enjoying breakfast, "sitting down with a coffee and splitting a newspaper" with their wives after the children had left for school (17) or participating in their wives' cherished activities (03, 05, 10). While husbands were committed to doing their utmost to engage in both routines, they recognized a need to <u>bring others on board</u> to assist and to <u>replenish</u> their energy in order to sustain their efforts.

Bringing others on board. <u>Bringing others on board</u> required husbands to let others take their place or perform on their behalf certain roles and responsibilities. Being able to bring others on board was contingent on their being willing to recruit others to help and others being available to take on tasks. It was somewhat easier to accept when husbands realized that they did not have to do everything themselves and that it did not mean they were shirking their commitment to <u>embrace their transformed life</u>. Instead, it enhanced their abilities to address the issues that mattered most in their lives. Time was at a premium for husbands, and the price for engaging in multiple roles/responsibilities on their own exhausted most husbands and frustrated others. Some husbands did not recognize their own health needs as a legitimate reason to delegate tasks and responsibilities. Indeed, a few husbands did not delegate care or responsibility to others unless it was absolutely necessary. Others delegated responsibilities to family members, friends, and/or neighbors or purchased services. The extent to which they delegated varied and was related to the women's health and the accessibility and willingness of informal and helpful formal support. Bringing others on board was achieved by using two strategies: accepting assistance and recruiting assistance from others.

Accepting assistance. Husbands were receptive to receiving assistance for transportation, meals, and finances provided by family members, friends, neighbors, or their community members. Concerned neighbors and adult children offered to provide transportation to the women to dialysis: however, husbands were only comfortable accepting their offers if: (a) they could pay the drivers for the costs of transportation, (b) the trip also served another purpose for those doing the driving, (c) their wives' health was stable, or (d) they recognized the need to take a break and replenish. In contrast, some husbands were hesitant to accept offers of transportation because they did not want to impose on the person's time: "They'd have to hang around for six hours or whatever, it would make it a long day for them" (05), and their wives often experienced adverse effects from dialysis treatment. In fact, some husbands tagged along (05, 08, 11) fearing that something might happen to their wives during or after dialysis. They wanted to be there to watch over her: "I could have stayed home but my wife was having enough trouble that I didn't really feel I should leave her here on her own, so I went with her" (05). For some men, accepting and receiving help generated feelings of guilt (05, 06, 15) "because you feel like you are imposing on them (15). For another husband, it was difficult "to accept help because I`m not the type and feel like a bum. I was brought up with my dad that said 'you get nothing for nothing, you have to do the work'" (06).

Neighbors played an important role in assisting with meals. They dropped off meals for couples (04, 05, 06, 12) or for their children on dialysis nights (15). Such support always seemed to "come at the right time" (05), after driving in treacherous weather to dialysis and when their wives had experienced adverse effects from dialysis. It made them feel like they were "not alone" (12). Three communities held fund-raising events to collect money to assist some couples (06, 08, 10) with transportation costs. These husbands were overwhelmed by the generosity of others, most of whom they had never personally met. In three cases (06, 08, 09), the husbands had provided unpaid assistance to their neighbors and the neighbors were now returning the favor.

Recruiting others. Husbands also purchased or recruited others' help. Purchasing assistance was contingent upon financial resources and of services for hire. In addition, the use of purchased assistance required their wives' endorsement. Assistance requested from family members, neighbors, or healthcare professionals was requested for the following reasons: to deal with their wives' health crises, to make difficult decisions regarding their wives' care, to watch over their wives' during their absence, and to handle situations they did not feel capable of managing themselves. However, husbands were only comfortable requesting assistance for their wives rather than themselves or if neither partner could perform the tasks.

Because of their wives' unpredictable responses to dialysis or health crises, some husbands developed a contingency plan to obtain assistance from family members or neighbors. Adult children or neighbors had agreed to be summoned to provide emergency transportation to the hospital at any time. Being able to recruit others to assist their wives was reassuring: "J'ai des bons enfants. Le garçon, ou la fille a dit, 'Papa, faites-vous en pas; quelque chose arrive? On est là'. Alors ça, c'est réconfortant, de savoir que je peux me fier sur eux autres" [translation: "both my son and daughter have said if something happens we're there for you. So that's reassuring to know that I can depend on them"] (10). Unfortunately, a few husbands had to implement their plans and seek emergency care for their wives when they experienced distressing symptoms. Confident that their wives needed help but unable to persuade them, husbands sometimes had to make independent decisions about seeking assistance. One husband shared his experience of getting an ambulance for his wife:

> I tried to call an ambulance and she said, 'No don't call' but I called anyway. They [ambulance attendants] were here within ten minutes, because what can I do? I mean I couldn't give her artificial respiration. The renal nurse told me I did the right thing to call 9-1-1 regardless of what [wife's name] said. (11)

While illness-related care could not be delegated to others because it required specialized training, household chores could be. Many husbands attempted to fulfill these responsibilities themselves, seeking help from others only when it became obvious that they needed assistance. Couples who traveled long distances to dialysis eventually hired someone to perform housekeeping duties: "We are delighted to have this gal help with the cleaning. She's still doing it and she's a real asset to us. We both like her" (05). In other situations, when both partners were experiencing health problems (01, 02, 03, 06), household responsibilities had become too physically demanding for them; and therefore, they either hired someone to help or community homemakers were provided free of charge: "Home care just got started and they will come in once every two weeks and help me with that sort of stuff. It's quite hard to do with my arthritis" (06).

Hiring someone to assist with household chores was contingent on the couple's finances and was not affordable to all, but could have been used by most. In addition, the decision to hire a housekeeper was made as a couple because husbands did not want to infringe upon their wives' independence. Some husbands reported that their wives had mixed feelings about having someone else do the housework. Some women welcomed the service, whereas others, particularly those who were younger, were less receptive, so their husbands waited until they were ready:

> [Wife's name] wouldn't even hear of somebody else coming in and doing some housework.... It's just over the last year, she kind of succumbed to being tired and then I managed to get somebody in once a week, but that was a struggle. She's always been you know the one that runs the household (17).

Purchasing pre-made meals was another approach used by two husbands (02, 06) whose wives were either completely bedridden or cognitively impaired. Meals were purchased from local services to supplement their own meal planning: "The VON puts out these frozen meals for about five dollars a meal which is cat's meow. And there's a variety too. So it's helpful" (06) or "meals on wheels for five fifty a meal" (02). Sometimes meals made specifically for a renal diet were purchased. The drawback of purchasing the services of a housekeeper and/or meals had to do with extra costs. For some men such services were unaffordable. One benefit of delegating to others, however, was that it assisted husbands to free up some of their time to replenish.

Replenishing. Replenishing refers to taking time to pursue activities, events, or interests that bring pleasure, provide relief, and distract the mind. It is a process of finding physical and mental space to temporarily experience ordinary life separate from the demands of the illness/treatments. Replenishing included resuming activities previously relinquished, set aside, or curtailed and/or finding new ways to nurture personal physical, emotional, intellectual, spiritual, and social needs as individuals, as a couple, and community members. Husbands also recognized the necessity to replenish based on their beliefs that failing to do so would compromise their physical and emotional capability to continue to provide support to their wives. One husband explained: "I've got to look after myself. So that I can be here to look after her [sobbing]" (09). Although all husbands recognized the importance of caring for themselves to assist their wives, replenishing was not an option for all, especially those who lived with women whose health was more compromised (02, 06) or who lacked informal support or who could not legitimize their need to replenish.

Engaging in replenishing activities sustained husbands' commitments to embrace their transformed life. Finding time to engage in activities by themselves or with friends required making difficult choices that often generated feelings of guilt. The ability to replenish varied; and occurred sporadically according to the following conditions: the women's health, their marital history, and formal and informal support. Replenishing was achieved by using two strategies: getting away from it and restoring togetherness.

Getting away from it. Taking part in activities that provided a "break away" alone or in the company of others provided distraction from the pressures and allowed husbands the opportunity to experience a more normal life. Some husbands built activities into the dialysis and daily routines, such as getting up one hour before the family to have quiet time (17), walking to and from work (17), resting while their wife dialyzed (01, 03, 15), and/or engaging in prayers late in the evening (15). Generally these types of activities were solitary. For others, getting away involved social activities such as spending a day golfing (07), fishing (006), riding a motorbike (13, 14) being involved in a church choir (01) or volunteering on a committee (02, 05, 12). Husbands agreed that getting away provided opportunities to care for themselves and to regain some normalcy in their lives: "I need those activities; they sort of provide balance in life" (18). Husbands' ability to make plans was limited by their wives' unpredictable health, which was frustrating because it meant "having to change plans at the last minute when I am looking forward to going out kind of wears me down a bit. Sometimes, I resent not being able to do things when I want to do things" (13). Husbands living with women who were more physically or cognitively debilitated (03, 06, 11, 18) had to reach a turning point in their lives before appreciating their need to replenish. Whether this turning point happened gradually or in one defining moment, they realized that getting away was important. For others, the onset of physical health problems triggered their need to replenish (05, 12, 16). One man recounted: "I was getting more tired, run down, just not properly looking after myself because I was focusing so much more on my wife. I got to the point where I realized that I needed to take more time for myself and rest" (15). Some men were more inclined to replenish when they were able to link the benefits of engaging in self-care activities with the prevention of negative emotional outcomes: "Personal activities such as skating or playing pool once a week… I must do if I want to function right…. Otherwise I would go berserk. It gives me a bit of balance… a little boost. It's like a pep pill" (18). By getting away, husbands were able to engage in self-care activities.

Despite the benefits of getting away, some husbands were reluctant to leave their wives alone. Concerns that something might happen to them during their absence made it difficult for three husbands (05, 07, 12) to get away: "I'm afraid she'll lose her breath and that she would die and I wouldn't be there for her [crying]. So, I need to stay home to keep an eye on her" (09). Feelings of guilt also acted as a powerful deterrent (03, 05, 06, 08, 09, 10, 11, 12) to getting away, as one husband explained: "It's hard to go out without her because it may seem like I don't give a hoot and that I`m dumping her and just going on with my life, which I can't do, you know?"(06).

Support and encouragement from their wives to get away to enjoy activities and pursue personal interests influenced a few husbands (07, 12, 15) to take time for themselves, but they only did so if their wives' health was stable: "First of all that she wants me to go back to curling and, secondly, that in my judgment it is safe to leave her through the day and even for an evening, but I wouldn't want to leave her overnight" (12). They only allowed themselves to be away for short periods of time and their thoughts often returned to their wives. In some cases, the women imposed restrictions on their husbands' pursuit of activities, especially when they were not feeling well: "Ma femme ne veut pas que je la laisse toute seule si longtemps, donc j'ai coupé mes marches" (translated:"I've had to cut down on my walking, she doesn't want to be left alone for any length of time”) (08). For other husbands, pursuing activities alone rather than as a couple reminded them of the many changes that had transpired in their lives. Pursuing activities as a couple was possible when women were feeling well which allowed them to restore togetherness.

Restoring togetherness. When couples resumed activities they had previously done as a couple or pursued new interests together they were restoring togetherness to maintain their emotional closeness or to reconnect emotionally. Certain activities required a great deal of planning, while others could be done spontaneously as part of their everyday routine, depending on the women’s health status. Restoring togetherness occurred when they could travel on day or extended trips. The ability to travel out-of-province for extended periods of time was contingent on women experiencing stable health, couples having the financial means to pay for hemodialysis treatments, and husbands being retired. Retired husbands were more flexible to take whatever time was available for dialysis and comply with the regulations of the units. Husbands took charge of making all necessary arrangements for out-of-province traveling which often required months of pre-planning to secure a dialysis facility that could accommodate treatment at an affordable cost. Only a few couples could afford to travel since “It cost about five hundred dollars per treatment and that’s considered cheap, plus the cost of blood work for going overseas” (07). One husband felt adamant that if couples were able to travel, “then it should all be paid for as far as I am concerned. There are a lot of patients that can’t travel that have dialysis so those of us that can travel, it should be paid” (07). Traveling did not always work for all couples, especially when they had to rely on their provincial department of health to make arrangements for out-of-province dialysis. In addition to cost, their wives’ health made it difficult to plan trips very far in advance. Rather than risk planning something that would not become a reality, they channeled their efforts towards making day or weekend trips.

Women’s reluctance to dialyze in other units also influenced their willingness to travel: “I went to Disneyworld with our son last summer, but she didn’t feel comfortable getting dialysis done in other centers, so that definitely affects our ability to travel as a family” (16). Families with dependent children (13, 14, 15, 16, 17) traveled without wives/mothers, provided the women’s health was stable and/or they could recruit someone to drive their wives to dialysis or watch over them during their absence. Resuming pre-illness activities as a couple provided opportunities to nurture their relationship, and this was particularly important for those who were experiencing marital difficulties: “Going to Newfoundland last summer on motorbike brought back some of the, I don’t know how would you say, some of the niceties about being married and going places and doing things as a team” (13). When activities were enjoyed as a couple and affection was rekindled, there was a tendency to plan similar activities in the future. When out-of- province or out-of-country dialysis was limited or unaffordable or traveling with their wives was not possible because of health issues, couples found alternative ways of spending time together to <u>restore togetherness</u>, such as going for drives in the country, going out for tea, shopping at the mall or going to the movies. One couple resumed swimming together: “We used to swim a lot and we hit a thousand miles swimming not very long ago. It’s a great thing, isn’t it? And she can handle the swimming” (05). In a few situations, the type of pre-illness activities couples had participated in influenced the type of dialysis treatment. If they could retain some of their valued activities, then their lives seemed less confining.

In contrast, there were couples who were not able to <u>restore togetherness</u>, especially when women were bedridden and/or cognitively debilitated (01, 03, 18). Husbands missed spending time together and/or socializing with other couples: “She is not interested in social activities now. I would enjoy going out more but she’s too tired or can’t walk any distance” (01). Husbands of wives who had been on dialysis for short periods of time remained hopeful that they would resume pre-illness activities once their wives’ health had improved: “If she can get back some strength in her legs we may go dancing yet! [laughs]” (06).

A negative consequence of not being able to <u>restore togetherness</u> was isolation “It’s her and the two animals. So I find that I`m living an illness-centered existence in some ways. A couple of neighbors drop in once in a while but that’s it” (06). Not being able to resume activities and interests previously pursued as a couple was also a harsh reminder of the extent to which their lives had been changed by this illness and brought a sense of urgency for their wives to receive a kidney transplant, a situation over which they had no control. Nonetheless, the uncertainty did not dampen their optimism and hope that a kidney transplant would occur someday to allow them to reclaim their lives.

Hoping for a kidney transplant. Husbands hoped that their wives would experience improved health and quality of life and regain a sense of normalcy in their lives and have a better future with a kidney transplant. Not all the women met the criteria for a transplant; and even among those who were eligible, a few husbands (07, 13, 16) stated that their wives were hesitant about the prospect of a kidney transplant. Fearing they might die or reject the transplant were factors that weighed heavily on the minds of the women. In addition, dreading the undesirable side effects of anti-rejection medications was another factor that dampened women's enthusiasm, especially for those who already had firsthand experience with these complications (08, 14, 15, 16). Discussing these fears as a couple with renal specialists helped them to understand the potential risks and benefits of a transplant. Despite the potential drawbacks of a kidney transplant, the benefits, even if short-lived, were far more appealing. Some husbands perceived that a kidney transplant would give them back their life, whereas dialysis deprived them of their life. Having a shared vision of a better future, one that would allow them to recapture some of the past and resume pre-dialysis pursuits such as being spontaneous in their outings, traveling overseas, socializing with friends, and more importantly freeing their wives from "being tied to a machine three times a week" (13) sustained their hopes that their wives would eventually get transplants. When the women's health was relatively stable, waiting for a kidney transplant was more bearable compared to times when the women (07, 15, 16, 17) had less remaining options due to poor vascular access or filtration problems. The sense of urgency to get a kidney transplant is apparent in this husband's voice:

> We've noticed that there are more degenerate side effects that go along with the dialysis now because she's not able to filter well enough and she's gets sick more often. Every time I see her sick there's always that moment of clarity, that reality that comes and says, "Oh my God, if she don't get a transplant soon, I'm gonna lose her. (17)

At the time of the interviews, women had been waiting an average of five years for their transplants; and for some husbands, their lives were on hold until the transplant occurred.

The phone was considered their "life-line" for receiving news about an available kidney, and missing the call was devastating for one husband: "We were gone for the weekend and on the Saturday didn't we get a phone call for a kidney? And we missed it. I think it was harder on me because we had lost an opportunity to get the freedom we've been looking for" (13). Some husbands had been tested to evaluate their suitability as a donor and discovered they were not a match. Others were waiting to be tested in the near future. Although, some adult children had offered to be tested, couples had made the decision not to burden their children because they had their whole lives ahead of them.

As much as the husbands were looking forward to the freedom that a transplant would bring to their lives, they knew "the sad part is that somebody had to die to do that" (13). In situations in which age and co-morbidities precluded some of the women (01, 02, 06, 08, 09, 10, 11, 12) from being a suitable candidate for a transplant, the husbands were generally accepting of their situation. They were grateful that dialysis improved their wives' health.

Finding positive meaning. Finding positive meaning is a strategy that buffered the negative impact of changes in husbands' lives as a result of living with wives on dialysis. Finding positive meaning consisted of appraising and espousing a positive attitude towards some of the changes in their lives and experiencing personal changes in their expectations, meaning, and outlook on life. Finding positive meaning was realized by being positive and experiencing personal growth**.**

Being positive. Husbands made a conscious decision to look for and find something positive in their situation. Six husbands (01, 03, 07, 16, 17, 18) shifted their mindset and attitudes about perceiving the multiple changes they were experiencing in their lives from being insurmountable to being challenges they could tackle. As one husband commented: "I know it's a situation that can't be changed... so I adjusted my mind to the limitations it creates and focused on making life as pleasant and meaningful as possible" (18). Witnessing improvements in their wife's health since starting dialysis helped them to be positive, optimistic, and hopeful (01, 03, 05, 06, 09, 10), especially when they could "see the light at the end of the tunnel with her dialysis, her fluid had gone down and her legs are getting smaller. It's a positive thing for a change" (06). Comparing their situation with that of others whom they considered to be less fortunate helped them to perceive their situation in a more favorably way: “There is always somebody worse than us. It keeps me going” (03). Focusing on what they had in life rather than what they had lost and not allowing self-pity, envy, or anger aided husbands to have a positive outlook on life. In some cases (09, 14, 15, 16, 17), their wives’ ability to deal with the impact of the illness and treatments strengthened the husbands’ ability to deal with their situation: “Anytime I start to think that things are tough, I just think of how she always seems to manage and cope. I get strength from her character (16). As well, when women acknowledged their gratitude for the assistance their husbands provided, it was valued but not expected: “She’s very conscious that I am playing an important role and she often thanks me, which is unnecessary because I want to help her” (12). Being positive was not easy to achieve and maintain especially when their wives’ health continued to deteriorate and/or when there was limited external support. In most situations, there was a co-existence of negative and positive thoughts and feelings about the illness and treatments.

Experiencing personal growth. Not only did the husbands experience changes that transformed their lives, but they also experienced personal changes and growth as a result of living with wives on dialysis. Seven husbands (01, 04, 05, 07, 09, 12, 18) developed new confidence and sense of worth in themselves from assuming multiple roles and responsibilities to assist their wives. One husband took great pride in his new set of skills of providing illness-related care, while others reported becoming more patient, compassionate, and/or caring (01, 03, 05, 06, 07, 08, 09, 10, 12, 14, 15, 16, 17, 18). Other husbands (01, 07, 15, 16) described experiencing an appreciation of what is really important in life, establishing different goals, and re-setting priorities:

> It [dialysis] makes me appreciate life a little bit more. Not necessarily that it’s good that she’s on dialysis, but it’s good that maybe our values have changed and our whole outlook on life is we see so many people that are go, go, go all the time and it’s all about money. For me what matters is that dialysis allows us to be together every day. (07)

Their first-hand experience of living with a wife on dialysis strengthened their understanding of how to help others and inspired them to share their experiences with others (07, 15, 17): “We’ve met with some couples to talk about what it is like to be on dialysis and what our life has been like. We don't give the impression that it's easy, but we tell them it's something that can be managed" (15). Finding positive meaning assisted husbands to balance difficult aspects of their lives with positive elements that mitigated some of the hardships of the illness and its treatment and enhanced husbands' courage to embrace their transformed life.

Summary Stage 4: Striving to Achieve Balance

The final stage of striving to achieve balance is a process of normalizing life within the constraints and changes imposed by the illness/treatments. Balance in their lives was difficult to achieve and maintain because of their wives' health. These husbands attempted with determination, commitment, and ingenuity to adjust their expectations, change what was changeable, and control what was controllable. They understood that life would never be the same, and were aware of the limitations, but they also seemed to be comfortable with them. Moreover, the husbands seemed to be living productive lives despite the limitations imposed by the illness. They attempted to achieve balance by using five sub-processes. Developing a dialysis and daily routine to create order and some stability in their lives required sophisticated problem-solving, decision-making, and coordination skills as well as flexibility to alter their routines to respond to their wives' needs. Replenishing was vital to enhance and maintain their physical/emotional well-being to continue to address their wives' needs and also to nurture their emotional connection with their wives. Bringing others on board to assist with certain roles and responsibilities lessened their load. However, recruiting and accepting assistance was dependent on the availability of informal support, husbands being comfortable with allowing others to assist, and their ability to pay for services. Hoping a for kidney transplant allowed them to envision a better future and renewed health and life quality for their wives. Finding positive meaning was both a strategy and an outcome that assisted husbands to appraise, experience, and perceive some of the changes in their lives in positive and growth-enhancing ways which assisted them to embrace their transformed life.

Conclusion

Embracing a transformed life of living with wives on dialysis is the basic social process of responding, adjusting, and integrating the myriad changes imposed by kidney disease and its management regimens. The process of embracing a transformed life is comprised of four stages of becoming aware, involving oneself, centering life on their wives, and striving to achieve balance in their lives. Although each stage prompted the husbands to engage in the subsequent stage, the basic social process is not linear but iterative. As husbands move along this continuum, the strategies for embracing a transformed life are influenced by four conditions: their marital relationship, the women's health status, and both informal and formal support. Embracing a transformed life provides a framework explaining how husbands have addressed the central issue of the myriad changes imposed by kidney failure and its treatment regimens. The framework provides direction for other dialysis-caregivers as they endeavor to assist and support family members on dialysis.

Chapter 5: Discussion of Implications

In this chapter, I provide an overview of the substantive theory of embracing a transformed life. The theoretical contributions of this model to nursing knowledge, practice, and research, as well as social policy development, will be presented. I also highlight the unexpected outcomes that were experienced by the husbands with regards to their health, finances, and/or employment. The limitations of this study are also discussed.

Review of the Substantive Theory

My purpose in this study was to discover a substantive theory that could explain the adjustment process of husbands living with women on dialysis. I discovered that the most central and difficult issue for the husbands was adjusting to changes in many areas of their lives created by kidney disease and its treatment regimens. Changes occurred in their roles and responsibilities at home and work, in their retirement, social and recreational activities, daily routines, relationships, income, as well as their life priorities. The emergent theory of embracing a transformed life provides a framework for understanding and explaining the complex interplay of strategies undertaken by husbands of women on dialysis to respond to, adjust to, and integrate a multitude of changes imposed by kidney disease and its management regimens.

The husbands adjusted to changes in their lives through a four stage process of becoming aware of changes in their wives' health, involving themselves in preparations to assist their wives with their care, centering life on their wives to address their needs and the demands of their treatment regime, and finally striving to achieve balance to regain some normalcy and quality of life. These phases operated in an iterative rather than a linear fashion whereby changes in the wives' health status or treatment plans prompted husbands to return to earlier stages of adjustment. In this way, the husbands' caregiving remained responsive to fluctuations in the wives' illness/treatment trajectory. In addition, influencing conditions such as the marital relationship, and the presence of informal and formal support impacted on the husbands' adjustment to the changes and their ongoing commitment to embrace a transformed life. Although most of the husbands had come to terms with the changes the illness and its treatment regimens imposed, it did not mean that they were pleased about the changes, but they accepted the fact that these were part of their lives and they had to somehow adjust. Balancing gratitude for the technology that kept their wives alive against the difficult impositions the changes placed on their lives influenced the husbands' appraisal of these changes as challenges they could manage rather than perceiving them as insurmountable obstacles. Park and Folkman (1997) noted that "people who believe they are efficacious and capable of surmounting obstacles are more apt to regard an event as a challenge to be mastered rather than as a threat to be endured" (p. 122). In the following section, I will address the contributions of my theory to enhance the knowledge and practice of nurses.

Contribution to Nursing Knowledge

More than three decades ago, Atcherson (1981) observed that two-thirds of patients who could not manage dialysis at home were women who were assisted by husbands and she claimed that this might be due to "husbands having difficulty adjusting" (p. 29). The husbands in this study challenged this notion by demonstrating incredible commitment to adjust to the changes that permeated their lives. From a broader perspective, the theory of <u>embracing a transformed life</u> expands our knowledge about a specific cohort of men living with women on dialysis and addresses a long-standing gap in our knowledge about this specific cohort of dialysis caregivers (Atcherson, 1981; Blogg & O'Shaughnessy, 1999; Brunier & McKeever, 1993; Daneker et al., 2001; Friesen, 1997; Lindqvist et al., 1999). My theory also highlights the path husbands took to integrate complex technology into the home, to sustain the well-being of their wives, and the strategies they used to manage these challenges. The findings of this study are timely given that the number of Canadian women diagnosed with kidney failure has been steadily increasing since 2000 from 35.5% to 40% in 2009 (CIHI, 2010) due in part to an increase in the prevalence of hypertension in this population (PHAC, 2010). This trend suggests that more men may be required to assist women on dialysis.

This report contains rich descriptions of the men's experiences with assisting and supporting women on dialysis that can readily be understood and utilized by others. In the section on nursing knowledge, I will highlight how the findings of this study resonates with, adds to, and differs from existing literature on family members of adults on dialysis, men as caregivers, and other related concepts such as coping, illness trajectory, normalization, and personal growth. As well, my theory of <u>embracing a transformed life</u> and its processes will be compared and contrasted to Meleis's (1984) transition theory, the models of transformation (Dubouloz, King, Ashe, & Paterson, 2010), the theories of moral reasoning (Gilligan, 1982; Kohlberg, 1985), as well as, Corbin and Strauss's theory (1988) about the management of chronic illness by couples. These concepts and theories have been selected because they explain and support the key elements of commitment, change, and transformation found in this study. These themes will be woven into the sections on nursing knowledge and practice, as well as social policy.

Commitment to embrace a transformed life. The husbands in this study highlighted ways in which they made decisions about and responded to real-life moral dilemmas which addresses an important gap in the literature (Haviv & Leman, 2002; Jaffee & Hyde, 2000; Walker, de Vries, & Trevethan, 1987; Wark & Krebs, 2000). The husbands' moral dilemmas arose from: (a) weighing the benefit of dialysis treatment in improving and sustaining the wives' lives against the adverse imposition of the technology on their daily lives, (b) advocating for their wives' treatment and care versus the need to stay on good terms with health professionals, and (c) considering the importance of fulfilling their promise to support their wives versus the advantages/disadvantages of walking away from this difficult situation. The husbands addressed these real-life moral dilemmas using both the principles of care and justice. According to Gilligan (1982), a care orientation is characterized by a focus on maintaining relationships, responding to the needs of others, and a responsibility not to cause hurt, whereas, Kohlberg's (1985) ethic of justice orientation is concerned with principles of fairness and equity. Although acknowledging that both men and women understand and can use justice and care orientations, Gilligan (1982; 1988) asserted that women were more likely to address moral dilemmas using an ethic of care orientation whereas, justice orientation was more likely to be used by men. Gilligan (1982) purported that the tendency to view moral issues in care-oriented or justice-oriented ways stems from gender-related differences in identity acquired during early socialization. However, Gilligan's (1982) dualistic view of gender differences in moral orientation has received mixed support by researchers (Agerstrom, Bjorklyund, & Carlsson, 2011; Jaffe & Hyde, 200; Skoe, Pratt, Matthews, & Curror, 1996; Stan, 2011). Researchers are reporting that the two moral orientations; justice and care are not gender-specific but rather are gender-related and that both genders may use both orientations, which is consistent with this study where husbands' moral orientations guided their management of real-life dilemmas.

Furthermore, the husbands' moral orientation was influenced by the type of dilemma under consideration or the issue of concern. This has been also found in other studies (Day, 2000; Havi & Leman, 2002; Jaffee & Hyde, 2000). For example in this study, when the husbands were concerned about incompetent care from healthcare professionals, they responded by seeking care, confronting these professionals, and advocating on behalf of their wives because they believed that their wives had the right to receive appropriate care, to be protected from unnecessary suffering, and they were committed to address their wives' needs. Again, their actions reflected both justice and care-based moral orientations. As well, their actions reflected Tronto's (1993) four elements of caring "attentiveness, responsibility, competence, and responsiveness to the care receiver" (p. 127).

In my study, the husbands perceived that embracing their transformed life provided them with opportunities to validate and demonstrate their love for the wives, fulfill their promise of being there for her in sickness and in health, and/or show their appreciation for previous and on-going support provided by their wives. Researchers claim that there is no greater testing of the strength of a marriage than when one of the spouses becomes seriously ill (LoboPrabhu, Molinari, Arlinghaus, Barr, & Lomax, 2005). The husbands' emotional closeness with their wives and their commitment to the relationship were either enhanced or diminished by the demands of kidney failure and its treatments.

The husbands who described their marriage and wives in a positive light and had strong conjugal ethics addressed their wives' needs and embraced their transformed life out of love and devotion; a finding consistent with other husbands caring for women with dementia (Motenko, 1988; Russell, 2007; Siriopoulos et al., 1999). These husbands viewed addressing their wives' needs as a natural progression of the marital relationship and also a means to reciprocate previous support they had received from their wives. These husbands' commitment to address their wives' needs and to embrace their transformed life derived from love and devotion and seemed to reflect more an "ethic of care" than an "ethic of justice" (Gilligan, 1982).

In contrast, I also found situations in which the commitment to the marital relationship and to embracing a transformed life was based more on obligation/duty than love. Three husbands became dissatisfied with their marital relationship as a result of the changes in their companionship, emotional closeness, and sexual intimacy with their wives. Consequently, having to adjust to the changes in their lives added a degree of resentment to the relationship which is consistent with the results from other studies where husbands as patients or partners reported higher levels of distress in the marriage than the wives (Soskolne & Kaplan De-Nour, 1989). Consequently, it was difficult for these husbands to attend to their wives' voice and to maintain their wives' cherished identity. According to Ducharme et al. (2007), the transformation of the relationship between spouses in caregiving is a major source of stress for men. Other researchers have found that, husbands as patients or partners reported higher levels of distress in the marriage than the wives after dialysis was initiated (Soskolne & Kaplan DeNour, 1989), while women on dialysis reported a decline in spousal support after starting treatments (Brunier & McKeever, 1993; Devins et al., 1997) and more marital role strain (Chowanec & Binik, 1989). Although marital difficulties led some of the husbands in this study to consider leaving their wives, feelings of moral obligation to fulfill their marital vows seemed to sustain their commitment. The husbands who experienced difficulties in their marital relationship seemed to maintain their involvement in their marriage out of "constraint commitment", which refers to "the forces that keep individuals in relationships whether or not they are dedicated" and that arise from either external or internal pressures (Stanley, 1998, p. 64). Although "constraint commitment" can negatively affect a relationship, it can also contribute to the stability of a marriage and "motivate partners to stay together and work through difficult times"; particularly when "concern for a partner's welfare remains a priority in the relationship" (Owen, Rhoades, Stanley, & Markman, 2011, p. 822). Similar to other husbands in this study, the commitment of these three men to embrace a transformed life was guided by both Gilligan's (1982) second developmental level of the ethic of care, "goodness as self-sacrifice", where the responsibility is to protect the feelings of others and to help someone in need, and Kohlberg, Levin, and Hewer's (1983) corresponding third stage of justice orientation, “good interpersonal relationships”, which emphasizes the importance of living up to social expectations and roles being honored.

All the husbands had the desire and the will to nurture, sustain, and rekindle their emotional connection and their relationship with their wives by restoring togetherness, which consisted of resuming pre-dialysis activities or pursuing new interests as a couple. This finding resonates with the strategy of “sustaining couplehood” used by spouses living with partners with dementia (Hellström, Nolan, & Lundh, 2007; Perry & O’Connor, 2002), but it also differs in that restoring togetherness was not limited to couples whose relationship had remained positive since the start of dialysis but included as well husbands who experienced marital difficulties. This finding aligns with Gilligan’s assertion (1982) that when faced with relationship dilemmas, both men and women will use an ethic-of-care orientation.

I also found that some of the husbands received unexpected support from their wives in the form of praise, acknowledgement, and encouragement for the assistance they provided. Although the husbands valued the offerings of symbolic expressions of support from their wives, it was not something they expected to receive because she was unwell. This is a phenomenon that Neufeld and Harrison (1998) have termed “waived reciprocity” (p. 961). Reciprocity is a dimension of social support that has been found to be important in caregiver’s ability to sustain a supportive relationship while giving care (Tilden & Galyen, 1987). Among the few studies that have specifically explored the concept of reciprocity from the perspective of men as caregivers, Neufeld and Harrison (1998) in a qualitative study of 22 men with varying relationships (14 were husbands or partners) to the women with dementia observed that the men experienced difficulty maintaining reciprocity due to the care-recipient’ difficulty/inability to communicate or the women’s disruptive behaviors. When reciprocity was absent, the non-spousal men (n = 8) described giving care based on obligation, especially when the relationship had been negative prior to the onset of cognitive impairment. In contrast, Neufeld and Harrison (1998) as well as other researchers have found that husbands caring for women with dementia and other chronic illnesses who reported receiving positive feedback on their quality of care from their wives experienced less caregiving stress and burden (Carruth, 1996; Kaye & Applegate, 1990; Picot, 1995). Interestingly, the husbands in this study who perceived embracing a transformed life as an opportunity to reciprocate the care received from their wives in the past were also the ones who received commendation from their wives, suggesting a desire on the part of both partners to sustain their on-going commitment to the marital relationship based on an ethic of care; similar to the couples in Corbin and Strauss's study (1985).

Gilligan (1982) proposed that the development of the ethic of care proceeds through three developmental stages. The first stage is characterized by an exclusive focus on one's own needs, the second is characterized by self-sacrifice and a focus on others' needs, and the third is distinguished by the ability to balance others needs and one's own needs (Jaffee & Hyde, 2000). In the present study, I found that some of the husbands moved from the second to the third stage of care orientation. In keeping with Gilligan's (1982) second stage of care orientation, they provided care to their wives at expense to themselves. Their concerns about their wives' well-being influenced them to sacrifice their own needs to protect their wives from suffering, to preserve their wives' dignity, and to enhance their quality of life at every stage of embracing a transformed life. In the second stage, they continued to sacrifice their needs to assume multiple role responsibilities. When the husbands strove to achieve balance in their lives, they faced the dilemma of how to contribute to the wives' well-being while taking care of themselves. Most resolved this issue by recognizing the necessity to replenish in order to continue to care for their wives. This aligns with Corbin and Strauss's (1988) belief in "sustaining oneself and each other" (p .123). Husbands' recognition of inter-reliance in the relationship is congruent with Gilligan's (1982) third stage of moral development, where there is an increasing realization that self and others are interdependent. However, not all husbands were able to achieve this level of insight about their caring relationship. A meta-analysis conducted by Jaffee and Hyde (2000) noted that "there has been little discussion in the literature of how or why individuals move from one level of care orientation to the next or if they can regress" (p.704). In the present study, certain factors seemed to influence the husbands' inability to move from one stage to another. These included: wives who were too debilitated, shouldering all the responsibility for their wives' peritoneal dialysis, inability to recruit assistance to replenish, and/or feelings of guilt and selfishness for participating in activities. In a study on family caregiver respite and leisure, Strang (2001) found that some “men perceived leisure as a right” while women perceived leisure “as a luxury to which they were not entitled” (p.76). The findings from the current study run counter to Strang’s work. For example, a few of the husbands reproached themselves for indulging in personal activities or enjoying themselves while their wives remained at home. Some were fearful that harm might come to their wives during their absence. This fear has also been reported by women assisting with home dialysis (Luk, 2002; Wellard & Street, 1999). It seems that although all the husbands could have benefitted from opportunities to replenish, some perceived themselves to be constrained by an ethic of care. Researchers (Skoe et al., 1996) claim that “the care of others must be balanced by care for oneself; otherwise generativity may degenerate into mere martyrdom” (p. 291). In situations where wives encouraged and supported their husbands to take a break, they seemed to be more receptive to the idea.

Changes. The husbands provided insight about the periodic, temporary, and/or permanent changes they experienced in their lives as a result of the impact of kidney failure and its treatment regimens and the strategies they use to adjust to changes. A group of researchers (Morelon et al., 2005) confirmed that changes are commonly experienced by dialysis caregivers; they found that only “2% of the partners of patients on dialysis reported experiencing no change in their daily life” compared to “32% of partners of kidney transplant patients”; however, the nature of these changes were not described (p. 1672). Meleis (1986) considered change to be an essential element in planned or unplanned situational, developmental, and/or health-to-illness transitions. While Meleis (1986) purported that a transition is both a result of and results in forced or chosen changes in lives, health, routines, relationships, and environment, as well as roles within the context of work and family, she also cautioned that not all changes result in transitions. The mid-range theories of embracing a transformed life and Meleis’s (1986) theory of transition share both similar and different perspectives with regards to the process, critical points and events, awareness, engagement, and disconnectedness as well as time span. I will illustrate these perspectives in the following section.

One common characteristic in both theories is the process of movement through distinct stages or phases that unfold over time. In my study, the basic social process of embracing a transformed life consisted of four interrelated stages that accounted for variations in the strategies used by husbands to adjust to the many changes that permeated their lives as a result of the impact and demands of the illness and its management. Likewise, a transition process has three distinct stages that consist of an entry, middle, and ending that describe the nature and scope of changes resulting from planned or unplanned developmental, situational, and health-illness situations (Meleis, Sawyer, Im, Schumacher, & Messias, 2000), and “the process that people go through to incorporate the change into their lives” (Kralik, Visentin, & van Loon, 2006, p. 324). Bridges (2004) described how a transition process follows a time span and commences from the first sign of anticipation, perception, or demonstration of change (entry); through a period of instability, confusion, and distress (a passage); to an eventual ending wherein stability and harmony are again experienced. However, the transition process does not address the “specific strategies/activities that facilitate transition,” an area that has been identified as a significant gap in transition research (Kralik et al., 2006; Kralik & van Loon, 2009, p. 114; Schumacher, Jones, & Meleis, 1999). In my study and in accordance with the work of Bridges (2004), the process of embracing a transformed life has a definite entry stage (stage 1: Becoming aware) and a passage stage (stage 2: Involving oneself and stage 3: Centering life on their wives); however, the final stage of Striving to achieve balance does not involve a clearly defined end point because the men were constantly having to adjust to their wives’ fluctuating health.

There seems to be a lack of consensus among researchers as to whether the stages in a transition process follow a linear (Schumacher et al., 1999), cyclical (Kralick, 2009), or spiral trajectory (Elmberger, Boland, & Lutzen, 2002). In contrast, the process of embracing a transformed life is clearly recursive in response to new or re-occurring changes created by the chronic nature of the illness, treatment regimens, and their wives’ precarious health. This meant that husbands returned to previous stages to revise or develop new adjustment strategies. Tanyi and Werner (2008) in their study on women with end-stage renal disease undergoing hemodialysis found a comparable trajectory of three interwoven, circular, and ongoing phases of adjustment (initiation, appreciation, and grappling) as a result of “the chronic nature of their illness which required them to continually strive to adjust in all domains of life” (p. 44). The use of a trajectory framework to understand chronic illness experiences from the perspective of the patient is not new (Rolland, 1987; Strauss & Corbin, 1988) however, my theory of embracing a transformed life provides a useful framework for understanding the husbands' unique experiences with different changes, demands, and adjustment within each stage so that supportive stage-specific interventions can be developed. In contrast to this study's model, the Nursing Model for Chronic Illness Management (Corbin & Strauss, 1991), which was based on a chronic illness trajectory framework includes family caregivers but fails to specify their unique experiences. Still, the key phases of illness drive the experiences of caregivers in Corbin and Strauss's model (1984; 1988) as well as in this study's framework.

Consistency between both the transitional model and my study's theoretical model is also found in the process of movement from one stage to another which is influenced by the occurrence of critical events (Glaser, 1978; Meleis et al., 2000; Schumacher et al., 1999). According to Glaser (1978), critical events determine whether a new stage is entered, skipped, or maintained, whereas Meleis (1986) indicated that critical events in a transition may reflect opportunities and/or crisis. Within each stage of the theory of embracing a transformed life, different illness and treatment related-critical events were experienced by the husbands that imposed different changes and required different adjustment strategies. Researchers have focused on the dialysis-caregivers' responses and involvement once the treatment is initiated, which reflects one of the critical events in the third stage of centering life on their wives. However, the disadvantage of focusing on only one critical event or discrete time period is that it captures only a "snapshot" (Kralick, 2009, p. 114), "snippet data" (Morse, 2004), or "little islands of knowledge" (Glaser, 1978, p. 148) rather than the breadth of an ongoing experience (Corbin & Strauss, 1988). The conceptual density of my theory goes beyond husbands adjusting to a singular event. My findings underscore the broad range of critical events that imposed change in the lives of husbands before, during, and after dialysis was initiated. In the next section, I highlight the types of critical events, the changes, and adjustments that permeated the husbands' lives within each stage of the process of embracing a transformed life.

Stage of becoming aware and involving oneself. In my study, the first two stages of becoming aware and involving oneself both fit with and extend previous understandings about the properties of awareness and engagement in Meleis's (1986) theory. According to Meleis et al. (2002), a transition can occur only if a person is aware of what has changed and how things are different, and this awareness in turn influences his or her engagement in activities. Similar to Meleis's (1986) theory, the husbands' awareness of the sudden or insidious changes in their wives' health marked a critical event in their lives that prompted them to get involved, though in my study, such awareness was not the only factor that influenced their involvement. I found that other conditions exerted an equal or a greater influence on the husbands which included the extent to which their wives were debilitated and how their self-care abilities were affected by the symptoms as well as, the husbands' desire to provide support to their wives and alleviate their suffering.

According to Low, Smith, Burns, and Jones (2008) family members play a pivotal role "even before end-stage disease is reached, as renal function deteriorates; patients frequently require additional support and it is often family members who provide it" (p. 76). On the other hand, the nature of support provided by family members to individuals during the pre-dialysis stage has not been discussed in the literature. The husbands in this study highlighted the extent of their involvement in providing support to their wives before dialysis by seeking care to ease their wives' suffering, seeking information to understand the meaning of the symptoms, and preparing by acquiring knowledge and skills to assist with illness-and-dialysis-related care.

Furthermore, the husbands reported that they began to experience changes in their lives even before their wives started dialysis that included taking on new and unfamiliar roles at home that their wives could no longer perform, altering their work schedule to accompany their wives to doctors' appointments, relocating temporarily or permanently to access care for their wives, and setting aside social activities. These changes persisted in varying degrees in subsequent stages, as did their involvement.

Stage of centering life on their wives. The women starting dialysis treatment marked another critical event in the lives of their husbands and one that focused their time and energy on addressing their wives' needs and fitting the demands of the illness and its treatment regimens into their daily lives. The third stage of centering life on their wives aligns with the passage phase of a transition which, according to Meleis (1986), is considered to be a period of disconnectedness wherein a disruption in the stability and predictability of daily life occurs. During this stage, the husbands' lives were imbued with uncertainty about the course of the illness and the effectiveness of dialysis to sustain life. This uncertainty was comingled with the hope that dialysis treatment would ease their wives' suffering, which motivated rather than immobilized them to embrace the changes in their lives. As with other spouses assisting their partners on home hemodialysis (Blogg & Hyde, 2002; Peterson, 1995; Quinan, 2005), the more the women were cognitively and/or physically debilitated by the kidney failure, dialysis, and/or other co-morbid illnesses, the more role responsibilities the husbands needed to assume and the more changes they experienced and had to make in their lives.

Assuming new roles and responsibilities. Consistent with what has been written previously about transitions (Meleis, 1986), centering on the wives required that husbands engage in role responsibilities that were new to them. By the time dialysis was initiated, the women were too debilitated to participate in their roles and responsibilities. They had to relinquish most of their household responsibilities to their husbands and accept being cared for by them. For the husbands in this study, this meant having to assume, juggle, and coordinate multiple roles of providing illness-related care, attending to their wives' voice, and engaging in protective support.

Providing illness-related care. All husbands in this study had to learn many new skills to assume responsibilities with providing illness-related care. The tasks associated with providing illness-related care both resonate with and add to existing literature about the responsibilities of dialysis-caregivers. These tasks involved: (a) performing some or all of the daily exchanges of peritoneal dialysis when their wives were too cognitively, emotionally, and/or physically debilitated to perform such treatment on their own (Beanlands et al., 2005; Belasco & Sesso, 2002; Srivastava, 1988; Wellard & Street, 1999); (b) providing transportation to and from the hospital for dialysis (Beanlands et al., 2005; Blogg & Hyde, 2008; Friesen, 1997; Low et al., 2008; Luk, 2002; Suri et al., 2011) (c) storing, taking stock of, and ordering peritoneal dialysis supplies (Beanlands et al., 2005); and (d) preparing and administering medications (Beanlands et al., 2005). Although the husbands were performing the tasks associated with being a caregiver (Beanlands et al., 2005; Belasco & Sesso, 2002; Blogg & Hyde, 2008), they did not identify with the role. While the retired husbands indicated that the assistance they provided to their wives was a full-time job, they did not consider their involvement to be "work" or a "late-life career". Furthermore, they did not describe themselves as "workers" (Harris, 1993, p. 554), a way of speaking that has been associated with a style of caregiving that is "cold and uncaring" (Russell, 2007, p. 301). Rather, all husbands perceived that providing illness-related care to their wives was a logical and natural expectation of being a husband. This reaction has also been echoed in other research about men living with women who have dementia (Cahill, 2000; Ribeiro, Paul, & Nogueira, 2007; Russell, 2001).

The husbands' involvement in providing optimal nutrition adds to the limited body of information on this issue (Beanlands et al., 2005; Isenberg & Trisolini, 2008). Similar to the responsibilities described by the women participants in both Beanlands et al.'s (2005) and Isenberg and Trisolini's (2008) studies, the husbands' involvement consisted of planning and preparing meals as well as, monitoring dietary restriction to ensure adequate and appropriate intake in order to improve their wives' well-being and prevent health crises. However, unlike this study, Beanlands et al.'s (2005) work did not specify whether any of their participants had to learn how to cook, grocery shop, follow recipes, and decipher food labels, which were new responsibilities for some men, especially the older husbands, since these activities had always been the primary responsibility of their wives. Differences between the participants in both studies may be explained by the sample in Beanlands et al.'s, (2005) study being predominantly female (68% women versus 32% men) and, perhaps, for them meal preparation was a familiar role. In a related study, Campbell (1998) indicated that it can be very difficult for family members caring for individuals on dialysis to assume unfamiliar roles, particularly late in life; however, this idea is not supported in my study, as older husbands took pride in their ability to learn a new skill like cooking even though it meant crossing gender-role boundaries. I also found that most husbands were quite adept and resourceful in using both formal and informal routes to expand their repertoire of skills and knowledge to find information about the dietary regime on the internet, from renal dieticians, and renal-specific recipe books. The strategy of enforcing the prescribed dietary regime aligns with the "coaching" and "policing" approaches used by family members in Beanlands et al.'s

(2005) study to encourage patients to adhere to the prescribed fluid and dietary regime in order to prevent a health crisis. Enforcing the prescribed dietary regime was easier to do when the women cooperated with their husbands' efforts; otherwise, it created conflict between the partners. Support from renal professionals for the husbands' involvement in providing optimal nutrition sustained their efforts.

Attending to their wives' voice. Researchers have found that the emotional support that family members provide to patients on dialysis can increase the latter's life satisfaction, buffer the emotional impact of the illness (Christensen, Turner, Slaughter, & Holman, 1989), and decrease the risk of mortality (Christensen, Wiebe, Smith, & Turner, 1994; Kimmel, Thamer, Christian, & Ray, 1998). However, the nature of the emotional support provided has not been described in the dialysis-caregiver literature.

The participants in my study highlighted the importance and implications of dialysis-caregivers providing emotional support to individuals on dialysis. Even though the husbands perceived they had always provided emotional support to their wives during the course of their marriage, attending to their wives' voice to make them feel appreciated and important in their lives and homes took on new meaning and importance after their wives began dialysis. Attending to the wives' voices was achieved by maintaining their wives' cherished identity, which consisted of making conscious efforts and decisions to bolster their wives' sense of self through ensuring that they involved them in family decisions, child discipline, meal preparations, and/or chores when they wanted or in ways that were still possible for them. In Corbin and Strauss's study (1985), the role of spouse-caregivers in sustaining the identity of adults with chronic illnesses was considered to be a form of "sentimental work" that was aimed at sustaining the dignity and integrity of the patient, which parallels the intention of the majority of the husbands in this study. In situations where couples were experiencing marital difficulties, it was more difficult and even impossible for the husbands to provide their wives with emotional support. Other husbands caring for partners with Alzheimer's disease have maintained their wives' identity by focusing on their outward appearance by applying makeup or curling their wives' hair to preserve a facade of normality even though the women were unaware of their appearance (Calasanti & Bowen, 2006; Hellstrom, Nolan, & Lundh, 2007; Perry & O'Connor, 2002). Perry and O'Connor (2002) found that when spouse caregivers "preserved the personhood" of their partners, they also preserved their own identities as husbands and wives and not simply as caregivers. This finding may explain why the husbands in this study did not consider themselves as caregivers.

A unique way that the husbands attended to their wives' voice was by accommodating their wives' wishes. Although the husbands had granted most of their wives' wishes prior to starting dialysis, their awareness that other dialysis patients had experienced further disabilities or death made it difficult for them to refuse any of their wives' requests. Regardless of the complexity or cost of their wives' wishes, the husbands were determined to fulfill them to enrich their wives' lives with joy and to buffer the impact of the illness. The intent of accommodating their wives' wishes is akin to the fulfillment of wishes of children with life-threatening conditions, which is "a palliative care and end-of-life intervention that can ease suffering and sorrow for the child and family" (Ewing, 2009, p. 81). Researchers (Ewing, 2008; 2009; Feeg, 2005) have found that the wish experiences of children and their families may improve their quality of life and/or enhance their transition towards death. Such findings may explain why the husbands also benefitted from accommodating their wives' wishes by helping them to minimize any regrets and to create enduring memories of their wives; such memories have been associated with anticipatory grieving when faced with the fear of losing someone or an anticipated loss (Clukey, 2008; Kehl, 2005).

Engaging in protective support. The husbands revealed that when they perceived actual or potential threats to their wives' well-being from the negative impact of the illness, dialysis, or unhelpful care from health professionals, they engaged in protective support. One of the strategies they used was to watch over their wives, which aligns with the concept of vigilance and in this study consisted of monitoring the progress of the disease, making decisions, and taking action to intervene on behalf of their wives (Carr & Clarke, 1997). According to Folkman and Lazarus (1984) individuals use vigilance in situations where an actual or potential threat exists, which explains the husbands' fear of their wives dying as the primary reason to watch over their wives. In Beanlands et al.'s study (2005), the family members of dialysis patients used strategies of appraisal and surveillance to monitor the health condition and responses to treatments. Vigilance has also been used by caregivers to keep individuals with Alzheimer's disease from injuring themselves and others (Mahoney, 2003; Parsons, 1997), to shelter patients with chemotherapy-induced neutropenia (Eggenberger, Krumwiede, Meiers, Bliesmer, & Earle, 2004), to oversee the care provided by health professionals to relatives hospitalized with sudden illness (Carr & Fogarty, 1999), and to buffer the emotional impact of chemotherapy (Wilson & Morse, 1991). Similar to the caregivers of individuals with dementia (Mahoney, 2003; Parsons, 1997), some of the husbands reported being on duty, on guard, or on call 24 hours a day to <u>watch over their wives</u>, especially when their health was unstable or they experienced post-dialysis complications. In contrast to other studies, in the present study <u>watching over their wives</u> was not only carried out in presence of the wives, but it also occurred when the husbands were absent. However, in those circumstances, they recruited others to monitor their wives.

The husbands emphasized that <u>watching over their wives</u> could have both negative and positive impact. On the one hand, it negatively affected the husbands' sleep patterns and certain aspects of their lifestyles and sometimes created conflict between the partners. On the other hand, it positively benefitted the husbands by allowing them to develop a unique type of knowledge about their wives' health and responses to treatments. This knowledge positioned them well to advocate on behalf of their wives, something also mentioned by the participants in Beanlands et al.'s (1985) study.

Simplifying life and concentrating on daily goals. The husbands provided insight about the extent to which their time and energy were consumed by <u>centering life on their wives</u>. To maximize their availability to focus on the role responsibilities and tasks at hand, the husbands had to <u>simplify their lives</u> and <u>concentrate on daily</u> goals which was considered to be both a strategy for and an outcome of <u>centering life on their wives</u>. As with other dialysis-affected carers, the husbands reported scaling down or giving up activities, events, and cherished pursuits as means of <u>simplifying their lives</u> (Bryan & Evans, 1979). Other family members have reported using strategies with a similar intent when they described "putting life on hold" to provide care to individuals with advanced cancer (Meeker, 2010), "sacrificing something important" in dementia care (Florczak, 2006), and "relinquishing" or "letting go" of relationships with dying family members (Furman, 2001; Read & Wuest, 2007). In a study of about 35 individuals living with a chronic illness, Charmaz (1991) found that while <u>simplifying life</u> helped the patients to discern which activities they could maintain and which they needed to discontinue, it also increased the workload of their caregivers. In a different negative way, simplifying life also impacted on the husbands' lives by interfering with their work and pursuit of new careers or more education. On the other hand, simplifying life also helped the husbands to concentrate on daily goals by affording them time to prioritize without getting too overwhelmed. This strategy is somewhat similar to living one day at time which has been described by other family members to manage the uncertainty and stressfulness associated with the implications of acquired immunodeficiency syndrome ([AIDS], Brown-Powell-Cope, 1991), mental illnesses (Jeon & Madjar, 1998), or individuals living with a chronic illness (Charmaz, 1991). However, the process of concentrating on daily goals captures a broader perspective than living one day at a time or existing from day-to-day, especially when the husbands strategized to refrain from looking at the big picture and to live each day fully. These strategies reflected a conscious decision to make every day as meaningful as possible for their wives and themselves while the opportunity existed, to give fewer thoughts to the future, to prioritize what mattered most in their lives, and to appreciate the fragility of life. This kind of decision has also been echoed by husbands caring for their partners with dementia (Hellstrom, Nolan, & Lundh, 2007; Williams, 2007).

Stage of striving to achieve balance. The critical event in the final stage was triggered by the women's experience of some stability in health, which influenced the opportunity for the husbands, families, and couples to strive to achieve balance in their lives. This stage has never been described in the literature about dialysis-caregivers. This final stage of striving to achieve balance somewhat parallels the exit stage of Meleis's (1986) theory where the transition concludes with a return to a stable phase. However, for individuals with end-stage renal disease and their families there is no identifiable end-point at which the health-to-illness transition is ever complete because like most chronic illnesses, kidney failure and dialysis treatment need to be managed daily to sustain life (Paterson, 2001; 2003). As a result, Robinson's (1993) "normalcy lens" could not be adopted by the husbands in this study because their need to center life around the illness and its treatment regimens made it impossible for them to minimize the differences between their own lives and those of other families living without a chronic illness.

Nonetheless, the husbands strove to achieve some balance in their lives by creating a routine and resuming pre-illness and dialysis activities that contributed to a sense of stability and opportunities to enjoy a good life; however, this is not a life that would be considered normal by others. A similar perception was reported by patients living with kidney failure in a recent meta-synthesis (Schick-Makaroff, 2012) when the term “abnormal normalcy” was used to describe both the freedom and restrictions that accompany the illness and treatments. According to Clarke-Steffen (1997), standards for “normal” are elastic and frequently redefined to suit a particular family’s circumstances. Similarly, some of the husbands in the present study did not expect to resume a normal life unless their wives received a kidney transplant which proved to be a difficult waiting period. Similar to other dialysis-caregivers, the husbands hoped for a kidney transplant to enhance their wives’ health and quality of life. However, not all women were eligible to receive a kidney transplant.

The stage of striving to achieve balance aligns with Corbin and Strauss’s (1988) “stable phase” whereby couples managing a chronic illness focus on keeping “the illness in a stable state and at the same time actively engage in living” (p. 210). Similar strategies were used in both studies to balance life and the illness and treatment demands that included creating routines (establishing routines to manage illness-related work and everyday life work), bringing others on board (finding and using outside help), and replenishing (getting a break from the work). Additional strategies were discussed by some of the husbands in this study such as finding positive meaning and hoping for a kidney transplant.

Creating routines. Consistent with one of the outcomes of most transitions is that new routines may need to be developed to accommodate changes (Meleis, 1986), which is what occurred for the husbands in this study when they too had to create two new routines: one to accommodate dialysis treatment and the other to attend to everyday activities. Similar results were reported by the couples in Corbin and Strauss’s study (1988) when they had to develop routines for managing illness-related work and everyday life work, as did the dialysis-caregivers in Beanlands et al.’s study (2005) for “routinizing” the dialysis regime. The husbands in this study received no assistance from health care professionals to develop these routines. The extent to which they were involved in the routines varied according to the women's health. In some cases, the husbands shouldered all responsibilities for both routines, whereas in other situations, the tasks were done collaboratively as a couple, or the husbands assisted their wives periodically. Similar to the tasks performed by Corbin and Strauss's (1988) participants, the work involved in creating routines was "invisible work" that required tremendous planning, sequencing, and coordinating of a cluster of activities prior to leaving home or performing peritoneal dialysis at home. Corbin and Strauss (1985) referred to the efforts to carry out a set of tasks smoothly and effectively as "articulation work" (p. 242). In this study, the dialysis routine could not be deferred or skipped to accommodate other plans, but rather it needed to be carried out at the same prescribed time or the women could experience dire health consequences. Therefore, the husbands could not adopt Deatrick, Knafl, and Murphy-Moore's (1999) fourth attribute of normalization, which consists of "developing a treatment regime that is consistent with normalcy lens" (p. 211) that involves liberally adapting the treatment regime for a chronic illness to achieve a more normalized family life rather than conforming to the recommendations of healthcare professionals (Deatrick et al., 1999; Gallo & Knafl, 1998; Knafl & Deatrick, 2002; Robinson, 1993).

Differences in the findings of these studies and the present study may be attributed to ESRD being both a chronic and life threatening illness. In this study, any activities that were part of the everyday routine needed to be fitted in between, during, or after dialysis treatment except for the children's schooling and activities. The wives' fluctuating health status sometimes required that the everyday routine be revised. Despite the rigidity of the treatment and household routines, the couple created some balance and predictability in their lives.

Bringing others on board. In order to balance the competing responsibilities of the treatment, activities of daily living (ADLs), family and work, and/or when these demands were beyond what the husbands or wives could handle, they brought others on board to help. Being surrounded by a network of individuals who provided instrumental, emotional, financial, and/or spiritual support conveyed caring to the husbands and enhanced their ability to cope (Chappell & Funk, 2011). However, there were circumstances in which the support provided by others was awkward for the husbands to accept, especially when they perceived that they were imposing on other people’s time and/or receiving more support than they could repay. In these situations, the husbands reported feeling guilty, dependent, and indebted which, according to researchers could have diminished the benefits (Gibson, 1992; Stewart, 1989; Tilden & Gaylen, 1987). The husbands’ desire to reciprocate the help they received from friends or neighbors supports the theoretical construct of equity (Gouldner, 1960). Although in equity theory, a balance in costs and rewards is necessary for the continuation of social relationships, the husbands did not refuse support that they were unlikely to reciprocate; they understood that people wanted to help and did not expect anything in return. While most husbands seemed more comfortable accepting assistance from individuals they had helped in the past, all were inclined to hire help provided that their wives approved.

Experiencing positive growth. Despite the overriding challenges arising from many changes in their lives, some of the husbands were able also to find positive meaning in their situations which is a strategy that has not previously been reported by dialysis-caregivers. Finding positive meaning was enhanced when the husbands were being positive about and experiencing positive growth from some of the changes that permeated their lives.

When some of the husbands were able to reframe the impact of certain changes in their lives in positive ways, it helped them to find positive meaning. This approach is similar to the strategy of positive-reappraisal which has been found to diminish distress, sustain coping efforts, and buffer against adverse physiological consequences of stress (Folkman & Lazarus, 1984, Folkman & Moskowitz, 2000; Park & Folkman, 1997; Park, 2010). In a qualitative study (Folkman, 1997), men caregivers of partners with AIDS appraised their caregiving activities as opportunities to demonstrate their love and preserve the dignity of their ill partner, which was also echoed by most husbands in this study. Folkman (1997) added that when individuals can focus on the value of their caregiving efforts and appraise them positively, it may sustain their efforts to provide care over long periods of time. In my study, finding positive meaning was achieved by comparing their situation with that of others whom they perceived to be worse off than themselves (Park & Folkman, 1997), focusing on what was still possible in their lives rather than dwelling on what they relinquished, and/or infusing ordinary events of daily life with positive meaning. Being able to witness improvement in their wives' health since starting dialysis, deriving strength from their wives' positive adjustment to the illness and treatment, and receiving commendation from their wives and health care professional about their efforts enhanced the husbands' ability to find positive meaning.

Some of the husbands also found positive meaning when they experienced unexpected positive personal growth or changes from embracing their transformed life. Unanticipated growth occurred in regard to having a greater appreciation for and redefined priorities in life, increased patience, skills, and confidence with new role responsibilities to address their wives' needs, and an enriched relationship with their wives. These outcomes have been associated with stress-related growth (SRG), benefit-finding, and post-traumatic growth (PTG) that occur in response to experiencing distress or struggles in dealing with difficult situation or trauma (Calhoun & Tedeschi, 1998; Park & Fenster, 2004). Furthermore, positive growth has also been related to the concept of transformation, which means "a forming over or restructuring" (Holland, 1998, p. 713). A number of researchers in the field of rehabilitation point to the coherence of Mezirow's (1990) description of transformation in adult learning as the process of acquiring knowledge, beliefs, and values as they relate to one's actions. Several qualitative researchers have explored ways in which adults experience the restructuring of self and the restructuring of an illness as a transformation in their rehabilitation after an injury or a disabling illness (Ashe, Taylor, & Dubouloz, 2005; Carpenter, 1994; Dubouloz, Chevrier, Savoie-Zajc, 2001; Dubouloz, Vallerand et al., 2002; Dubouloz, Laporte, Hall, Ashe, & Smith, 2004; Paterson, Thorne, Crawford, & Tarko, 1999).

More recently, a group of researchers (Dubouloz, King, Paterson, Ashe, Chevrier, & Moldoveanu, 2010) has used the results from the six previously mentioned studies to develop two meaning-perspective transformation models for individuals experiencing a disability and/or chronic illness. The first model describes "The Process of Transformation Model: Rehabilitation of Chronic Illness and Disability", which includes three phases: the trigger, the process of changing, and the outcomes phase. The second model depicts "The Process of Transformation: Chronic Illness and Primary Care" as three distinct and sequential phases: the initial response, embracing new challenges, and integrating of new ways of being. According to these researchers, "the catalyst for movement from one phase to the next is the patients' ability, willingness, and readiness for change", though it may take an individual up to five years to move from the first to the second phase in each model (p. 609). The usefulness of these models to guide professionals as facilitators of patients' learning to live with and transforming the meaning of their chronic illness and/or disability is emphasized; however, to date there is no published evidence to support their usefulness as a guide to practice (Dubouloz et al., 2010). Moreover, these models were specially designed for individuals who are actively engaged in rehabilitation programs and are being closely monitored by health professionals; they are not applicable when it comes to explaining the husbands' experience of personal growth in the present study.

In a recent concept analysis of personal transformation, Wade (2008) identified that "transformation is proceeded by a disorientating dilemma that disrupts the order of one's life", and that for transformation to occur the individual must "make a deliberate choice to confront the conflict or dilemma" (p. 716). These notions are in keeping with the husbands' decisions, choices, and shifts in mind-set to respond to the illness-treatment related changes by appraising them as opportunities and by tackling them as challenges rather than perceiving them as burdensome. By doing so, the husbands restructured the meaning of the illness and its treatment regimens and experienced unexpected positive growth which is more consistent with the concepts of SRG or PTG developed by Calhoun and Tedeschi (1998).

A number of theorists have explained how positive changes or growth may be co-experienced in stressful situations: worldviews (Janoff-Bulman, 1989); cognitive processing (Park, 1998; Tedeschi & Calhoun, 1994); and appraisal and coping processes (Lazarus & Folkman, 1984). The literature is replete with studies and reports of SRG/PTG experienced by individuals directly affected by the impact of stressful events, crises, or trauma (see Tedeschi & Calhoun, 2004 for a review). More recently, researchers have recognized that SRG/PTG may be extended to close family members. Investigators have focused on the experiences of SRG/PTG in spouses living with partners with breast cancer (Ostroff, Winkel, Goldstein, & Fox, 2004; Weiss, 2002; 2004), myocardial infarction (mostly wives) (Senol-Durak & Ayvasik, 2010), and prostate cancer (Manne, Babb, Pinover, Howitz, & Ebbert, 2002; Thorton & Perez, 2006), using Tedeschi and

Calhoun's (1994) posttraumatic growth conceptual model (PTGM) and Post Traumatic Growth Inventory ([PTGI], Tedeschi & Calhoun, 1996). Collectively these researchers found that the spouses experienced small to moderate levels of SRG/PTG as a result of dealing with their partners' life-altering illness.

Among the investigators who have explored SRG/PTG from the perspective of husbands, Weiss (2004) used the PTGI to study 72 partners of women diagnosed with early-stage breast cancer and found that they experienced small to moderate growth or changes in their relationships with others such as their families and their wives, personal strength and confidence, and appreciation for life, which corroborates my findings and the results of Manne et al.'s study (2004) which focused on husbands of women with breast cancer. Furthermore, Weiss (2004) found that the strength of the marital relationship, including support and depth of commitment was positively correlated with the husbands' experiencing PTG, whereas marital conflict was negatively correlated with PTG. This finding may explain why the husbands in this study who experienced marital difficulties did not report experiencing positive growth. Alternately, they may not have experienced growth because SRG is neither an inevitable nor a universal outcome of managing a stressful situation (Tedeschi & Calhoun, 2004). Tedeschi and Calhoun (2004), indicated that for individuals who report growth, it does not mean that the stressful situation is desirable, nor does it negate the adverse impact and suffering that people typically experience from difficult life situations or events, but it "seems, instead to be another aspect of the overall experience of coping with and adjusting to stressful events" (Parks & Fenster, 2004, p. 196). Furthermore, Manne et al. (2004) found that husbands who engaged in positive reappraisal experienced more PTG, which may explain why the husbands in this study who used positive-meaning strategies were also those who experienced positive growth.

In the present study, husbands of all ages reported experiencing personal growth, which differs from previous studies (Manne et al., 2004; Weiss, 2002; 2004) where investigators found younger husbands of women with breast cancer experienced more PTG. The authors offered no explanation for their age-related finding. Furthermore, Weiss (2002; 2004) and Manne et al. (2004) found that the husbands reported PTG and positive benefits shortly after their wives were diagnosed with breast cancer and continued to do so at 3 years. Although it is not clear when the husbands in this study began to experience personal growth, some reported experiencing personal growth at 3 months to 20 years after their wives had started dialysis. Helgeson, Reynolds, and Tomich, (2006) reported in their meta-analysis that some variability but no positive relationship exists between growth and time. However, Tedeschi and Calhoun (2004) indicated that the absence or presence of positive growth does not mean that some husbands are struggling more or less than others with the changes imposed by the illness and treatment. Rather, in both situations the men may need as much support to get through the challenges throughout the four stages of <u>embracing a transformed life</u>.

Health-related outcomes. In addition to experiencing changes in various domains of their lives, the husbands also reported experiencing unexpected changes in their health. Several researchers have found that assisting with home hemodialysis negatively impacted the caregivers' physical and emotional health (Belasco & Sesso, 2002; Ekelund, Westman, & Andersson, 2004; Gee, Howe, & Kimmel, 2005; Pruchno, Lemay, Feild, & Levinsky, 2005). The husbands highlighted additional factors that negatively impacted on their health which have not been previously described in the literature on dialysis-caregivers.

A few husbands were dealing with their own health issues before their wives started dialysis, while others described experiencing unexpected adverse changes in their physical, emotional, and/or sexual well-being as a result of the demands of ESRD and dialysis. None of the husbands perceived that their health had interfered with their efforts to embrace their transformed life. However, experiencing health issues provoked significant concern for the husbands because, it could potentially impede their ability to continue to support their wives. Such concern, prompted most husbands to engage in self-care activities to replenish their energy and sustain their health.

All the husbands in this study reported experiencing varying levels of fatigue as a result of juggling multiple role responsibilities associated with: (a) assisting their wives with daily peritoneal dialysis exchanges, (b) organizing routines, (c) getting up at night to <u>troubleshoot</u> alarms for continuous cycling peritoneal dialysis (CCPD), (d) <u>watching over their wives,</u> (e) traveling long distances three times a week and having to drive in treacherous weather to the hospital dialysis, and/or (f) assuming new domestic duties that were typically performed by their wives over and beyond their own familial and/or career-related obligations. Researchers (Belasco & Sesso, 2002; Belasco, Barbosa, Bettacourt, Diccini, & Sesso, 2006) have found that a moderate-to-strong positive relationship exists between fatigue and depression among caregivers (primarily wives) of individuals on home hemodialysis.

Although the psychological well-being of the husbands was not measured in this study, some of them expressed a range of emotions during the interview, especially when discussing their concerns about their wives' suffering and the uncertainties about the success of dialysis treatment, the risk of death, sense of isolation and invisibility, and/or the availability of a kidney transplant. Some of the husbands reported being surrounded by a network of supportive people with whom they could share their feelings, while others were alone or tended to control or shield their emotions to not burden others, including their wives. Further, issues related to death and dying were seldom discussed between the partners. Yet, fears about their wives dying or that they would die before their wives weighed heavily on the husbands because they were concerned about how their wives would manage in their absence. Use of self-control strategies may have conveyed to others that they were not distressed or they were managing well and support was not needed (Dunkel-Schetter, Folkman, & Lazarus, 1987). Similarly, other researchers (Coe & Neufeld, 1999; Harris, 2002; Sandberg & Eriksson, 2007) have found that men caring for women with dementia were reluctant to use formal support; and when they finally did, they were experiencing a crisis.

The concealment of feelings by some husbands may be explained by the results of studies on masculinity and health-seeking behaviors (O'Brien, Hunt, & Hart, 2005; Seymour-Smith, Wetherell, & Phoenix, 2002). These researchers reported that some men may be unwilling to seek help from others, including health care professionals, about fatigue and emotional difficulty because they perceive that it is "unmanly" to discuss these issues (O'Brien et al., 2005, p. 515). Therefore, according to Ducharme et al. (2007), men's cultural attitudes are an important consideration when addressing the question of support and services for men.

All the husbands expressed disruption or cessation in their sexual intimacy with their wives since starting dialysis. Such information increases our knowledge regarding an area that has received limited attention in the literature (Lindqvist et al., 2000; Morelon et al., 2005). Reduced sexual and reproductive functions among dialysis patients are major stressors that frequently occur due to uremia, hormone imbalances, and the side effects of medications (Harwood et al., 2009; Tavallaii et al., 2009). Lowry and Atcherson (1981) found that "marital discord and sexual dysfunction were closely related to the level of depression in both patients and spouses" (p. 23). Most of the husbands in this study seemed to accept the disruption or cessation of sexual intimacy and continued to experience affection, gratitude, and love for their wives. However, my study also sheds light on the influence of changes in sexual intimacy on marital satisfaction which led a few husbands to consider leaving their wives; a finding that seems to validate dialysis patients' fear of personal abandonment by their spouse (Tavallaii et al., 2009). While no studies were found that addressed the impact of sexual dysfunction on divorce or separation among individuals on dialysis, a recent study found that the strongest predictor of separation or divorce within a year was a diagnosis of either a malignant brain tumor, solid tumour with no nervous system involvement, or multiple sclerosis in the wife (Glantz et al., 2009). The findings that all the husbands in this study reported changes in sexual intimacy emphasizes the importance of addressing the topic of emotional and sexual intimacy with the patients and spouses early in the stages of chronic kidney disease and to be especially sensitive to early indications of marital discord in couples.

Interactions with health care professionals. The husbands in this study provided insight about the ways in which their interactions with and the interventions of healthcare providers either complicated or enhanced their efforts to embrace their transformed life before and after dialysis was initiated. On the one hand, the helpful support provided by these professionals assisted husbands to address their wives' needs. Conversely, when the support was unhelpful, the husbands' workload and sense of isolation increased.

Pre-dialysis phase. While most husbands described very positive interactions with health care professionals before dialysis was started, others expressed concerns about the quality of care provided to their wives. The husbands perceived the care provided by renal professionals such as nephrologists, nurses, and dieticians to be very helpful. The finding is consistent with Thorne and Robinson's (1988) stage of naive trust, based on the evolving relationships between 26 family members caring for individuals with a chronic illness and healthcare professionals. The husbands in this study appreciated that renal professionals valued their involvement, welcomed their input and questions, involved them in decisions, and provided them with information and skills, which is similar to Luk's (2002) qualitative study of caregivers of home dialysis patients.

In some situations where the women were being monitored by non-renal specialists, the husbands perceived that their wives were receiving suboptimal care. They appeared to be situated in Thorne and Robinson's (1988) stage of disenchantment; their concern about their wives' suffering and fear that they might die if they did not intervene prompted them to seek care with and for their wives, to question and challenge decisions and interventions, to provide suggestions for care, and, in one case, to switch physicians. Although, the Canadian Society of Nephrology (CNS) has developed chronic kidney disease (CKD) clinical practice guidelines to facilitate physicians' early detection, management, and monitoring of CKD, as well as timely referral to nephrologists, studies have shown that family physicians may not be aware or use these guidelines (Agrawal, Ghosh, Barnes, & McCullough, 2009; Coritsidis, Linden, & Stern, 2011; Levin et al., 2008; Stevens, Farmer, & Hallan, 2010). The ratio of men to women (60:40) on dialysis in Canada has remained constant for more than a decade (CORR, 2011). As Levin (1999) explains, the difference in the proportions of men and women may reflect gender bias in referrals since women tend to be referred to nephrologists later than would be considered appropriate (Agrawal et al., 2009) which may increase mortality risk from complications of kidney failure before the need for dialysis is recognized. Such explanation may clarify why some women received a diagnosis of kidney failure after experiencing a sudden and unexpected health crisis, while others waited for prolonged periods of time before being referred to and diagnosed by a nephrologist. Although the number of individuals with CKD referred to a nephrologist less than three months prior to starting dialysis has improved to 42% in 2001 from 31% in 2009 (CORR, 2011) on-going educational efforts are necessary for non-renal health care professionals including nurse practitioners to raise awareness about the CKD guidelines and the importance of timely referral. Furthermore, monitoring the utilization of such protocols needs to be an important priority to meet the standards of care identified by various associations including the Canadian Association of Nephrology Nurses and Technologists (CANNT, 2008) and CSN (2012) who are working collaboratively to improve the delivery of health care to kidney disease patients in Canada.

Dialysis phase. In this study, the husbands perceived a lack of power in their interactions with healthcare professionals when the women started dialysis. When the husbands witnessed, or their wives expressed receiving sub-optimal, unprofessional, or insensitive care from healthcare professionals, the men advocated on behalf of the wives and confronted these professionals to ensure that competent services, treatments, and care were provided to their wives. Similar caregiving behaviors have been described by other researchers (Beanlands et al., 2005; Tong, Sainsbury, & Craig, 2010). In line with Thorne and Robinson's (1988) conceptualization of the types of relationship between family members and healthcare professionals, the actions of the husbands in the present study were consistent with the stages of disenchantment and guarded alliance. They were caught in the dilemma of being fearful that their wives' care could be further compromised if they questioned healthcare professionals too much or made too many suggestions for better care; but prior experiences had taught them that by remaining silent, their wives could suffer unnecessarily, a concern also expressed by other caregivers of dialysis patients (Beanlands et al., 2005; Tong et al., 2010).

In this study, the husbands' level of comfort in approaching renal professionals varied according to the length of time the women had been on dialysis. Husbands whose wives had been on dialysis for a significant period of time learned to navigate the system, to elicit support and care from professionals by using non-threatening strategies such as creating a humorous ambiance and being courteous with their questions and suggestions also reported by Beanlands et al. (2005) and Campbell (1998). In contrast, those whose wives had been on dialysis for short periods of time walked on egg shells when approaching care professionals or remained silent rather than risk alienating them or being labeled troublemakers. This latter stance was echoed by some family members in Thorne and Robinson's (1988) study and Campbell's (1998) report on caregivers of aging ESRD patients. Similar to the caregivers in other studies, the husbands in this study wanted the renal professionals to provide more emotional support to their wives (Campbell, 1998; Wagner, 1996). This finding is not surprising considering the fact that a recent meta-synthesis of the experiences of dialysis patients by Shick-Makaroff (2012) found that patients felt emotionally distant from healthcare professionals and that discussions rarely progressed beyond a superficial level, which left their needs and concerns neither acknowledged nor addressed. In such situations, the husbands were often alone in shouldering the responsibility for addressing their wives' emotional needs.

For some husbands, the negative aspects of their interactions with healthcare professionals were to a certain extent counterbalanced by their positive experiences with exceptional renal professionals who provided compassionate and supportive care to their wives and themselves along the way. These will be addressed in the following section on the implications for practice.

Implications for Practice

The theory of embracing a transformed life is consistent with some research, conflicts with other work, and extends information in the areas of dialysis-caregivers, men as caregivers, and other related concepts discussed in the previous sections. The introduction of the substantive theory is timely because it provides direction for dialysis-caregiver interventions consistent with the ever growing numbers of individuals diagnosed with ESRD. Moreover, the focus on husbands living with women on dialysis begins to close an existing gap in knowledge about the impact of kidney failure and its treatment regimens. The identification of discrete stages in the theory of embracing a transformed life provides a framework for nurses to better understand the various changes dialysis-caregivers may experience during different phases of the patients' illness trajectory and to implement supportive care to enhance their adjustment and sustain their efforts.

The husbands played a major and important role in providing illness-related care as well as emotional and protective support to their wives. The husbands began to experience changes in their lives as soon as they became aware that their wives' health was failing. For some husbands, changes occurred suddenly in response to their wives unexpected health crisis, whereas for others, changes occurred gradually in concert with their wives' progressive deteriorating health. Hence, the diagnosis of kidney failure and need for dialysis initiated a period of significant distress and adjustment for both these groups of husbands to a long-term chronic but also life-threatening illness. In response, the husbands experienced considerable anxiety and uncertainty, which are common responses to situations in which there is a threat of potential loss or harm (Folkman & Lazarus, 1984). Such emotional reactions suggest that while the husbands provided support to their wives before dialysis was initiated, they too needed emotional support. According to Sherman, Kaparian, and Mireskandari (2010), the extent of support a partner can provide during the diagnostic phase of a life-threatening illness is limited by his or her own ability to cope with the situation. This suggests that health professionals need to consider the emotional needs of the husbands, not just the needs of those for whom they care. As well, most men indicated that they would have appreciated being better prepared to assist their wives with the adverse effects of ESRD and dialysis and to manage dialysis-related expenses. Such information would have helped them to anticipate, to prepare for, and to adjust to changes over the span of the illness trajectory.

The husbands wanted to be involved in seeking care and information, as well as acquiring the necessary knowledge and skills to assist and support their wives with illness-related care before dialysis was initiated. Support received from nephrologists facilitated the husbands' involvement when they were encouraged to attend pre-dialysis care with their wives and to ask questions. The support also assisted them to make sense of the situation, particularly when simple language and visual materials were used. Hence, it is important to continue to prepare and support dialysis-caregivers before dialysis is initiated.

The husbands appreciated being provided with hands-on training sessions for CAPD or CCPD and receiving a general orientation to the dialysis unit by renal nurses. Such information assisted the husbands to develop confidence in their ability to perform peritoneal dialysis (PD) and to buffer the impact of seeing their wives for the first time on a dialysis machine. The extent of PD training the husbands received varied across dialysis units within the same province and across different provinces. Therefore, developing standardized training protocols may provide more consistency. The husbands of women on CAPD or CCPD appreciated having access to renal nurses via a 24-hour pager system and receiving follow-up visits at home or phone calls shortly after dialysis. Such contact provided husbands with opportunities to ask questions, seek advice, and receive feedback about PD. Unfortunately, such follow-ups were short-lived and focused only on dialysis-related tasks and not on the husbands' adjustment to providing assistance with dialysis.

Hence, periodic follow-up from renal nurses to assess changes in the husbands' level of involvement with PD and their need for additional preparation and emotional support would be helpful. The information gathered would provide a framework for consistent and individualized care and the development of early and on-going interventions to assist these caregivers.

Although most husbands found CAPD or CCPD to be convenient, they also reported that assuming complete responsibility for managing their wives home dialysis to be isolating. Campbell (1998) indicated that while most dialysis-caregivers are incredibly dedicated to assist with dialysis-related care, they cannot be expected to continue to manage care on a long term basis without the assistance of others (Campbell, 1998). Therefore, in order to reduce the emotional and physical strain of assisting with dialysis on the caregivers, it would be helpful to teach other family members to assist with PD in order to provide relief to and/or to take the place of the dialysis-partner when sick or unavailable to perform dialysis (Courts, 2000).

The husbands benefitted from opportunities for formal exchanges of information with members of the renal team. When healthcare professionals tapped into the husbands' rich experiential knowledge of their wives and their understanding of their wives' responses to both kidney failure and dialysis treatment, the husbands felt valued, supported, and reassured that their wives were receiving the best care. Akin to previous studies, the husbands in the present study wanted to be seen by healthcare professionals as crucial partners in a cooperative process (Beanlands et al., 2005; Campbell, 1988; Friesen, 1997; Wagner, 1996). As Beanlands et al. (2005) indicated, dialysis-caregivers may serve as valuable allies to renal professionals and suggested that their input be routinely and regularly sought. Renal nurses working in hospital or home dialysis units are in a position to be strong advocates for spouse-caregivers when they feel unheard or misunderstood. It would be helpful for dialysis-caregivers to have access to clinical nurse specialists or nurse practitioners with expertise in caring for renal patients and their families. These nurses could serve as a patient-family advocates and resources as well as, facilitators of communication between families and the other healthcare professionals.

The husbands perceived themselves to be invisible to healthcare professionals, particularly those who had limited contact with the renal staff because they dropped their wives off at the hospital dialysis unit or assisted with peritoneal dialysis at home. Furthermore, social isolation was reported by husbands whose wives were more physically and cognitively debilitated by the illness. These husbands compared the extent of their isolation to “being in solitary confinement” and “being tied down.” Such findings highlight that they may not have been adequately prepared and did not have the support they required to function optimally in their new roles. Occasionally the husbands were praised by health care professionals for their efforts to enforce the dietary regime, however, other role responsibilities remained unseen and unacknowledged. For the husbands whose presence is less visible around dialysis unit, emotional support needs to be extended beyond the boundaries of hospitals into the homes. Researchers suggest that a phone call and a separate interview with a spouse periodically would be beneficial to determine the impact of the illness on their daily lives, their health, and coping over the span of the ill partner’s illness (Campbell, 1998; Srivastava, 1988). Further, healthcare institutions need to explore the feasibility of using technology as a mean of connecting with dialysis-caregivers, given that some of the husbands in this study were both familiar and skilled with using computers, facetime, and video calling on Skype. They may also benefit from having access to a specifically designed Dialysis-Caregiver Web site that provides comprehensive and reliable information about interventions on caring for themselves, managing their own health, and providing assistance to dialysis patients. Other researchers have found that when caregivers who provide home parenteral nutrition accessed evidence-based interventions, information, and guidelines on caregiver Web sites, their quality of life and health improved (Fitzgerald, Yadrich, Werkowitch, Piamjariyakul, & Smith 2011; Smith et al., 2003)

For the husbands who wait outside the hospital dialysis unit for their wives to complete their treatment, supportive strategies could be implemented during that time period. Creating a welcoming environment by allowing husbands to sit with their wives while they dialyzed provided opportunities for husbands to support their wives while in turn, it positioned them well to receive support from the renal staff. Moreover, when the nurses invited both partners to engage in meaningful conversations about the effect of illness on their lives, it proved to be an important intervention that assisted them to move beyond and overcome challenges.

In this study, a few husbands did not have anyone with whom they could share their feelings, while some masked their emotions from others, including their wives. In a discussion forum about the role of men in caregiving, the Canadian Caregiver Coalition (2003) recommended that community supports services and groups be specifically designed to address the needs and emotional responses of male-caregivers. Healthcare providers also need to develop a strategic set of skills and techniques to encourage men to become active participants in such programs because it may be difficult for some men to participate especially those who ascribe to the hegemonic masculine ideal that asking for help is a weakness (Gillon, 2007). Researchers have found that participation in an exclusive male support group provided a more comfortable milieu for caregiving men to discuss their fear about losing their wives, concerns about emotional and sexual intimacy with their wives, and challenges with assuming non-traditional gender roles (Harris, 1993; Sabo et al., 1986). Therefore, those planning, organizing, and conducting caregiver support services need to be sensitive to the needs of male caregivers. In this study, a small group of husbands whose wives had been on dialysis for extended periods of time were involved in providing one-on-one support to dialysis patients and their family through The Kidney Connect Peer Support Program of the Kidney Foundation of Canada (KFC, 2012). Therefore, men may be more open to opportunities to mentor or be mentored by another male caregiver prior to the start of dialysis and beyond. The peer mentoring program may provide opportunities for husbands to interact with others who have experienced personal growth from embracing a transformed life of living with wives on dialysis.

Juggling multiple role responsibilities impacted on the husbands' work, social life, leisure activities as well as their emotional and physical health. Healthcare professionals need to explore the impact of changes on the spouses' health, be vigilant in monitoring for signs of distress, depression, and fatigue and intervene to provide psychological support and make appropriate referrals. In keeping with the Canadian Caregiver Coalition guidelines (2012) all dialysis-caregivers should be assessed for their specific needs and provided with emotional, psychological, and physical support in order to sustain their contribution to the provision of care. Nurses can implement gender sensitive strategies to elicit health information and issues that male caregiver may be reticent to discuss. The information gathered would provide a framework for consistent and individualize care and the development of early and on-going interventions that focus on rest, sleep, and respite to prevent physical and emotional depletion and improve well-being.

Social Policy

Adjusting to changes also impacted on their career and/or education opportunities as well as their finances. I will discuss the implications of these findings on the development of social policies to enhance and sustain the adjustment of husbands.

Employment and career-outcomes. The husbands indicated that kidney failure and its associate treatment affected their employment more than their employment impacted their involvement in multiple role responsibilities. Two decades ago, Brunier and McKeever (1993), in a review of the literature on families of individuals on home dialysis, recommended that researchers investigate the impact of dialysis treatment on the employment of family members; however, information about this issue remains limited (Blogg & Hyde, 2008; Morelon et al., 2005). The husbands began to experience changes in their work during the second stage of involving oneself when they had to periodically take time off from work to go to doctors' appointments with their wives. Once the women started dialysis, the husbands took an employer-approved leave of absence from their work for varying periods of time to center life on their wives, similar to the husbands of women with breast cancer during chemotherapy treatments (Hasson-Ohayon, Goldwaig, Braun, & Galinsky, 2009; Wagner, Das, Bigatti, & Storniolo, 2011). Unlike the participants in prior research on women assisting family members on home hemodialysis (Blogg & Hyde, 2008; Morelon et al., 2005) or husbands caring for wives with multiple sclerosis (Boeije, Duijnstee, & Grypdonck, 2003), none of the husbands in this study had to permanently give up their employment, take early retirement, or switch from full-time to part-time work to assist their wives. Differences between the findings of this study and others may be attributed to two factors: the husbands did not need to assist with home hemodialysis and more than half of the husbands (55.5%) were already retired by the time their wives' started dialysis.

According to recent reports on Canadian caregivers (Hollander, Liu, Chappell, 2009; Keefe, 2011) and data from the 2010 General Social Survey (Statistics Canada, 2010), researchers consistently estimate that more women than men experience changes in their work and career opportunities in order to provide care to a person who needs assistance due to a disability, illness, or other difficulty. However, the husbands made similar employment-related changes to those reported by women. For example, the husbands made permanent changes to their work patterns such as working weekends or evenings to be available to assist their wives with illness-related care and they also had to turn down opportunities for additional training or responsibilities especially if traveling or working long hours were involved.

Keefe (2011) predicts that any changes women make to carers to provide care to others will have "long-term consequences for women's economic security, as they may affect pension contributions and retirement saving" (p. 8). It is not known from the literature whether family members who assist those on dialysis are at risk or have already experienced similar consequences. In response, there has been much debate concerning the issue of remunerating family caregivers in recognition of the care they provide to a family member with a disability or chronic long term illness. Currently, Canada does not have any policies to financially compensate family caregivers in the form of salary/wages or allowances for part/full-time care work they provide (White & Keefe, 2005). However, Australia, Sweden, United Kingdom, and Norway have compensation programs that offer carers monthly or bi-weekly taxable allowances and pension credits. These have been recommended as important initiatives for the Canadian health care system to undertake.

In a recent initiative, the Government of Canada (2011) introduced a new Family Caregiver Tax Credit and removed the limits on eligible expenses to be claimed under the Medical Expense Tax Credit for families assisting financially dependent ill family members. These programs which have been designed to recognize the personal sacrifices that Canadian caregivers make to provide care to others and to lighten their load are a step in the right direction. However, they fall short of addressing the long-term financial impact of assisting with dialysis care. Policy makers need to support programs that bring family caregivers and professionals together to engage in discussions of effective ways to support ESRD families.

Financial-related outcomes. Another unexpected outcome of assisting with dialysis treatment and adopting the renal dietary regime was the extra expenses that created a financial burden for the husbands and their families. This finding has also been mentioned in a number of studies on family members of individuals on dialysis (Luk 2002; Peterson, 1985; White & Grenier, 1999; Ziegert, Fridlund, & Lidell, 2006). However, the nature of the expenses and the overall impact of the financial burden were not described. This is not surprising given that a recent Canadian Caregiver Coalition report (2012) and other researchers (Clabaugh & Ward, 2008; Piamjariyakul et al., 2011) have revealed that information on out-of-pocket, non-reimbursable expenses paid by families who provide care to individuals dependent on technology at home is absent, underestimated, or underreported in the literature. The husbands provided insight into the types of out-of-pocket expenses they absorbed weekly, monthly, or periodically. Although the overall cost of these expenses was not collected in this study, a report from the Kidney Foundation of Canada (2012) indicated that families can spend approximately $21,381 annually of their own money on comparable dialysis-related expenses (KFC, 2012). None of the husbands in this study had expected or prepared for these extra expenses during their working or retirement years.

In the present study, the average age of the women was 61.2, with an age range of 45 to 64 (34.9%), which is slightly above the average age of 58 for Canadians with ESRD (CIHI, 2012), whereas the husbands' ranged in age from 41 to 82, with a mean age of 63.5. This suggests that most of the couples were situated in Erickson's (1980) mid-life development stage of *generativity vs. stagnation* (35 to 65 years of age), which covers a key period of life when individuals are most likely to be focusing on developing a career, providing for their family, generating income, saving for retirement, or planning for or transitioning into retirement (Erickson, Erickson, & Kivnick, 1986; Gee, Howe, & Kimmel, 2005). Consequently, some of the husbands reported having to live on a strict budget (Luk 2002; Peterson, 1985), while others resumed part-time work to supplement their retirement income or delayed their retirement, contemplated declaring bankruptcy, or had to draw from the savings they had planned for future use.

While it costs the health care system approximately $60,000 per patient annually to provide hospital hemodialysis (CIHI, 2010), the burden of the costs associated with dialysis is clearly also borne by patients and their families. Although medical tax benefits, the disability tax credit, and the compassionate care leave benefit covered by employment insurance may be useful for some, they are also restrictive (Government of Canada, 2012). For example, in order to claim medical tax benefits, the husbands needed to travel a minimum of 80 km each way per dialysis session. However, there were a number of situations where the husbands were not eligible for the refund, even though their combined weekly millage for three dialysis treatment sessions per week exceeded that distance. As well, eligibility criteria for the compassionate care benefit program required that the care recipient be “gravely ill and be at significant risk of dying within 26 weeks (six months)”. The average life expectancy for patients on dialysis is approximately 5 years (CIHI, 2012), thus most families do not qualify. Revising the eligibility criteria for compassionate care benefits from “significant risk of death” to “significant need of caregiving due to a life threatening illness” could make the benefits possible for dialysis-caregivers. Dialysis couples need to be informed about the financial costs of on-going treatment and eligible tax credits for illness-treatment-related expenses. As well, on-going efforts for patients to have access to satellite dialysis centers closer to where they live would reduce some of the travel costs and reduce fatigue.

Study Limitations

The substantive theory is limited by the small sample of husbands that participated in the study. Nonetheless, diverse age groups, education levels, socio-economic status, and geographical locations were represented within three Maritime Provinces. The men were all Caucasian and mostly Anglophone, except for two who were unilingual Francophone, and one who was bilingual. Therefore, the theory may not be transferable to husbands from other ethno cultural groups or communities. A second limitation is that all husbands who participated in this study were married in the church and therefore, the experiences of other conjugal relationship such as common-law partners, and those who have been married in a civil ceremony may not share the same values and beliefs that influenced the husbands’ commitment to embrace a transformed life. Third, none of the participants were provided with an opportunity to take part in a repeated interview with the researcher. However, member checking about the developing substantive theory did occur with some participants when they were asked to comment, elaborate, and clarify the provisional analysis from previous interviews.

A fourth limiting factor, “elite bias”, relates to the study population (Sandelowski, 1986, p. 32). The husbands who agreed to participate in this research project may have been somehow different than those who chose not to or were not provided with the opportunity to participate. For example, some of the potential participants refused to take part in an interview but would have readily responded to a questionnaire, others who did participate were initially reluctant because they did not believe they were sufficiently educated to take part in the study. A number of other husbands took part after receiving encouragement from their wives, and a significant number were not provided the opportunity to choose to take part because the husbands were not directly approached to be recruited.

A fifth limitation is associated with not having included husbands whose wives were in the pre-dialysis stage and, therefore, the passage of time between the women starting dialysis and the interview may have influenced the husbands’ ability to recall information about the changes and adjustment before dialysis was initiated. The final limiting factor is related to the process of grounded theory construction, whereby “the investigator makes many choices about paths to follow that are influenced both by the data and the investigators’ theoretical sensitivity” (Wuest & Merritt-Gray, 2001, p. 169). For this study, every attempt was made to analyse the information in an unbiased manner. Wuest (2007) argues that in grounded theory, there are advantages to researchers bringing to the study and the process of data analysis their pre-existing knowledge and familiarity with information and theories, particularly from their own field of expertise.

Future Directions for Research

Grounded theory is an approach to theory development that is consistent with the constructivist worldview. Thus, this middle range theory developed in the present study is context specific and open to modification. Glaser (1978) calls for extending substantive grounded theories toward formal theory in order to build a cumulative body of knowledge. Glaser (1978) suggests that one means of moving toward grounded formal theory is by “expanding a single, existing substantive theory with comparative data of other areas, and comparative analysis of several existing substantive theories…” (p. 144). The present theory is a small step toward such cumulative knowledge development;

however, it must not end here. The next step is to continue the constant comparative method by collecting data in other substantive areas.

Directions for further studies of men's experiences with adjusting to living with women/partners on dialysis are indicated. The experiences of men in which the marital relationship has been strained by the demands of kidney failure and its treatment regimens, those who have divorced or separated after their wives started dialysis treatment, as well as those who provided assistance under conditions where there is no reciprocity in the relationship need to be explored.

The research needs to be expanded to include men of different ethno-cultural communities including same-sex couples to determine how social diversity influences the process of embracing a transformed life. The findings from this study indicated that the marital relationship changed. Therefore, another area for additional research would be to include both partners in a longitudinal study to better understand how couples' relationships are affected favorably and unfavorably.

In the current study, several participants were experiencing health issues prior to the wives starting dialysis, while others experienced changes in their health after the women started dialysis. The impact of juggling multiple role responsibilities on the husbands' physical and emotional well-being needs to be further investigated. Investigating the impact of providing dialysis assistance on the caregiver's health may guide health care professionals to implement early interventions to prevent and/or address health issues. As well, exploring the men's experiences in seeking support would provide valuable information to health care providers in planning, developing, and implementing gender specific caregiving services and programs.

The number of Canadians age 65 and older experiencing ESRD and co-morbidities such as diabetes and cardiovascular diseases is projected to continue to grow over the next decade (CIHI, 2011). Furthermore, the life expectancy between the sexes has been shrinking with women presently being 83 years of age and 79 years of age for men (Statistics Canada, 2012). Both of these trends will likely influence the number of older dialysis-caregivers who will be required to assume not only more complex role responsibilities but also for a much longer duration than previous generations. Hence, focusing on this older generation of dialysis caregivers may guide nurses to develop age appropriate interventions. Another implication of being an older dialysis-caregiver may involve having to make difficult decisions with or on behalf of their spouse or other family member to withdraw (discontinue) or withhold (not initiate) dialysis treatment. Identifying the changes created by end-of-life circumstances would provide additional information about another important stage in life that has been transformed by ESRD.

Summary

The theory of husbands <u>embracing a transformed life of living with women on dialysis</u> begins to close an existing gap in knowledge about the impact of kidney failure and its treatment regimens. It highlights the complex process of adjustment husbands undergo in response to the multiple changes in their lives. The findings underscore the abilities of husbands to learn and carry out complex roles, responsibilities, and routines that require sophisticated observation, decision making, and technical and problem-solving skills. Underpinning this repertoire of skills was their personal knowledge of their wives as individuals and their understanding of their wives responses to the illness and its treatment. Such knowledge positioned them well to address their wives' physical and emotional needs. Regardless of age and prior experience, they had to learn tasks associated with household work that required most to traverse gender-role boundaries. Some men derived satisfaction from learning these skills, while others considered them to be unpleasant chores. Many of the husbands' efforts to assist, support, and care for their wives were invisible to others. This was especially the case for husbands who shouldered all responsibilities for illness-related care, had limited contact with healthcare professionals, received no support from family members, and/or did not want to burden others. Consequently, some of these men experienced isolation, resentment, and/or frustration living with women on dialysis. Despite the hardships inherent in the changes imposed by the illness and its treatments, the husbands did not waver in their commitment to <u>embrace a transformed life</u>. This was rooted in their desire to be there for their wives, to validate their love for them, and to reciprocate their appreciation for the support previously provided to them.

<u>Embracing a transformed life</u> is an on-going process of engaging, integrating, managing, and adjusting to changes in their lives. It also represents a progression from one way of living, being, and doing to other ways that allow husbands to accommodate

the demands and changes imposed by a chronic illness and its treatments. With ingenuity, courage, and personal efforts, most of these husbands rose to the occasion of incorporating changes in their lives, adjusting their expectations, and making the most of their newly redefined life. In doing so, they were able to <u>embrace their transformed life</u>.

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Appendix A: Renal Replacement Therapies

The incidence and prevalence of ESRD have greatly increased in Canada over the last two decades (Canadian Institute for Health Information [CIHI], 2011). According to the most recent annual report of the Canadian Organ Replacement Registry (2009) close to 38,000 Canadians were living with kidney failure in 2009 which is more than triple the number of individuals (N = 11,000) in 1990. The largest increase occurred in older age groups, with prevalence rates escalating by more than 500% for those ages 75 and older. Patients in this age group account for 20% of all kidney failure cases (CIHI, 2011).

Nationally, there are more men living with ESRD (n = 59.6%) than women (n = 40.4%) (CORR, 2011), however, the number of women diagnosed with kidney failure has been increasing steadily over the last decade due in part to the increase prevalence of hypertension among women (Public Health Agency of Canada, [PHAC], 2010).

Causes of end-stage renal disease

The two most common causes of ESRD are diabetes and high blood pressure, but kidney disease can also be caused by an inherited kidney disease such as polycystic kidney disease, infection or by trauma (KFC, 2012). Diabetes is the leading cause of ESRD, accounting for 35% of incident in patients: one in three people with kidney failure have diabetes (CIHI, 2011). Diabetic nephropathy is a serious complication associated with long-term diabetes. Over the years, high blood glucose levels and high blood pressure can damage the kidneys and prevent them from functioning properly or even cause them to fail completely (Canadian Diabetes Association, [CDA] 2012). About one-third of people who have had diabetes for more than 15 years will develop kidney disease, but good diabetes management and regular screening can prevent or delay the loss of kidney function (CORR, 2011). In Canada, more than 3 million Canadians are living with diabetes and this number is expected to reach 3.7 million by 2020 as a result of increases in rates of obesity and inactivity, as well as an aging population (CDA, 2012). These trends will likely increase the number of individuals who may need dialysis.

Cardiovascular disease (CVD) is the second cause of kidney failure and is the most common cause of death in patients with ESRD (CORR, 2003). The most common cardiovascular abnormality is hypertension, which usually present pre-ESRD and is worsened by sodium retention and increased extra cellular fluid volume (Holechek, 2004). Nearly 6 million Canadians aged 20 years and older which represents more than one in five adults were living with a diagnosis of hypertension in 2006/07 (PHAC, 2010). During that period of time, more women (24.0%) than men (21.3%) had hypertension. It is predicted that within the next decade, about 7.3 million Canadians will be living with hypertension which will represents an estimated increase of about 25.5% individuals since 2006/07 (PHAC, 2010).

Renal replacement therapies

Three major treatment approaches exists for ESRD: center or home-based hemodialysis, home-based peritoneal dialysis (continuous or automated), and renal transplantation. There is no cure for ESRD and therefore, these treatment options are life-prolonging. Dialysis "is a technique in which substances move from the blood through a semi-permeable membrane and into a dialysis solution (dialysate)" (Holechek, 2004, p.1228). It is used to correct fluid and electrolyte imbalances and to remove waste products in renal failure (Holechek, 2004). According to the CIHI (2011), the unadjusted 5 year survival rates for individual are 51% for those on peritoneal dialysis, 41.4% for hemodialysis, 89% for recipients of living-donor kidneys and greater than 80% for recipients of deceased-donor kidneys. Among Canadians who were treated for ESRD in 2010, 59% were on dialysis and 41% were living with a kidney transplant (CORR, 2011). The vast majority of patients receive hospital hemodialysis (n = 18,244), followed by home peritoneal dialysis (n = 4,110), and home hemodialysis (n = 834) (CORR, 2011). More men than women are on all three types of dialysis modalities.

In hemodialysis, blood is filtered through semi-permeable membranes in the dialyzing machine to remove toxins and excess fluid. Hemodialysis is a procedure which requires the patient to be "on" the dialysis machine up to three times each week, from two to five hours each session (Holechek, 2004). The number and duration of treatment sessions depend on the amount of loss of kidney function. Hemodialysis can be performed either in the patient's home or in a hospital setting.

In home hemodialysis, the patient collaborates with a caregiver usually a spouse in using, monitoring, and operating the dialysis equipment (Smeltzer & Bare, 2000). Both patient and caregiver receive intensive training sessions of four to six weeks duration to learn about preparing, operating, and dissembling the machine, maintaining and cleaning the equipment, administering medications, and handling emergency problems associated with the dialysis machine or patient (Holochek, 2004). Because home hemodialysis places primary responsibility for treatment on the patient and the caregiver, it is essential that they understand and can competently perform all aspects of the hemodialysis procedure (Smeltzer & Bare, 2000). In hospital hemodialysis, the patient receives dialysis treatment from the hospital staff who operate, prime, and maintain the machine as well as monitor blood pressure, fluid, and chemical levels (Holochek, 2004).

An alternative treatment to hemodialysis is peritoneal dialysis in which no blood is removed from the body. Instead, a catheter is inserted through the anterior abdominal wall and dialysate fluid is introduced through the tubing into the peritoneum, causing dialysis of water and waste material to occur slowly and continuously through the peritoneal sac (Holochek, 2004). There are two types of peritoneal dialysis performed at home: Continuous Ambulatory Peritoneal Dialysis (CAPD) and Automated Peritoneal Dialysis (APD). CAPD is carried out manually by exchanging 1.5 to 3 L of peritoneal dialysate at least four to five times a day, seven days a week at intervals scheduled throughout a 24-hour period of time (Holochek, 2004). It is critical in peritoneal dialysis that the patient maintains aseptic technique to avoid peritonitis that results from contamination of the dialysate or catheter tubing (Smeltzer & Bare, 2000). In APD, an automated device called a cycler is used to deliver the dialysate. The machine cycles three to five, 2 liter exchanges per night, seven nights a week. Alarms and monitors are built into the system to make it safe for the patient to dialyze while sleeping. The patient disconnects from the machine in the morning and usually leaves dialysate fluid in the abdomen during the day (Holochek 2004; Smeltzer & Bare, 2000). Compared to hemodialysis, peritoneal dialysis allows the patient to be more mobile, causes less hemodynamic instability (i.e., hypotension, nausea, vomiting) and requires less food and fluid restrictions.

Decision making about dialysis modality is made by the patients, significant others, and/or physicians (Courts, 2000). While some patients have medical or psychological problems that preclude a particular dialysis modality, the majority of the patients do have a choice (King, 2000). Several studies have identified the following factors that may influence a patient's choice of dialysis modality: (a) patient's need for autonomy, independence, and control; (b) patient's fear of needles and blood, concerns about being tied to a machine and threats to body image; (c) health care professionals' assessment that one type of treatment may be more or less effective or convenient for a particular individual; and (d) patient's refusal or lack of motivation to assume self-care responsibilities for home dialysis and/or spouse or other family member's refusal to assist with dialysis care at home (Whittaker & Albee, 1986).

With advances in kidney transplant methods and improvements in transplant success, a kidney transplant is now widely considered to be the best way of treating ESRD for many people (KFC, 2012). An advantage of kidney transplantation compared to dialysis is that it reverses many of the pathophysiological changes associated with renal failure and eliminates the dependency on dialysis and accompanying dietary and lifestyle restrictions (Molzahn, Starzomski, & McCormick, 2003). A successful transplant will typically last 10 to 20 years (KFC, 2012). Additionally, transplantation in comparison to both CAPD and hemodialysis improves patients' and families' quality of life (Evans et al., 1985; Winsett & Hathaway, 1999). Unfortunately, in Canada as in the rest of the world, there is a critical shortage of available kidneys for transplantation (CORR, 2011). As a result, suitable candidates for kidney transplantation may not only have to endure a lifetime commitment to dialysis treatment, but some may die waiting (CORR, 2011). Between the period of 2001 and 2010, there was an average of 68 deaths per year involving people on the waiting list for a kidney transplant and 3,000 people waiting for period that vary between two to five years for a transplant depending on where the individual lives in Canada (CORR, 2011).

Cost of Kidney Failure and Renal Replacement Therapies

The annual cost for hospital hemodialysis which is the most common form of dialysis is approximately $60,000 per patient year, while the average cost of a one-time kidney transplant is $23,000, plus approximately $6,000 per year for necessary medication to maintain the transplant. According to CIHI (2011) in 2009, patients living with kidney transplant saved the health care system an estimated 800 million dollars. The burden of kidney failure includes not only the direct costs associated with medical care but also the psychological and social costs borne by patients and their families.

Appendix B: Demographic Information

The following information will be obtained from the informants during the interview and observation sessions.

Address: Type of domicile (apartment, house) ___________________________________
Employment status (full-time, part-time, retired, or unemployed) ___________________
Presence of dependent children in the home (number, age, and gender) ______________
Presence of grown-up children outside the home (type of assistance they provide, distance they live from parents, gender, age) ___________________________________
Spouse/Partner`s health (presence of health problems)____________________________
Age of the spouse/partner_________________ Age of the patient__________________
How long have they been married or living together______________________________
How long has the wife/partner been on dialysis _________________________________
Type of dialysis received _______________________, changes in dialysis type (when and why)_____________________, transplant candidate ________________________
Type of care required by wife (activities of daily living i.e., bathing, toileting, medicating) ____
Type of assistance the husband provides with dialysis care or other care ____
Number of hours of care per day/week____
Community Services (i.e., paid caregiver, community nurse, meals on wheels, transportation, cleaning services)____
Number of hours of community care per day/week ________________________________
How long have community services been in use? ________________________________

Annexe B: Données Démographiques

Les renseignements suivants seront recueillis auprès des informateurs lors des entrevues et des séances d'observation.

Adresse: type de domicile (appartement ou maison) ____________________________
Situation par rapport à l'emploi (temps plein, temps partiel, retraité ou sans emploi) ____
____
Enfants à charge au foyer (nombre, âge et sexe) ________________________________

Enfants d'âge adulte à l'extérieur du foyer (type d'aide fournie par ces enfants, distance entre leur lieu de résidence et celui des parents, sexe et âge) _______________________

Santé de l'époux ou du conjoint (présence de problèmes de santé) _________________

Âge de l'époux ou du conjoint _______________ Âge de la malade _______________

Nombre d'années de mariage ou de vie commune ______________________________

Nombre d'années de dialyse de l'épouse/conjointe ______________________________

Type de dialyse reçue _____________________; changement du type de dialyse (quand et pourquoi) ___________________; candidate à une greffe _____________________

Types de soins requis par l'épouse/conjointe (activités de la vie quotidienne, p. ex., se laver, aller aux toilettes, prendre des médicaments) _____________________________
____
Type d'aide fournie par l'époux/conjoint en ce qui a trait à la dialyse et aux autres soins
____
Nombre d'heures de soins requis par jour/semaine ______________________________

Services communautaires (p.ex., soignant rémunéré, infirmière communautaire, service de repas à domicile, transport, service ménager) ________________________________
____
Nombre d'heures de services de soins communautaires requis par jour/semaine ________

Depuis combien de temps fait-on appel aux services communautaires? ______________

Appendix C: Information Letter to Women on Dialysis

Dear Patient:

My name is Maryse Pelletier-Hibbert. I am a doctoral nursing student at McGill University in Montreal. I am doing a study to learn what it is like for husbands/partners to live with women on dialysis.

I would like to speak with husbands/partners who live with women on dialysis and who are at least 19 years of age. At some point in the study, you may also have a chance to meet with me during an informal visit with your husband/partner to share your comments.

One of the nurses who works in the dialysis unit has approached you to see if you would be willing to give an envelope with information about the study to your husband or partner and to ask him if he would accept having the nurse share his phone number with the researcher (Maryse) so that she can call him about the study.

If you are comfortable with doing this, please give your husband/partner the envelope that the nurse has given you. The nurse will do a follow-up with you in about a week. I appreciate your help.

Thank you

Maryse Pelletier-Hibbert

Annexe C: Lettre D'information aux Femmes en Dialyse

Bonjour chère patiente,

Je m'appelle Maryse Pelletier-Hibbert. Je suis étudiante au doctorat en sciences infirmières à l'Université McGill, à Montréal. Je mène une étude dont le but est d'apprendre ce que vivent les hommes dont l'épouse ou la conjointe suit un traitement de dialyse.

J'aimerais discuter d'une étude avec des époux/conjoints qui sont âgés d'au moins 19 ans et qui vivent avec des femmes qui se font dialyser. Plus tard au cours de l'étude, vous aurez peut-être vous aussi l'occasion de me rencontrer et de me faire part de vos commentaires lors d'une rencontre informelle en compagnie de votre époux/conjoint.

L'une des infirmières du service de dialyse vous a demandé si vous accepteriez de;

a) remettre une enveloppe avec information à propos de l'étude à votre époux ou conjoint.
b) demander à votre époux ou conjoint s'il accepterait de partager son numéro de téléphone avec Maryse Pelletier-Hibbert.

Je vous saurais gré de bien vouloir lui donner l'enveloppe brune que l'infirmière vous a remise. L'une des infirmières du service de dialyse fera un suivi avec vous au cours des prochains jours.

En vous remerciant de votre aide, je vous prie d'agréer l'expression de mes sentiments les meilleurs.

Maryse Pelletier-Hibbert

Appendix D: Information Letter to Husbands/Partners

Dear Husband/Partner

My name is Maryse Pelletier-Hibbert and I am a doctoral nursing student at McGill University. I am doing a study to better understand how husbands/partners adjust to living with women on dialysis. Very little is known about the positive and the difficult things men experience. Understanding your experiences may provide nurses with information to better prepare men to adjust to the impact and the demands of this serious chronic illness and dialysis on their daily lives.

If you agree to take part in this study you will be involved in at least one interview which you may choose to do in person or by phone. The interview will be tape recorded and will take about 1 to 2 hours of your time. You may also be asked to take part in a second interview that may take about one hour of your time

Your participation in this project is strictly voluntary. Refusing to participate will in no way affect the medical care you and your wife/partner are entitled.

If you are at least 18 years of age, live with your wife/partner who is on dialysis, would like to know more about the study, or are willing to take part in the study, please respond by:

1) mailing me your response in the address and stamped envelope provided,
2) calling me toll free at **1-877-770-7979, OR**
3) e-mailing me at **spoparwd@unb.ca**

I thank you for considering this request.

Maryse Pelletier-Hibbert

____

Reply slip: Cut on the line and mail your response in the envelope provided

Name:___________________________
Phone: Home:_____________ Work________________
When and where is it best for me to call you? _____________________________

I look forward to speaking with you. Thank you

Annexe D: Lettre D'information Destinée aux Époux/Conjoints

Bonjour;

Je m'appelle Maryse Pelletier-Hibbert et je suis étudiante au doctorat en sciences infirmières à l'Université McGill. Je mène une étude dont le but est d'apprendre ce que vivent les hommes dont l'épouse ou la conjointe suit un traitement de dialyse. Il n'existe aucune information au sujet des retombées positives et des difficultés vécues par ces hommes. Si l'on parvient à mieux comprendre ces expériences, les infirmières auront accès à des renseignements leur permettant de mieux préparer les époux/conjoints à faire face aux répercussions de cette grave maladie chronique et de la dialyse sur leur vie quotidienne.

Si vous acceptez de participer à cette étude, vous prendrez part à au moins une entrevue qui sera enregistrée sur audiocassette et qui durera de une à deux heures environ. Vous pouvez choisir de faire votre entrevue en personne ou par téléphone. Je vais peut-être vous demander de participer à une deuxième entrevue d'une durée maximale d'une heure.

Votre participation à ce projet est entièrement volontaire. C'est à vous de décider si vous voulez participer ou non à cette étude. Peu importe votre décision, les soins que vous et votre épouse/conjointe recevez resteront inchangés.

Si vous êtes âgé d'au moins 18 ans, que vous vivez avec votre épouse/conjointe qui se fait dialyser et que vous aimeriez obtenir de plus amples renseignements au sujet de l'étude ou y participer, veuillez:

1) faire parvenir votre réponse par la poste dans l'enveloppe ci-jointe,
2) communiquer par téléphone au numéro sans frais au **1-877-770-7979 OU**
3) communiquer par courriel à l'adresse **spoparwd@unb.ca.**

En vous remerciant de l'attention que vous accorderez à ma demande, je vous prie d'agréer l'expression de mes sentiments les meilleurs.

Maryse Pelletier-Hibbert

Répondez et poster votre réponse dans l'enveloppe fournie.

Nom : __________________________
Téléphone : _____________ (domicile) ________________ (travail)
À quel endroit et à quel moment est-il préférable que je vous appelle ?

Au plaisir de discuter avec vous. Merci!

Appendix E: Follow-up Letter

Dear Patient;

A few weeks ago one of the nurses who works in the dialysis unit asked if you would be willing to;

a) give a package of information about a study to your husband/partner

b) ask him if he would accept having the nurse share his phone number with the researcher (Maryse Pelletier-Hibbert) so that she can call him about the study.

If you have already given the package of information to your husband/partner and approached him, I thank you for your efforts.

If you haven't had a chance to give the package to your husband/partner and ask him to share his number, I would appreciate if you could do so.

Sincerely,
Maryse Pelletier-Hibbert

Annexe E: Lettre de Suivit

Chère Patiente;

Il y a quelques semaines, une des infirmières du service de dialyse vous a demandé si vous :

(a) accepteriez de remettre une trousse d'information à votre époux/conjoint. Cette trousse contient des renseignements au sujet d'une étude portant sur les hommes qui vivent avec une femme qui se fait dialyser.

(b) demanderiez à votre époux ou conjoint s'il accepterait de partager son numéro de téléphone avec Maryse Pelletier-Hibbert.

Si vous avez déjà remis la trousse à votre époux/conjoint, je vous en remercie.

Si vous n'avez pas encore eu l'occasion de le faire, je vous saurais gré de bien vouloir lui remettre l'enveloppe brune dès que possible.

En vous remerciant encore une fois, je vous prie d'agréer l'expression de mes sentiments les meilleurs.

Maryse Pelletier-Hibbert

Appendix F: Interview Guide Questions

These interviews will be semi-structured in that questions will be formulated throughout the course of the study. The paucity of knowledge about the focus of this study requires the utilization of open-ended exploratory questions. Within each interview, participants replies are expected to give rise to new questions that will guide the exploration of themes that emerge. All questions will be translated into French and back-translated into English in order to ensure consistency.

- Tell me about your wife/partner's problems with her kidneys (probe when did she begin to have problems with her kidneys, how did you both discover that she had kidney problems, and when did she start dialysis).
- What was it like for you to learn that her kidneys had stopped working and that she needed dialysis?
- What kind of positive things have you experienced in your life since your wife/partner has become ill and has started dialysis? (probe for changes in social, sexual, and/or marital life, employment status, roles and responsibilities).
- What kind of difficult things have you had to adjust to since your wife/partner has become ill and has been on dialysis? (probe for changes in social, sexual, and/or marital life, employment status, roles and responsibilities).
- What kind of things do you do that helps you to manage your wife's/partner's illness and dialysis?
- What advice would you have for another spouse/partner who may be experiencing a similar situation?
- Is there anything else I should know about what is it like to live with a spouse/partner with kidney failure that I didn't ask?

Annexe F: Guide D’entrevue

Les entrevues seront semi-structurées en ce sens que les questions seront formulées au fil de l’étude. Étant donné la pénurie de connaissances relatives au thème étudié, il faut se servir de questions d’exploration ouvertes. On s’attend à ce que les réponses données par les participants lors de chaque entrevue entraînent de nouvelles questions qui guideront l’exploration de nouvelles catégories. Toutes les questions seront traduites vers le français et retraduites vers l’anglais afin d’assurer la congruence d’une langue à l’autre.

Parlez-moi des troubles rénaux de votre épouse/conjointe. (Approfondir : à quel moment ces troubles ont-ils commencé? Comment avez-vous découvert qu’elle souffrait de troubles rénaux? À quel moment a-t-elle commencé à se faire dialyser?)

- Comment vous êtes-vous senti lorsque vous avez appris que ses reins ne fonctionnaient plus et qu’elle devait se faire dialyser?

- Quelles ont été les retombées positives de la maladie de votre épouse/conjointe et de son traitement de dialyse sur votre vie? (Approfondir : changements sur le plan des activités sociales ou sexuelles, de la vie conjugale, de la situation d’emploi, du rôle et des responsabilités.)

- Quels obstacles avez-vous eu à surmonter depuis que votre épouse/conjointe est malade et qu’elle se fait dialyser? (Approfondir : changements sur le plan des activités sociales ou sexuelles, de la vie conjugale, de la situation d’emploi, du rôle et des responsabilités.)

- Quelles mesures avez-vous prises pour vous adapter à la maladie et au traitement de dialyse de votre épouse/conjointe à votre vie?

- Si vous aviez à donner des conseils à un autre époux/conjoint dans une situation semblable à la vôtre, que lui diriez-vous?

- Est-ce que vivre avec une épouse/conjointe atteinte d’insuffisance rénale comporte d’autres éléments que je n’ai pas mentionnés?

Appendix G: Examples of First Level Codes

Affected everything
Afraid she’ll lose her breath
After each complication it gets easier
Aftermath of dialysis
All of a sudden it [kidney failure] caboom, and it was a shock
Allowing other to do
Alot of it is familiarity
Already knew what to expect
Alteration in house to accommodate PD
Altered dietary regime
Altered work to accommodate start dialysis
Altering work to stay with wife
Alternative to dialysis is worst [death]
Alters work schedule to address issues with son
Always ask her what she wants to eat
Always done household chores prior to marriage
Always look forward to the following day
Amazed at how my wife is very resilient
Anticipated dialysis
Anticipated something going wrong over the years
Anything that goes wrong with the machine itself I call nurses
Anything that happens to her is pretty much my crisis
Arrange work schedule to shuttle her to hospital hemo
Asked to extend shore time
Je savais pas dans quoi je m’embarquais
Je serais prêt à prendre 25 pour cent de ses maladies
Je sors moins longtemps
Je sors moins souvent
Je suis obligé de mettre en place des ressources
Je suis toujours craintif
Je trouve que ma femme est beaucoup mieux
Juggle work and dialysis schedules
Juggled work and visiting her at the hospital
Juggling work and dialysis schedule difficult
Juggling work and household responsibilities hard to keep up
Juggling work schedule and dialysis schedule
Just be there for her
Just do it
Just go with the flow
Just grin and bear it
Just keep an open mind
Just keep going forward
It’s what you make out of it
J`ai peur qu’il va lui arriver de quoi quand je suis pas là
J’ai coupé ma marche
J’ai des bons enfants
J’ai été obligé de canceller d’autres jobs

Appendix H: Examples of Categories and Sub-Categories

Categories/properties		Participants																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
1.Becoming aware or noticing changes in well being pre-dialysis symptom (n=8)	√	√		√	√	√			√		√	√						
2. Finding out or discovering need for dialysis (anticipated vs unanticipated																		
2A Anticipating eventual need for dialysis (n=7)		√	√	√			√					√	√			√		
2B Being hit with unexpected dx of kidney failure and need for dialysis (n=12)	√			√	√	√		√	√	√	√	√		√			√	√
3. Monitoring downward progression of kidney function; countdown to start of dialysis (n=7)	√	√	√			√					√	√	√					
4. Reacting to illness crisis and reacting to FINDING OUT or discovering need for dialysis(n=7)			√			√		√	√	√	√		√					
5. Moving/relocating permanently or temporarily																		
5A Permanently (n=3)	√	√	√															
5B Temporarily(n=4)								√	√	√	√							
6. Mobilizing resources to get answers and relief care to ease the suffering																		
6A Searching for a dx; seeking care from physician (n=6)					√	√		√		√	√		√					
6B Recruiting assistance from HCP for emergency care (n=9)					√	√		√	√	√	√	√		√	√			
6C Searching for information (n=6)		√	√	√	√										√	√		
7. Being unable to make plans for the day and beyond (n=8)	√		√	√		√							√			√	√	√
8. Being tied down, losing the freedom to do things due to life revolving around dialysis (n=12)		√	√			√			√		√	√					√	√
9. Appraising and appreciating positive benefits of dialysis																		
9A Witnessing improvement in wife's well being since starting dialysis influences positive appraisal of dialysis tx (n=6)		√	√		√	√			√	√								
9B Contemplating the alternative to not having dialysis (n=5)	√				√				√					√		√		√

Appendix I: Memos

Memo June 06, 2006

I am wondering if the wife's stability with her well-being, level of energy, whether multiple co-morbid illnesses, not being affected by dialysis treatment during and after treatment, influences (a) the husband's level of involvement with homecare, household chores, (b) level of uncertainty or type of uncertainty husband experiences, (c) how tied down he feels (d) how much his life revolves around dialysis and her responses (e) whether the husband's own state of well-being impacts on their responses to KF and dialysis.

I'll have to pay close attention to these influencing factors and their impact on adjusting to KF and dialysis.

Memo July, 2008

I am starting to see that finding out or discovering that their wives' kidneys have failed can be sudden/unexpected or there is time to prepare because the couple has known for 8 months to 1 year that dialysis was inevitable.

What is interesting is that for those whose wife was diagnosed unexpectedly like # 4 and 5, finding out propels them to seek information about KF, dialysis and both used the Net and sought information from H.C.P. Participants # 1 to 3 on the other hand had known for some time prior to starting dialysis that their wife would eventually need this treatment, they relocated in anticipation of dialysis treatment closer to the hospital to access dialysis treatment, emergency care in times of need, and cut down on the amount of driving to and from dialysis treatment.

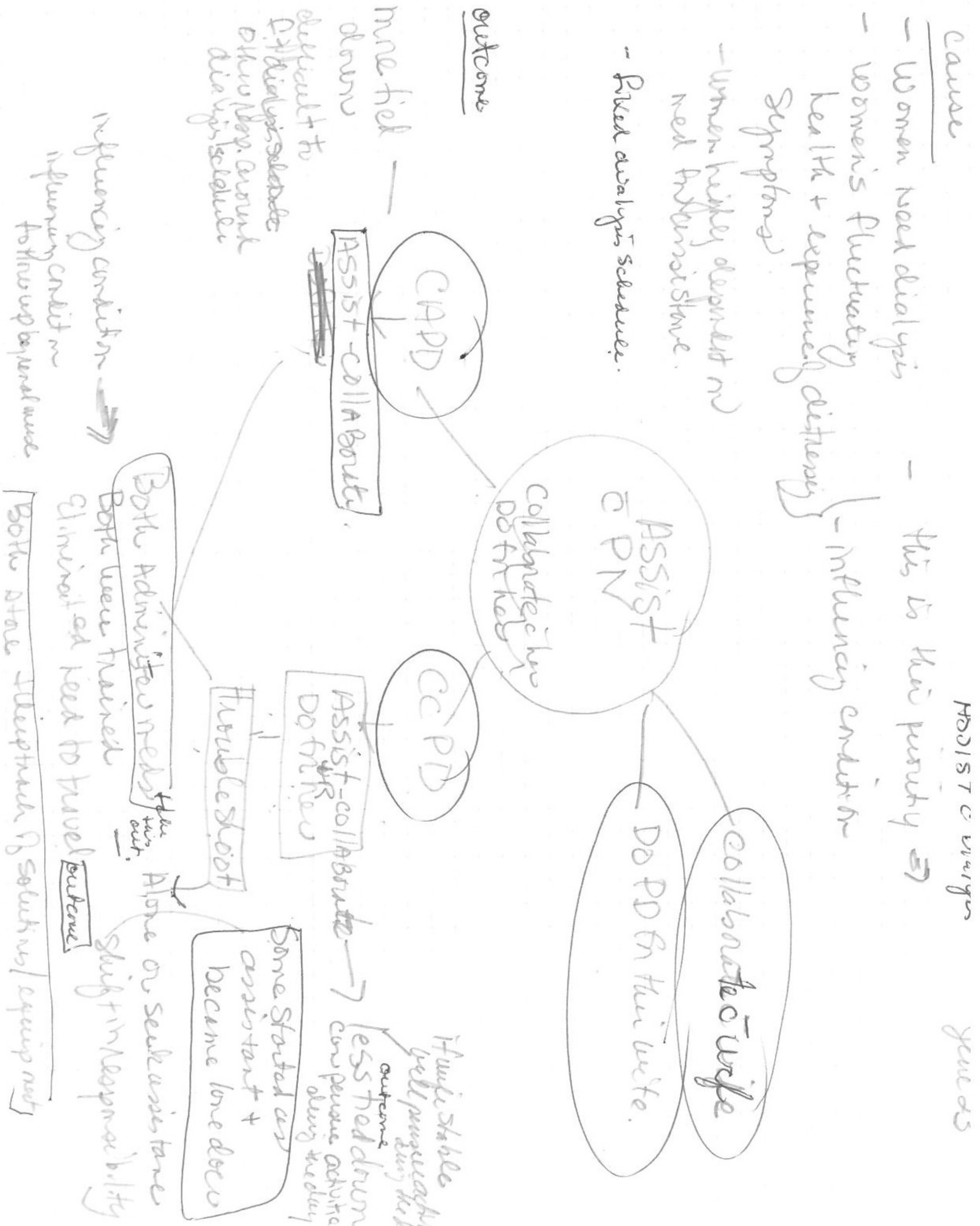
Once dialysis treatment is initiated and even before treatment is started, life begins to revolve around the anticipated start of dialysis. They prepare by relocating or seeking information the moment diagnosis is made.

Once dialysis treatment is initiated they are trying to adjust to changing patterns of daily living due to dialysis schedule, unpredictable aftermath or response to dialysis treatment, hypotensive, increased tiredness, unpredictable state of being days of dialysis, increased tiredness which leads to decreased socialization, decreased outings, and/or living an illness centered existence where wife's needs overrides their own needs

Deal with this by

- Rearranging their lives
- Move schedule their own appointments around dialysis schedule
- Put on hold their own activities
- Take over some household responsibilities such as cooking, housecleaning, so assume various roles including that of a
- Gatekeeper of amount/type of food wife takes to prevent complications associated with the electrolytes and excessive fluid consumption

Appendix J: Diagram of Analysis



Appendix K: Families of Theoretical Codes

Families	Examples and Meaning
1.The Six C's	Causes, Contexts: Contingencies: Consequences: outcomes of actions/interactions Covariances: Conditions: the circumstances or conditions that form the structure of the studied phenomenon
2. Process	A series of two of more phenomenon grouped into stages, phases, or passages to reflect movement, progressions, transitions, trajectories.
3. Degree	Refers to extend, range, intensity, level of variability.
4. Dimension	Is about breaking the whole into parts, segments, slices,
5. Type	Indicate variations in the whole such as a form, kinds, styles.
6. Strategy	The act of doing something; a strategy, a tactic, a manipulation that is purposeful.
7. Interactive	Entails capturing the interaction, reciprocity, and the connectedness between two or more issues and how they influence each other.
8. Identity-Self	The dimensions of self or identity such as self- image, self-worth, transformation of self.
9.Cutting Point	This has to do with critical, turning, cutting, or breaking point. Helps to demarcate where differences occur.
10.Means-goal	Anticipated consequences, the end, a goal, a result or product.
11.Cultural	Has to do with norms, values, beliefs, rules that shape personal characteristics.
12.Consensus	Agreements, uniformities, opinions, conflict.
13. Mainline	Social control and social order are examples.
14. Theoretical	Has to do with conceptual level, fit, clarity, relevancy, modifiability. Important in critiquing and judging the theory in terms of trustworthiness.
15.Ordering or Elaboration	Sequencing of categories, what comes before/after, how one category predicts or explains another.
16. Unit	The clustering into categories that clearly represent a specific group, organization, aggregate, context.
17.Reading	Hypotheses, concepts, problems.
18. Models	Pictorial model of a theory.

Adapted from Glaser, B. (1978). *Theoretical sensitivity.* Mill Valley, CA: The Sociology Press.

Appendix L-1 Original: Information and Consentment

Title: The Adjustment Process of Husbands/Partners Living with Women on Dialysis

Principal Investigator: Maryse Pelletier-Hibbert, RN, PhD. (candidate), School of Nursing, McGill University, Tel.: 1-877-770-7979.

Supervisors: Dr Margaret Purden, RN, PhD., School of Nursing, McGill University
Tel.: (514) 398-2417.
Dr Frank Carnevale RN, PhD., McGill University Health Centre and
School of Nursing, McGill University

Introduction

You are being asked to participate in a study by Maryse Pelletier-Hibbert, a doctoral nursing student at McGill University. This project will be supervised by Dr Margaret Purden and Dr Frank Carnevale. This study is part of the requirements of the student's program. It will help her to better understand how husbands/partners adjust to living with women on dialysis.

Before deciding to participate in this study, it is very important that you fully understand what is expected of you, as well as the potential risks and benefits of participating. This document provides information about the study. It may contain words you do not fully understand. Please read it carefully and ask the researcher any question you many have. The researcher, Maryse Pelletier-Hibbert will discuss the study with you in detail. You may take this form and discuss this study with anyone else before making a decision. If you decide to participate, you will be asked to sign this form and a copy of it will be given to you.

Purpose of the Study

The purpose of the study is to better understand (a) the main concern that husbands/partners experience with adjusting to living with women on dialysis and (b) how the husbands/partners manage or deal with this main concern Very little is known about_ the experiences of men who live with women on dialysis. Understanding their experiences may provide nurses with information to better prepare husbands/partners to deal with the impact of kidney failure and dialysis on their daily lives.

Description of the Study

Interview (s). If you agree to take part in the study, you will be asked to meet with the researcher for at least one interview which will take about 1 to 2 hours of your time and will be audio taped to help the student recall details of the discussion. You will choose a time and place that is convenient to be interviewed. During this interview you will be asked questions about what it is like for you to live with a wife/partner who is on dialysis. You may also be asked to take part in a second interview, at about 4 to 6 weeks following the first interview which will take about one hour of your time. This may give you a chance to add information or to clarify comments. You may participate in the study even if you refuse to be audio-taped and instead notes will be taken by the researcher.

Informal Visit. You will also be invited to take part in an informal visit with your wife/partner. The purpose of the informal visit is to provide both of you with an opportunity to share with the researcher typical events, activities, situations, and/or settings that you both have had to adjust and include in your daily lives as a result of living with kidney failure and dialysis treatment. The visit will take no more than 2 hours of your time and will occur at a time and place of your choosing.

Voluntary Participation and/or Withdrawal

Your participation in this study is strictly voluntary. You may refuse to take part or may discontinue your participation at any time without explanation and without penalty or loss of benefits to which you and your wife/partner are otherwise entitled. If you decide to not participate or if you discontinue your participation you and your wife/partner will suffer no prejudice regarding medical care you are both entitled to or participation in any other study. In case of withdrawal, information collected to that point will be used to preserve the integrity and quality of the study project. The student and/or project supervisors may end your participation in the study if it is felt to be in your best interest. Should this happen, the reason(s) will be explained to you.

Potential Risks

There are no known risks for you to take part in this study. Some individuals may find that discussing their experiences raises unpleasant or upsetting feelings, thoughts, or memories. In this case, you will be offered the opportunity to speak with Louisette Chiasson or Francine Prosser renal social workers at the George Dumont Hospital at 506-862-4105**.** If you become tired during the interview or visit, you may take a break, or rebook another interview or visit. If at any time, you wish to stop the discussion or visit; your wishes will be respected. This will not affect the care you or your wife/partner is entitled to. Should you decide to end your participation you may ask that your tapes of the interview(s) be returned to you or destroyed. But as mentioned in the previous paragraph, the information collected to that point will be used.

Potential Benefits

There are no known personal benefits for taking part in this study, although some individuals may find it helpful to talk to the student about their experiences. In addition, the information collected over the course of this study may be of benefit to other husbands/partners and/or couples, and to health care professionals to help them with the assistance they provide to men and couples in similar situations.

Cost and Reimbursement

You will not be offered any payment or reimbursement for your participation in the study. We do not anticipate that your participation will create any additional costs to you.

Confidentiality

All personal information obtained during this study will be kept strictly confidential. In order to protect your identity, your name will be coded and the code list, demographic information, interview notes, and audiotapes will be locked in the office of the researcher, Maryse Pelletier-Hibbert. Only the supervisors of the study project and the researcher will have access to documents containing personal information and transcribed information for the purpose of analysis. A research assistant will transcribe the interviews and this person will be required to sign a privacy and confidentiality form prior to beginning transcription. The information will be kept until the study is completed or for a period of five years maximum and then destroyed. Further ethical review will be done if secondary analysis is done with the transcribed information.

The results from this project may be published but your identity or any other identifying information will not be revealed in any scientific publication or report. The results from this study can be made available to you, upon request, before any publication. The ethics committee of McGill University may review the records containing your personal information in order to ensure proper management of the project.

Questions and Contact Information

Should you have any questions concerning your rights as a study participant at any time during the study, you may contact the administrative secretary of the research ethic committee, Annie Arseneault, at 506-862-4220. If you have any questions regarding the study, please contact Maryse Pelletier-Hibbert at 1-877-770-7979 or the project supervisor Dr. Margaret Purden, at (514) 398-2417.

Statement of Consent

I have read this consent form and I voluntarily agree to participate in the study project. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I have been given sufficient time to consider the information and seek advice should I choose to do so.

I authorize Maryse Pelletier-Hibbert to collect, exchange, communicate, and use my personal information for the purpose and in the Manneer mentioned above.

I understand that I have the right to access my personal information and to make corrections, subject however to applicable laws and regulations. This consent is valid until the study is completed, however I may discontinue my participation in this study at any time without loss of benefits or treatments that I or my wife/partner is otherwise entitled. I will be given a signed copy of this consent form. By signing this consent form, I do not give up any of my legal rights.

By signing this consent, I agree to:

Participate in an audio-taped interview with the student-researcher.
YES ____ NO___
Participant's Signature: ______________________ Date: ______________________
Investigator's Signature:______________________ Date:______________________
By signing this consent, I agree to:
Participate in a visit with the student-researcher and my wife/partner:
YES____ NO____
Participant's Signature: ______________________ Date: ______________________
Investigator's Signature:______________________ Date:______________________
Feedback: I wish to receive a summary of the results.
Yes ______ No ___________ Mailing address_________________________

Annexe L-1: Originale: Information et Formulaire de Consentement

Titre: Le processus d'adaptation des époux/conjoints vivant avec une épouse/partenaire qui suit un traitement de dialyse

Chercheuse principale: Maryse Pelletier-Hibbert, inf. imm., Ph.D. (étudiante),
École des sciences infirmières, Université McGill, Tél.:
1-877-770-7979
Superviseurs: Margaret Purden, inf. aut., Ph.D., École des sciences
infirmières, Université McGill, Tél. : (514) 398-2417.
Frank Carnevale inf. aut., Ph.D., Centre de santé de
l'Université McGill et École des sciences infirmières,
Université McGill

Introduction

On vous a demandé de participer à une étude menée par Maryse Pelletier-Hibbert, une étudiante au doctorat en sciences infirmières à l'Université McGill. Ce projet est supervisé par Margaret Purden et Frank Carnevale de l'Université McGill et il fait partie des exigences du programme d'études de M^{me} Pelletier-Hibbert. Les résultats permettront à la chercheuse de mieux comprendre le processus d'adaptation des hommes qui vivent avec une épouse/conjointe qui suit un traitement de dialyse.

Avant de décider de participer à cette étude, il est important que vous compreniez clairement ce qu'on attend de vous ainsi que les risques et les avantages. Le présent document contient divers renseignements au sujet de l'étude. Il est possible que certains mots soient difficiles à comprendre, alors lisez le document attentivement et n'hésitez pas à poser à la chercheuse toutes les questions qui vous préoccupent. Cette dernière se fera un plaisir de vous expliquer l'étude en détail. Vous pouvez garder ce formulaire et en discuter avec des personnes de votre choix avant de prendre votre décision. Si vous décidez d'y prendre part, on vous demandera de signer ce formulaire et on vous en remettra une copie.

But de L'étude

Cette étude a pour but de déterminer (a) la principale difficulté vécue par les hommes qui doivent s'adapter à la vie avec une épouse/conjointe qui suit un traitement de dialyse et (b) comment l'époux/conjoint gère ou surmonte cette difficulté. Il n'existe aucune information au sujet des expériences vécues par les hommes dont l'épouse/conjointe se fait dialyser. Si l'on parvient à mieux comprendre ces expériences, les infirmières auront accès à des renseignements leur permettant de mieux préparer les époux/conjoints à intégrer à leur vie quotidienne les exigences de l'insuffisance rénale et de la dialyse.

Procédures de L'étude

Entrevue. Si vous acceptez de participer à l'étude, vous prendrez part à au moins une entrevue, laquelle sera enregistrée sur audiocassette et durera de une à deux heures environ. C'est vous qui choisirez le moment et l'endroit qui vous conviennent pour l’entrevue. Durant la première entrevue, on vous posera des questions à propos de votre vie avec une femme sous dialyse. Entre quatre et six semaines après la première entrevue, on pourrait vous demander de participer à une deuxième entrevue d’une durée de moins d’une heure. Vous auriez ainsi l’occasion de fournir de l’information supplémentaire ou de clarifier les commentaires recueillis lors de la première rencontre. Si vous acceptez, ces entrevues seront enregistrées sur bande sonore pour aider l’étudiante à se rappeler des détails de l’entrevue. Vous pouvez participer à l’étude même si vous refusez l’enregistrement sonore. La chercheuse prendra des notes à la place.

Rencontre. On vous demandera également de participer à une rencontre informelle en compagnie de votre épouse/conjointe. Cette rencontre a pour but de vous donner l’occasion, tous les deux, de faire connaître à la chercheuse les activités ou les situations typiques auxquelles vous avez dû vous adapter et que vous avez dû intégrer à votre vie quotidienne depuis que vous vivez avec l’insuffisance rénale et le traitement de dialyse. La rencontre ne durera pas plus de deux heures et elle se déroulera au moment et à l’endroit de votre choix.

Participation Volontaire et Retrait

Votre participation à cette étude est entièrement volontaire. Vous pouvez refuser d’y participer et vous pouvez vous en retirer en tout temps sans aucune explication: on respectera votre décision. De plus, votre décision n’aura aucun effet sur les soins auxquels vous et votre épouse/conjointe avez droit. Si vous décidez de ne pas participer et/ou de vous retirer de l’étude, dans le cas d’un retrait, les données recueillies jusqu’au moment du retrait seront utilisées afin de préserver l’intégrité et la qualité de l’étude. L’étudiante ou les superviseurs peuvent mettre fin à votre participation à ce projet s’ils jugent que c’est dans votre intérêt. Si cela devait se produire, les raisons de votre retrait de l’étude vous seraient expliquées. Votre décision de refuser de participer ou de vous retirer de cette étude en tout temps n’influencera pas la qualité des soins que vous ou votre épouse/conjointe reçoivent ou sommes en droit de recevoir, ou votre participation à d’autres projets de recherche.

Risques Potentiels

Vous ne courez aucun risque connu en participant à cette étude. Vous pouvez décider d’arrêter la discussion pendant votre entrevue ou votre rencontre, et ce en tout temps. Votre volonté sera respectée. Si vous décidez de ne plus participer à cette étude, vous pouvez demander que l’on vous fasse parvenir les enregistrements sonores de(s) entrevue(s), ou que l’on détruise ceux-ci. Cependant, comme mentionné précédemment, l’information qui aura été recueillie jusqu'à ce point dans l’étude sera utilisée dans les analyses.

En discutant de leurs expériences, certaines personnes éprouveront peut-être des sentiments, des pensées ou des souvenirs désagréables ou bouleversants. Si vous éprouvez des difficultés à la suite des entrevues ou de la rencontre, vous aurez l’occasion de parler avec Louisette Chiasson ou Francine Prosser travailleuses sociales spécialisées dans les maladies du rein à l’Hôpital George-L.-Dumont. Vous pouvez joindre Louisette ou Francine au (506) 862-4105. Si vous vous sentez fatigué durant l’entrevue ou la rencontre, vous pourrez prendre une pause ou fixer une autre entrevue ou une autre rencontre. Cela n'aura aucun effet sur les soins auxquels vous et votre épouse/conjointe avez droit.

Avantages Potentiels

Bien que cela puisse faire du bien à certaines personnes de parler de leurs expériences, la participation à cette étude ne vous procurera aucun avantage connu. De plus, l'information recueillie au cours de ce projet pourrait être bénéfique pour d'autres époux/conjoints et pour les professionnels de la santé qui travaillent auprès de personnes dans la même situation que vous. Les données recueillies pourraient permettre d'améliorer l'aide offerte aux hommes et aux couples par les professionnels de la santé.

Coût et Remboursement

Aucune compensation ne vous sera offerte pour votre participation à ce projet. Nous ne prévoyons aucun coût additionnel, pour vous, associé à votre participation à cette étude.

Confidentialité

Tout renseignement personnel obtenu dans le cadre de cette étude sera maintenu en stricte confidentialité selon les limites de la loi. Votre nom sera identifié par un code. La liste reliant votre nom à un code, les renseignements personnels, les notes d'entrevue et les audiocassettes seront rangés sous clé dans le bureau de Maryse Pelletier-Hibbert. L'adjointe à la recherche qui dactylographiera les entrevues devra respecter la nature privée de l'étude et signer un formulaire de consentement pour protéger la confidentialité des renseignements.

Seuls la chercheuse et ses superviseurs auront accès à toutes informations personnelles et aux données transcrites, et ce à des fins d'analyse. Les données seront conservées pour une période de cinq ans, après quoi elles seront complètement détruites. Si l'on utilise l'information transcrite pour d'autres analyses, on procédera à d'autres examens d'ordre déontologique.

Les résultats de cette étude seront mis à votre disposition, sur demande, avant toute publication. Afin d'assurer la qualité des données, il est possible que les membres du comité d'éthique de l'Université McGill consultent celles qui représentent vos renseignements personnels.

Les résultats de cette étude pourraient être publiés. Cependant, votre identité et toute information permettant de vous identifier ne seront dévoilées dans aucune publication ni aucun rapport. Sur demande, vous pourrez obtenir une copie des résultats avant qu'ils soient publiés.

Questions et Personnes-ressources

Si, au cours de l'étude, vous avez des questions au sujet de vos droits, vous pouvez communiquer avec Annie Arsenault, secrétaire administrative du comité d'éthique de la recherche au (506) 862-4220. Pour obtenir des renseignements supplémentaires au sujet de l'étude, veuillez communiquer avec Maryse Pelletier-Hibbert, au 1 877- 770-7979, ou sa superviseure, Margaret Purden, Ph.D., au (514) 398-2417.

Déclaration de consentement

J'ai lu le formulaire de consentement et j'accepte volontairement de participer à cette étude. J'ai eu la possibilité de poser des questions et on a répondu à mes questions à ma satisfaction. J'ai eu suffisamment de temps pour réfléchir à l'information reçue et pour demander conseil si tel est mon choix. J'autorise Maryse Pelletier-Hibbert à recueillir, partager, communiquer et utiliser mes renseignements personnels aux fins et selon les moyens mentionnés ci-dessus.

Je comprends que j'ai le droit d'accès à tous mes renseignements personnels, ainsi que le droit de les modifier; toutefois, ces corrections doivent respecter les limites prévues par la loi. Ce consentement est valide jusqu'à la fin du projet.

Je recevrai une copie signée de ce formulaire de consentement. En signant ce formulaire de consentement, je ne renonce à aucun droit reconnu par la loi.

En signant ce formulaire, je consens à :

Participer à une entrevue enregistrée sur audiocassette et dirigée par l'étudiante :
OUI______ NON______
Signature du participant: ______________________ Date : _____________________

Signature de la chercheuse:______________________ Date : _____________________

Participer à une rencontre avec Maryse Pelletier-Hibbert en compagnie de mon épouse/conjointe:

OUI______ NON______
Signature du participant : ______________________ Date : _____________________
Signature de la chercheuse :______________________ Date : ________________
Rétroaction : J'aimerais recevoir une copie des résultats sommaires.
Oui ______ Non ___________
Adresse postale : ____

Appendix M-2 (Revised): Information and Consent Form

Title: The Adjustment Process of Husbands/Partners Living with Women on Dialysis

Principal Investigator: Maryse Pelletier-Hibbert, RN, PhD. (candidate),
Supervisors: Dr Margaret Purden, RN, PhD., School of Nursing, McGill University
Tel.: (514) 398-2417.
Dr Frank Carnevale RN, PhD., McGill University Health Centre and
School of Nursing, McGill University

Introduction

You are being asked to participate in a study by Maryse Pelletier-Hibbert, a doctoral nursing student at McGill University. This project will be supervised by Dr Margaret Purden and Dr Frank Carnevale. This study is part of the requirements of the student's program. It will help her to better understand how husbands/partners adjust to living with women on dialysis.

Before deciding to participate in this study, it is very important that you fully understand what is expected of you, as well as the potential risks and benefits of participating. This document provides information about the study. It may contain words you do not fully understand. Please read it carefully and ask the researcher any question you many have. The researcher, Maryse Pelletier-Hibbert will discuss the study with you in detail. You may take this form and discuss this study with anyone else before making a decision. If you decide to participate, you will be asked to sign this form or to give verbal consent and a copy of it will be given or mailed to you.

Purpose of the Study

The purpose of the study is to better understand (a) the main concern that husbands/partners experience with adjusting to living with women on dialysis and (b) how the husbands/partners manage or deal with this main concern. Very little is known about the experiences of men who live with women on dialysis. Understanding their experiences may provide nurses with information to better prepare husbands/partners to deal with the impact of kidney failure and dialysis on their daily lives.

Description of the Study

If you agree to take part in the study, you will be asked to meet with the researcher for at least one interview which will take about 1 to 2 hours of your time and will be audio taped to help the student recall details of the discussion. You will choose a time and place that is convenient to be interviewed. During this interview you will be asked questions about what it is like for you to live with a wife/partner who is on dialysis. You may also be asked to take part in a second interview, at about 4 to 6 weeks following the first interview which will take about one hour of your time. This may give you a chance to add information or to clarify comments. You may participate in the study even if you refuse to be audio-taped and notes will instead be taken by the researcher.

Voluntary Participation and/or Withdrawal

Your participation in this study is strictly voluntary. You may refuse to take part or may discontinue your participation at any time without explanation and without penalty or loss of benefits to which you and your wife/partner are otherwise entitled. If you decide to not participate or if you discontinue your participation you and your wife/partner will suffer no prejudice regarding medical care you are both entitled to or participation in any other study. In case of withdrawal, information collected to that point will be used to preserve the integrity and quality of the study project. The student and/or project supervisors may end your participation in the study if it is felt to be in your best interest. Should this happen, the reason(s) will be explained to you.

Potential Risks

There are no known risks for you to take part in this study. Some individuals may find that discussing their experiences raises unpleasant or upsetting feelings, thoughts, or memories. In this case, the researcher will help you identify resources that may be accessible to you in your community, family, or work environment. If you become tired during the interview, you may take a break, or rebook another interview. If at any time, you wish to stop the discussion or visit; your wishes will be respected. This will not affect the care you or your wife/partner are entitled to. Should you decide to end your participation you may ask that your tapes of the interview(s) be returned to you or destroyed. But as mentioned in the previous paragraph, the information collected to that point will be used.

Potential Benefits

There are no known personal benefits for taking part in this study, although some individuals may find it helpful to talk to the student about their experiences. In addition, the information collected over the course of this study may be of benefit to other husbands/partners and to health care professionals to help them with the assistance they provide to men and couples in similar situations.

Cost and Reimbursement

You will not be offered any payment or reimbursement for your participation in the study. We do not anticipate that your participation will create any additional costs to you.

Confidentiality

All personal information obtained during this study will be kept strictly confidential. In order to protect your identity, your name will be coded and the code list, demographic information, interview notes, and audiotapes will be locked in the office of the researcher, Maryse Pelletier-Hibbert. Only the supervisors of the study project and the researcher will have access to documents containing personal information and transcribed information for the purpose of analysis. A research assistant will transcribe the interviews and this person will be required to sign a privacy and confidentiality form prior to beginning transcription. The information will be kept until the study is completed or for a period of five years maximum and then destroyed. Further ethical review will be done if secondary analysis is done with the transcribed information.

The results from this project may be published but your identity or any other identifying information will not be revealed in any scientific publication or report. The results from this study can be made available to you, upon request, before any publication. The ethics committee of McGill University may review the records containing your personal information in order to ensure proper management of the project.

Questions and Contact Information

Should you have any questions concerning your rights as a study participant at any time during the study, you may contact the Senior Ethics Administrator at McGill University, Ms Ilde Lepore at 514-398-8302. If you have any questions regarding the study, please contact Maryse Pelletier-Hibbert at 1-877-770-7979 or the project supervisor Dr. Margaret Purden, at (514) 398-2417.

Statement of Consent

I have read this consent form (or have had the consent form read to me) and I voluntarily agree to participate in the study project. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I have been given sufficient time to consider the information and seek advice should I choose to do so.

I authorize Maryse Pelletier-Hibbert to collect, exchange, communicate, and use my personal information for the purpose and in the manner mentioned above.

I understand that I have the right to access my personal information and to make corrections, subject however to applicable laws and regulations. This consent is valid until the study is completed, however I may discontinue my participation in this study at any time without loss of benefits or treatments that I or my wife/partner is otherwise entitled. I will be given a signed copy of this consent form. By signing this consent form, I do not give up any of my legal rights.

For person-to-person interview: **By signing this consent, I agree to**:

Participate in an audio-taped interview with the student-researcher.

YES ____ NO___
Participant's Signature: ______________________ Date: _____________________

Investigator's Signature:______________________ Date:_____________________

For telephone interview: By giving verbal consent, I agree to:
Participate in an audio-taped interview with the student-researcher.
YES ____ NO___
Feedback: I wish to receive a summary of the results.
Yes ______ No ___________
Mailing Address:____________________________

Annexe M-2 (Revisée): Information et Formulaire de Consentement

Titre: Le processus d'adaptation des époux/conjoints vivant avec une épouse/partenaire qui suit un traitement de dialyse

Chercheuse principale: Maryse Pelletier-Hibbert, inf. imm., Ph.D. (étudiante), École des sciences infirmières, Université McGill, Tél.: 1-877 770-7979

Superviseurs: Margaret Purden, inf. aut., Ph.D., École des sciences infirmières, Université McGill, Tél. : (514) 398-2417. Frank Carnevale inf. aut., Ph.D., Centre de santé de l'Université McGill et École des sciences infirmières, Université McGill

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Introduction

On vous a demandé de participer à une étude menée par Maryse Pelletier-Hibbert, une étudiante au doctorat en sciences infirmières à l'Université McGill. Ce projet est supervisé par Margaret Purden et Frank Carnevale de l'Université McGill et il fait partie des exigences du programme d'études de M^{me} Pelletier-Hibbert. Les résultats permettront à la chercheuse de mieux comprendre le processus d'adaptation des hommes qui vivent avec une épouse/conjointe qui suit un traitement de dialyse.

Avant de décider de participer à cette étude, il est important que vous compreniez clairement ce qu'on attend de vous ainsi que les risques et les avantages. Le présent document contient divers renseignements au sujet de l'étude. Il est possible que certains mots soient difficiles à comprendre, alors lisez le document attentivement et n'hésitez pas à poser à la chercheuse toutes les questions qui vous préoccupent. Cette dernière se fera un plaisir de vous expliquer l'étude en détail. Vous pouvez garder ce formulaire et en discuter avec des personnes de votre choix avant de prendre votre décision. Si vous décidez d'y prendre part, on vous demandera de signer ce formulaire ou donner votre consentement verbale et on vous en remettra ou postera une copie.

But de L'étude

Cette étude a pour but de déterminer (a) la principale difficulté vécue par les hommes qui doivent s'adapter à la vie avec une épouse/conjointe qui suit un traitement de dialyse et (b) comment l'époux/conjoint gère ou surmonte cette difficulté. Il n'existe aucune information au sujet des expériences vécues par les hommes dont l'épouse/conjointe se fait dialyser. Si l'on parvient à mieux comprendre ces expériences, les infirmières auront accès à des renseignements leur permettant de mieux préparer les époux/conjoints à intégrer à leur vie quotidienne les exigences de l'insuffisance rénale et de la dialyse.

Procédures de L'étude

Si vous acceptez de participer à l'étude, vous prendrez part à au moins une entrevue, laquelle sera enregistrée sur audiocassette et durera de une à deux heures environ. C'est vous qui choisirez le moment et l'endroit qui vous conviennent pour l'entrevue. Durant la première entrevue, on vous posera des questions à propos de votre vie avec une femme sous dialyse. Entre quatre et six semaines après la première entrevue, on pourrait vous demander de participer à une deuxième entrevue d'une durée de moins d'une heure. Vous auriez ainsi l'occasion de fournir de l'information supplémentaire ou de clarifier les commentaires recueillis lors de la première rencontre. Si vous acceptez, ces entrevues seront enregistrées sur bande sonore pour aider l'étudiante à se rappeler des détails de l'entrevue. Vous pouvez participer à l'étude même si vous refusez l'enregistrement sonore. La chercheuse prendra des notes à la place.

Participation Volontaire et Retrait

Votre participation à cette étude est entièrement volontaire. Vous pouvez refuser d'y participer et vous pouvez vous en retirer en tout temps sans aucune explication: on respectera votre décision. De plus, votre décision n'aura aucun effet sur les soins auxquels vous et votre épouse/conjointe avez droit. Si vous décidez de ne pas participer et/ou de vous retirer de l'étude, dans le cas d'un retrait, les données recueillies jusqu'au moment du retrait seront utilisées afin de préserver l'intégrité et la qualité de l'étude. L'étudiante ou les superviseurs peuvent mettre fin à votre participation à ce projet s'ils jugent que c'est dans votre intérêt. Si cela devait se produire, les raisons de votre retrait de l'étude vous seraient expliquées. Votre décision de refuser de participer ou de vous retirer de cette étude en tout temps n'influencera pas la qualité des soins que vous ou votre épouse/conjointe reçoivent ou sommes en droit de recevoir, ou votre participation à d'autres projets de recherche.

Risques Potentiels

Vous ne courez aucun risque connu en participant à cette étude. Vous pouvez décider d'arrêter la discussion pendant votre entrevue ou votre rencontre, et ce en tout temps. Votre volonté sera respectée. Si vous décidez de ne plus participer à cette étude, vous pouvez demander que l'on vous fasse parvenir les enregistrements sonores de(s) entrevue(s), ou que l'on détruise ceux-ci. Cependant, comme mentionné précédemment, l'information qui aura été recueillie jusqu'à ce point dans l'étude sera utilisée dans les analyses.

En discutant de leurs expériences, certaines personnes éprouveront peut-être des sentiments, des pensées ou des souvenirs désagréables ou bouleversants. Si vous éprouvez des difficultés ou vous aimeriez parler davantage de certaines choses qui vous préoccupent, l`étudiante vous aidera à identifier des sources de soutien auprès de vos intervenants, votre famille, ou la communauté. Si vous vous sentez fatigué durant l'entrevue, vous pourrez prendre une pause ou fixer une autre entrevue ou une autre rencontre. Cela n'aura aucun effet sur les soins auxquels vous et votre épouse/conjointe avez droit.

Avantages Potentiels

Bien que cela puisse faire du bien à certaines personnes de parler de leurs expériences, la participation à cette étude ne vous procurera aucun avantage connu. De plus, l'information recueillie au cours de ce projet pourrait être bénéfique pour d'autres époux/conjoints et pour les professionnels de la santé qui travaillent auprès de personnes dans la même situation que vous. Les données recueillies pourraient permettre d'améliorer l'aide offerte aux hommes et aux couples par les professionnels de la santé.

Coût et Remboursement

Aucune compensation ne vous sera offerte pour votre participation à ce projet. Nous ne prévoyons aucun coût additionnel, pour vous, associé à votre participation à cette étude.

Confidentialité

Tout renseignement personnel obtenu dans le cadre de cette étude sera maintenu en stricte confidentialité selon les limites de la loi. Votre nom sera identifié par un code. La liste reliant votre nom à un code, les renseignements personnels, les notes d'entrevue et les audiocassettes seront rangés sous clé dans le bureau de Maryse Pelletier-Hibbert. L'adjointe à la recherche qui dactylographiera les entrevues devra respecter la nature privée de l'étude et signer un formulaire de consentement pour protéger la confidentialité des renseignements.

Seuls la chercheuse et ses superviseurs auront accès a toutes informations personnelles et aux données transcrites, et ce à des fins d'analyse. Les données seront conservées pour une période de cinq ans, après quoi elles seront complètement détruites. Si l'on utilise l'information transcrite pour d'autres analyses, on procédera à d'autres examens d'ordre déontologique.

Les résultats de cette étude seront mis à votre disposition, sur demande, avant toute publication. Afin d'assurer la qualité des données, il est possible que les membres du comité d'éthique de l'Université McGill consultent celles qui représentent vos renseignements personnels.

Les résultats de cette étude pourraient être publiés. Cependant, votre identité et toute information permettant de vous identifier ne seront dévoilées dans aucune publication ni aucun rapport. Sur demande, vous pourrez obtenir une copie des résultats avant qu'ils soient publiés.

Questions et Personnes-ressources

Si, au cours de l'étude, vous avez des questions au sujet de vos droits, vous pouvez communiquer avec Mme Ilde Lepore, secrétaire administrative du comité d'éthique de l`Université McGill au 514, 398-8302. Pour obtenir des renseignements supplémentaires au sujet de l'étude, veuillez communiquer avec Maryse Pelletier-Hibbert, au 1 877- 770-7979, ou sa superviseure, Margaret Purden, Ph.D., au (514) 398-2417.

Déclaration de Consentement

J'ai lu le formulaire de consentement ou (le formulaire de consentement ma été lu) et j'accepte volontairement de participer à cette étude. J'ai eu la possibilité de poser des questions et on a répondu à mes questions à ma satisfaction. J'ai eu suffisamment de temps pour réfléchir à l'information reçue et pour demander conseil si tel est mon choix. J'autorise Maryse Pelletier-Hibbert à recueillir, partager, communiquer et utiliser mes renseignements personnels aux fins et selon les moyens mentionnés ci-dessus.

Je comprends que j'ai le droit d'accès à tous mes renseignements personnels, ainsi que le droit de les modifier; toutefois, ces corrections doivent respecter les limites prévues par la loi. Ce consentement est valide jusqu'à la fin du projet.

Je recevrai une copie signée de ce formulaire de consentement. En signant ce formulaire de consentement, je ne renonce à aucun droit reconnu par la loi.

Entrevue personnelle: **En signant ce formulaire, je consens à**:

Participer à une entrevue enregistrée sur audiocassette et dirigée par l'étudiante:
OUI______ NON______
Signature du participant: ______________________ Date: _____________________

Signature de la chercheuse:______________________ Date: ______________________

Entrevue téléphonique: En donnant mon consentement verbale, je consens à**:**
Participer à une entrevue enregistrée sur audiocassette et dirigée par l'étudiante :
OUI______ NON______1
Rétroaction : J'aimerais recevoir une copie des résultats sommaires.
Oui ______ Non ___________
Adresse postale : ____

Appendix N: Confidentiality Agreement of Transcriptionist

Study Title: The Adjustment Process of Husbands/Partners Living with Women on Dialysis

The procedures for the above-mentioned study involves individual interviews that will be audio tape-recorded and transcribed. You have been approached to transcribe the audio-taped interviews and as a transcriptionist your responsibilities will consist of:

- Keeping all information that is discussed, taped, and transcribed confidential.
- Assigning code names to all transcripts (for example, P1, P2 etc.) and refraining from using participant names or study site locations in any transcripts.
- Deleting all electronic files in your possession, shredding any hard copies of any transcripts, and returning all tapes after completing transcription and transferring a file(s) of the transcribed data to the principal investigator.
- Returning all tapes, floppy disks or CDs or other sources containing electronic files, and/or transcripts related to the study to the principal investigator upon completion of the study or in the event of termination of employment.

My signature below indicates that I have read the above and fully agree to maintain confidentiality as outlined.

Name (Printed) ____

Signature ____

Date Signed ____

Name of Witness (Printed)____

Signature of Witness ____

Date Signed ____

Annexe N: Contrat de Confidentialité du Transcripteur

Titre de l'étude: Le processus d'ajustement des partenaires qui vivent avec une conjointe sous traitement de dialyse rénale.

Les procédures de l'étude mentionnée ci haut impliquent que des entrevues ont été réalisées avec des partenaires et ont été enregistrées sur bande audio. Vous avez été rencontré(e) afin de vous demander de transcrire ces bandes audio et où vos responsabilités en tant que transcripteur seront de:

- Maintenir la confidentialité de toutes les informations discutées et enregistrées sur les bandes audio ainsi que les informations qui seront transcrites;
- Assigner un code à toutes les transcriptions réalisées (par exemple, P1, P2 etc.), ne pas utiliser les noms des participants dans les transcriptions, ni les lieux où les entrevues se sont réalisées;
- Effacer tous les fichiers électroniques que vous avez en votre possession, déchiqueter toutes les copies papier des transcriptions, retourner toutes les bandes audio après leurs transcriptions et transférer tous les fichiers électroniques des données transcrites à l'investigatrice principale;
- Retourner toutes les bandes audio, les disquettes, les cd, ou tous autres supports contenant les fichiers électroniques, et/ou les transcriptions de cette étude à l'investigatrice principale au moment où l'étude sera complétée, ou au moment où votre embauche se terminera.

Ma signature ci-dessous indique que j'ai lu les informations décrites dans le contrat décrit ci haut, j'accepte de maintenir la confidentialité des données et de respecter les responsabilités associées au rôle de transcripteur.

Nom (Lettres moulées) : ______________________________

Signature: ______________________________

Date de la signature: ______________________________

Nom du témoin (Lettres moulées) : ______________________________

Signature du témoin : ______________________________

Date de la signature du témoin : ______________________________