

**WOMEN'S EXPERIENCE OF HEMODIALYSIS AND SEXUALITY:  
A QUALITATIVE STUDY**

by

**Deborah Joan Harkness**

**A thesis submitted in conformity with the requirements  
for the degree of Master of Science  
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University of Toronto**

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## **ABSTRACT**

**Women's experience of hemodialysis and sexuality:  
A qualitative study**

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**Deborah Joan Harkness**

**Graduate Department of Nursing Science**

**University of Toronto**

The purpose of this study was to describe women's experience of hemodialysis and sexuality. Ten women living with hemodialysis were interviewed, using an in-depth, unstructured, face-to-face format. The data were analyzed by a method similar to Giorgi's (1975) phenomenological method. Data seemed to fall into three broad categories: 1) Physical sexual activity, 2) Relationship factors, and 3) Body image/self-concept/self-esteem. Sexuality included a physical sexual relationship for all women. Sexual activity was not of central importance to most women. All sexually active women experienced interference with, and changes in their sexual lives and feelings of guilt or obligation. Interpersonal factors influenced women's ability to re-establish a mutually acceptable sexual relationship (e.g., positive exchange of communication, understanding partners and role support). Women were self-conscious about body changes and how others perceived and reacted to them. Most women possessed positive self-concepts. All women experienced role changes however their acceptance of these changes varied.

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## CHAPTER I

### THE RESEARCH PROBLEMS AND PURPOSES

#### Background to the Problem

Living with chronic renal failure (CRF) means facing a myriad of changes in one's life. CRF permeates and threatens an individual's "self-worth, identity, control of one's body, intimate relationships, and life itself" (Anderson & Wolf, 1986, p.168). With no cure available, individuals who choose to be treated, endure a life long commitment to dialysis unless transplantation occurs.

While technical improvements have eased some of the rigour and burdens of hemodialysis, patients continue to report a range of physical and psychosocial changes and stress related to living with hemodialysis (Baldree, Murphy, & Powers, 1982; Galpin, 1992; Kaplan De-Nour, 1983; Muthny & Koch, 1991; Rittman, Northsea, Hausauer, Green & Swanson, 1993; Soskolne & Kaplan De-Nour, 1989). Ongoing and/or intermittent struggles with fluid and dietary restrictions (Baldree et al., 1982; O'Neill & Glasgow, 1991), sleep disturbances, fatigue, blood pressure oscillations, weight gains and losses, and muscle cramping are physical problems commonly expressed by patients (Fuchs & Schreiber, 1988; Gurklis & Menke, 1988; Kline, Burton, Kaplan De-Nour, & Bolley, 1985; Muthny & Koch, 1991). Physical changes resulting from intercurrent diseases and those secondary to CRF (i.e., cardiac, vascular, bone, and endocrine disease) exacerbate health problems and reduce the potential for optimal well-being.

Reported psychosocial changes include those related to interpersonal relations, lifestyle, and physical appearance. These changes are often accompanied by alterations in body-image; sexual function; roles; vocation; and family, social, and intimate relations (Rickus, 1987; Schlebusch, Botha, & Bosch, 1984). Furthermore, studies have documented a high incidence of anxiety and depression, low self-esteem and low self-concept associated with patients on hemodialysis (Galpin, 1992; Muthny & Koch, 1991; Rickus, 1987; Tucker, Chennault, Green, Ziller, & Finlayson, 1986). In particular, some studies found that women on hemodialysis voice more physical and psychological ailments (Chowanec & Binik, 1989; Muthny & Koch, 1991) and more difficulty with domestic, social, and sexual aspects of life than men on hemodialysis (Soskolne & Kaplan De-Nour, 1989). Kaplan De-Nour (1982) found that women exhibited greater anxiety and psychosocial problems than men.

Women constitute approximately 42% of the hemodialysis population in Canada (Dr. D Churchill, personal communication, January, 10, 1997). More specifically, within the Toronto region women currently represent 39.5% of the total dialysis population and 38% of the hemodialysis population (The Toronto Region Dialysis Registry, 1998). Despite these figures and the narrow focus of previous research on sexuality, the bulk of studies refer mostly to men on hemodialysis.

The researcher's experience as a practitioner in dialysis is that sexuality is a topic scarcely broached by women or their health care providers. The researcher developed an interest in the

topic during an undergraduate clinical experience with a visually impaired woman dependent on peritoneal dialysis. This woman asked the researcher to meet with her and her husband to discuss their marital and sexual difficulties. The researcher's lack of knowledge about sexuality and lack of training in this area of health care, not to mention discomfort with this type of counselling, acted as a catalyst for further exploration of the concept of sexuality in women dependent on hemodialysis.

Since the researcher's initial undergraduate experience, few studies have focused exclusively on women on hemodialysis or examined sexuality from a broad perspective. Also, since first introduced to the notion or thought of chronic illness and sexuality ten years ago, the researcher has not witnessed any notable changes or strides in the practice setting or the education offered to nephrology nursing staff that aim to address women's sexual health issues and that provide support to this dimension of well-being. If the goal of care is to help people on hemodialysis achieve maximal health and well-being, the above observations suggest that the level of health care concerning sexual issues currently practiced in the clinical practice setting needs further exploration.

The majority of research concerning hemodialysis and sexuality tends to focus on optimizing aspects of sexual function in men on dialysis rather than in women (Campese & Liu, 1990; Kaplan De-Nour, 1978; Schover & Jensen, 1988), and delineating gender specific changes and hormonal factors responsible for alterations in sexual

functioning and sexual activity. Studies involving women on long term dialysis place a similar emphasis on the need to optimize sexual function, but fail to address any concepts related to sexual healing and the ways in which women re-establish their physical sexual relationship and restore their general sexual health.

Sexuality is an important and fundamental dimension of humanness in both health and illness. It is the result of a close interdependent relationship between the mind and body (Fisher, 1983; Sheridan, 1983) that exemplifies individuals' whole human experience (Fearing, Hart, Milde, & Cox, 1994). Throughout life, human beings accumulate life experiences that influence, and possibly alter, the development of various aspects of their sexuality. Life experiences may change an individuals values, beliefs and attitudes which, in turn may influence certain aspects of their sexuality.

In particular, the event of hemodialysis often generates an intricate web of disruption in sexuality for patients as they face unfamiliar and diverse changes in their physical, sexual, psychological and emotional health, and lifestyle. As Anderson and Wolf (1986) point out, chronic illness threatens several key aspects of sexuality (i.e., sexual identity, intimacy, and generativity).

Thus it is limiting to think of sexuality as being only about sexual activity in a purely physical or biological sense. Nonetheless, the bulk of past research about sexuality involving hemodialysis patients has focused mainly on the bio-physical

dimension of sexuality and the various aspects within this dimension related to normative sexual activity and functioning (i.e., the frequency of sexual intercourse, orgasm, and the measurement of blood hormonal levels). A review of the wider body of literature underscores that sexuality is more than basic responses brought about as a result of primitive biological instincts. In fact, at a minimum, sexuality involves the complex orchestration of biophysical, psychosocial, intellectual, and cultural aspects of being.

This study, in conceptualizing sexuality, takes a more holistic approach than that which is normally associated with the conventional biomedical model of sexuality. From this perspective, human sexuality includes more than physical sexual activity that is influenced by mere bio-physical sexual responses. For this study, sexuality is conceptualized as an expression of self as a sexual being through intimate, physical and emotional relationships. It encompasses sexual relations, intimate relationships and notions of closeness, affection and companionship. It is influenced by other dimensions of being like body image, self-concept, self-esteem, and social relations that are each affected by an individual's personality, total life experience, and a number of physical, psychological, emotional, socio/cultural and interrelational factors. It is the inter-relationships among these factors that influence individuals' expression of sexuality. Grounded in life experiences, sexuality seeks positive affirmation of oneself and physical and emotional expression of warmth, contact, tenderness,

and love in order to satisfy one's needs for love and belonging. Thus, sexuality embodies a sense of connection with one's life and being in the world.

The literature has reported that many aspects of female sexuality are subject to alteration from hemodialysis therapy (Davison, 1986; Rickus, 1987; Ulrich, 1987). Women on hemodialysis report a loss of spontaneity and waning sexual desire, decreased sexual activity, difficulty achieving orgasm during intercourse (Levy, 1973; Mastrogiacomo et al., 1984; Rickus, 1987; Rozenman, Gurewicz, Blickstein, Shoham, & Bar-Khayim; 1990), menstrual abnormalities, premature reproductive changes (Campese & Liu, 1990; Mantouvalos, Metallinos, Makrygiannakis, & Gouskos, 1984; Milde, Hart, & Fearing, 1996), and a number of psychosexual concerns (Alleyne, Dillard, McGregor, & Hosten, 1989; Kutner & Gray, 1981; Rickus, 1987). Although studies have confirmed the high incidence of particular changes in female sexual function such as a decrease in the frequency of sexual activity and orgasmic ability, they have failed to elucidate the meaning of the changes from the perspective of women. Knowledge concerning the impact of hemodialysis on different aspects of sexuality, including the ways in which women maintain, redefine or reconstruct notions of their sexuality, remains inadequate.

#### **Problem Statement**

The fundamental problem this study addressed was the lack of knowledge about women's perspectives regarding their experience of sexuality while undergoing routine hemodialysis. In the past,

research has focused on physiological and quantitative aspects of sexual dysfunction, reducing and isolating sexual function from the whole context of women's lives. It would be useful to gather information which will increase our insight and understanding of women's lived experience of sexuality while receiving hemodialysis. Such insight could help to augment understanding of women's responses to dialysis by contextualizing several aspects of sexuality in relation to women's lives. Future approaches to caring could then be grounded in meaning derived from the experiences of women rather than only the perspective of researchers.

#### **Literature Review**

Previous studies have examined the impact of various renal treatment modalities on male sexual functioning, and to a lesser extent on female sexual functioning. However, they have failed to address the scope and meaning that the changes associated with hemodialysis may have particularly in relation to sexual functioning. The literature will be highlighted under four headings: (a) the conceptualization of sexuality; (b) sexual function and sexual satisfaction of women on hemodialysis; (c) psychosocial aspects of sexuality; and (d) reproductive aspects of sexuality.

#### **The Conceptualization of Sexuality**

Sexuality has been examined from a wide number of perspectives. Anthropological, psychological, sociological, cultural, and feminist perspectives have contributed valuable analysis and understanding about the construction and

conceptualization of sexuality. In Western society however, biological determinism, more than any other perspective, continues to underpin and influence the majority of sexual research, the development of sexual therapies, and thus the evolution of knowledge concerning sexuality.

Most studies of women living with hemodialysis were conceptualized within a biomedical model of sexuality (Alleyne et al., 1989; Di Paolo, Capotondo, Gaggiotti, & Rossi, 1990; Levy, 1973; Mastrogiacomo et al., 1984; Rozenman et al., 1990) and rooted in biological assumptions of universality, naturalness, heterosexuality, and reproduction. These empirical studies emphasized the loss of, and the importance of women sustaining or regaining, conventional sexual norms associated with sexual function, sexual activity, and to a lesser extent their sexual satisfaction following their diagnosis of chronic renal failure.

Despite sharing a biomedical perspective, studies regarding female sexuality possess wide variations in the specific way sexuality, sexual function and sexual dysfunction have been defined. Many studies fail to define study terms and the reader is forced to guess at the probable definition of terms based on the context of the study and particular aspects of sexual function outlined in the study procedure or questionnaire. Many of the methodological shortcomings in research on sexuality and end-stage renal disease are briefly outlined in Binik and Mah's (1994) review of such literature. For example, whereas Mastrogiacomo et al.'s (1984) study placed emphasis on the degree of libido, the frequency



of intercourse, and the ability to reach orgasm both before and after the diagnosis of CRF, Rozenman et al.'s (1990) study examined the frequency of and desire for intercourse, duration of foreplay, reaction to courting, and ability to reach orgasm.

Although many researchers recognized sexual function as a complex aspect of life that could be influenced by a number of physical, biophysical, psychosocial, and treatment related variables (Alleyne et al., 1989; Golden, Milne, & Chir, 1978; Levy, 1973; Steele, Finkelstein, & Finkelstein, 1976; Toorians et al., 1997; Zarifian, 1994), most studies adopted the narrow perspective of the biomedical model. Many of these studies limited their focus of sexuality to the causal relationships between changes in sexual function, activity, and performance; and biophysical changes (Di Paolo et al., 1990; Mastrogiacomo et al., 1984) and compared aspects of women's sexual response cycle both before and after starting hemodialysis (Golden, Milne, & Chir, 1978; Levy, 1973; Mastrogiacomo et al., 1984).

A few exceptions to this approach were noted. Alleyne et al. (1989), Milde et al. (1996), Rickus (1987) and Steele et al. (1976) expanded their conceptual definitions of sexuality beyond that of pure biological determinism even though their focus was on sexual function. Although explicit definitions were not always provided in the study reports, readers were led to believe that sexuality is influenced by more than biophysical factors. For example, Rickus (1987) stated that many areas of sexuality were interconnected and proceeded to explore women's concerns of several psychosocial

variables such as femininity and role changes in addition to sexual function. Alleyne et al. examined mental distress and self-concept, and Steele et al. evaluated patients' and their spouses' psychological status and marital discord, in conjunction with sexual function. In addition to exploring the frequency of subjects' sexual and fertility dysfunction and level of satisfaction, Milde et al. (1996) also included measures to examine subjects' level of physical function, intimacy attitudes and patterns, marital relationship (e.g., affection given and received and the balance of domination/submission in the sexual relationship), intimate relationship (e.g., degree of change in self-disclosure, sexuality and affection), and quality of life. This broadening of perspectives suggests that, at least for some researchers, sexual function exists interdependently and is influenced by other aspects of being.

Only one study involving hemodialysis patients deviated significantly from the biomedical framework (Charmet, 1990). Using a psychoanalytic framework, Charmet conceptualized sexuality as a process that consists of symbolic, affective, and relational aspects and interpreted prevalent symbolizations found in the dreams of individuals on dialysis.

However, in some non-research articles, a much broader, more descriptive approach was used to conceptualize sexuality (Anderson & Wolf, 1986; Degen, Strain, & Zumoff, 1983; Fearing et al., 1994; Lubkin, 1986; Sheridan, 1983; Uttley, 1996; Woods, 1987). In case studies (Streltzer, 1981; Whitson, 1982; Zarifian, 1994) and the

clinical practice experiences of the researcher, patients' descriptions of their experience with illness and sexuality presented a more comprehensive picture than the empirical data collected within the scientific studies. This could be because patients were given the opportunity to talk about the meaning of their experiences. In conversation with the researcher as a staff nurse, patients not only expressed dramatic changes in their sexual life but changes in their stamina and energy level, self-concept and self-esteem, social relationships, and self-consciousness of their dialysis access sites since being on hemodialysis.

Additional variables which broaden the concept of sexuality include concepts of affection, intimacy, friendship, and companionship. Although the importance of these elements within the marriage of individuals living with dialysis (Davison, 1986; Milde et al., 1996; Rickus, 1987), chronic illness (Anderson & Wolf, 1986), and the general population (Keystone & Kaffko, 1992) has been previously highlighted, these concepts have not been studied in-depth for the hemodialysis patient. Additionally, body image, self-concept, and self-esteem have been the focus of individual articles (Galpin, 1992; Lubkin, 1986; Woods, 1987), and discussed in relation to sexual function (Lubkin, 1986). However, the significance of these factors was rarely explored in studies in conjunction with sexual function in a comprehensive way.

Because sexuality embodies more than sexual function, there is a need to look beyond this single aspect of sexuality. A broader perspective is needed to capture new insights and a greater

understanding of the experience of sexual function and dysfunction in relation to other aspects of women's sexuality. Also understanding is required regarding the healing processes that take place for women as they attempt to (re-establish sexual intimacy and) and preserve what is most valued about their sexuality.

#### **Sexual Function and Sexual Satisfaction of Women on Hemodialysis**

The technical difficulties associated with measuring female sexual function have thwarted research on women in this area (Bommer, 1986; Kaplan De-Nour, 1978; Mastrogiacomo et al., 1984; Schover & Jensen, 1988; Stupak Shah, 1991). Most studies on hemodialysis patients have focused primarily on men rather than on women (Binik & Mah, 1994; Campese & Liu, 1990; Kaplan De-Nour, 1978; Schover & Jensen, 1988), exploring the causes of men's sexual dysfunction, changes in their sexual response and behaviour, and enhancement of their performance. Information about the sexual function and sexual satisfaction of women was scattered throughout the literature and involved extracting data from a range of studies.

The changes in sexual function most often experienced by women include: (a) a decline in the frequency of sexual intercourse; (b) a decrease in sexual libido, desire, or urge; (c) a decrease in orgasmic ability (Levy, 1973; Mastrogiacomo et al., 1984; Rozenman et al., 1990); (d) and lessened sexual satisfaction (Alleyne et al., 1990; Golden et al., 1978; Kutner & Gray, 1981). Levy reported that 25% of women experienced a decrease in sexual function following the initiation of dialysis, and Di Paolo et al. (1990)

found that women's sexual function declined significantly (p.<0.0078) after starting dialysis. In Wilde et al.'s (1996) study 76% of participants identified a decline in sexual frequency once starting dialysis therapy, and 65% considered their sexual relationship dissatisfying. However, the authors did not provide data specific to women.

Mastrogiacomo et al.'s (1984) study of 99 Italian women found that women on dialysis exhibited more sexual dysfunction than age-matched healthy women. Similarly, Jewish women on hemodialysis and continuous ambulatory peritoneal dialysis experienced less frequent intercourse (p.<0.004), less desire for intercourse (p.<0.05), shorter length of foreplay (p.<0.01), and more resistance to their partners' attempts to initiate intercourse (p.<0.001) than a group of married, similar aged healthy Jewish women free of gynecological disease (Rozenman et al., 1990). It is unknown, however, whether or not these changes were in fact problematic for women because the findings are limited to quantitative changes reported by women rather than their descriptions of the meaning of the changes.

While in-depth descriptions about the significance of changes in sexual function have not been undertaken, there is some evidence that women attribute various factors to the changes they experience. In Rickus' (1987) descriptive study, 35% of women believed the side effects of their medications decreased their sexual activity. Other women claimed that medications caused changes in vaginal lubrication and orgasmic difficulties (Rickus, 1987). In Brown et al.'s (1978) study, women reported a loss of

energy, dialysis access devices, and a lack of opportunity or spontaneity as reasons for decreased sexual activity.

The relationships between sexual dysfunction and various blood hormonal levels represents a sizeable area of research. Researchers have examined the association between hormone levels and sexual dysfunction (Mastrogiacomo et al., 1984; Rozenman et al., 1990; Toorians et al., 1997), the deterioration of sexual function in women as it relates to erythropoietin, hematocrit and various hormonal changes (Di Paolo et al., 1990), and the effect of bromocriptine treatments (Weizman et al., 1983) and use of epoetin alfa (Schaefer, Kokot, Wernze, Geiger, & Heidland, 1989) on sexual function and prolactin levels.

Rozenman et al.'s (1990) findings revealed no relationship between elevated parathormone levels and sexual dysfunction. Mastrogiacomo et al. (1984) and Weizman et al. (1983) found an association between high prolactin levels and sexual dysfunction in women on hemodialysis. Yet Di Paolo et al. (1990) reported that sexual function worsened in patients independent of a further loss of renal function, drop in hematocrit, and any relationship to hormonal changes studied. Based on some researchers' concluding study comments, there is reason to believe that the answers to sexual dysfunction do not lie in blood hormonal levels alone (Di Paolo et al., 1990; Weizman et al., 1983), if at all (Toorians et al., 1997).

Based on biochemical and self-report data, as well as psychophysiological data (e.g., stimuli, genital and subjective

measures) in four different groups of patients (hemodialysis, peritoneal dialysis, transplant and rheumatoid arthritis) that were willing to undergo the assessment, Toorians et al. (1997) reported that chronic renal disease and biochemical or endocrine variables failed to explain the presence of sexual (dys)function in patients. However, the authors also documented that analysis of biochemical or endocrine data was purposely omitted on women due to the absence of significant findings in data from male patients that were studied (Toorians et al., 1997).

Studies have emphasized the incidence of specific sexual dysfunctions in women but have paid little attention to the findings related to women reporting either no change or some improvement in their sexual function since starting dialysis therapy. For example, Rickus (1987) found that 50% of women noted no change in their sexual activity. Levy (1973) found that a total of 61.3% of his participants, which included women, denied any emergence of problems, were unsure of any problems, or failed to answer the question. Similarly the sexual changes experienced by single, widowed, and divorced women were seldom examined or expanded upon, despite the fact that the context of singleness raises different issues for patients (Streltzer, 1981).

There is only a limited understanding of what it means for patients on dialysis to be sexually satisfied or dissatisfied. Studies focusing only on sexual function may not add much to this understanding. Schnarch (1991) points out that sexual functioning does not necessarily correlate positively with sexual satisfaction

(as cited in Keystone & Kaffko, 1992). In one study, patients ranked sexual satisfaction and the importance of their sexual life as low, although Ferrans and Powers (1993) did not examine gender differences or women's account of their rankings. Milde et al. (1996) noted significant relationships between sexual satisfaction and the variables of partner satisfaction, arousal, occurrence of orgasm, and acceptance of partners' advances, but the authors did not describe findings specific to women. Moreover, subjects who were satisfied with their sexual relationship were more physically active, worked more hours per week, experienced less change in their previous intimacy patterns, had high levels of mutual affection, were more satisfied with life, and considered their present and future life and health status higher compared to dissatisfied subjects (Milde et al., 1996). Kutner and Gray (1981) reported that the majority of patients were less satisfied with their sexual lives compared to the time when they were well. Patients reported that a loss of interest in sex and reduced ability to perform sexually were two factors that negatively affected their satisfaction with their sexual lives. Other studies have simply reported that patients on hemodialysis experienced less sexual satisfaction than patients on other renal modalities (Morris & Jones, 1989; Muthny & Koch, 1991; Simmons & Abress, 1990) without providing any further analysis.

There is reason to believe that dialysis treatments impact uniquely on the sexual lives of women. Rozenman et al. (1990) found that, while all women in the study had experienced both



hemodialysis and peritoneal dialysis treatments at one time or another, 30% of women expressed no treatment preference in relation to their sexual lives, 55% preferred hemodialysis to peritoneal dialysis in terms of their sexual life, and 15% preferred peritoneal dialysis over hemodialysis. However, the reason(s) for women's treatment preference in regard to their sexual lives and, as well, the impact and meaning of treatment preferences for women was not expanded on.

It is clear from the literature that the emergence of changes in female sexual function while on hemodialysis are multifactorial, highly individual, and difficult to predict. Thus, it remains difficult to ascertain, "...the relative strength of the contribution which each factor makes alone and in concert with others to produce impaired capacity for sexual functioning" (Golden et al., 1978, p.879). As is evident, studies have focused on biophysical factors and the physical manifestations associated with the female sexual response cycle and minimized understanding of women's experience of changes in sexual function or dysfunction. As Steele et al. (1976) write, dysfunction "...must be viewed in relation to...overall adjustment to illness and the quality of interpersonal relationships" (p.921). In a similar vein, Dailey (1998) warns that failure to address problems in the area of sexual functioning beyond the realm of physiological issues simply provides "the seed bed for continued struggles in the sexual bond and in the relationship in general" (p.82).

### **Psychosocial Aspects of Sexuality**

Changes in sexual function have been described as stressful for patients on hemodialysis. Fuchs and Schreiber (1988) and Kline et al. (1985) found that study participants, of whom almost half were women, ranked decreased libido and changes in sexual function as a significant source of stress. While fatigue, dependency on others, sleeping disturbances, and decreased social function were identified as other notable stressors for patients (Gurklis & Menke, 1988; Fuchs & Schreiber, 1988), the relationship and impact of these stressors to changes in sexual function was not examined. As no studies were found that focused on the impact of concurrent changes on the lives of women, it is unknown to what degree sexual stressors arise from, or influence the development of other stressors or changes related to sexual well-being.

Women on hemodialysis experience concurrent changes in aspects of life that embrace notions of body-image, self-concept and self-esteem. According to Muthny and Koch (1991), women have more difficulty than men with changes in their physical appearance. Hair thinning and/or loss, changes in texture of skin, hair, and nails, and loss of muscle mass are not only reminders of illness but also are defeminizing and difficult to camouflage. Although dialysis access sites, surgical scarring, and weight gain were most disturbing to women, they perceived their spouses as being most troubled by the presence of scars and weight gains (Rickus, 1987). Furthermore, in over two thirds of women studied (N=34), physical changes caused them to abstain from sexual experiences (Rickus,

1987). Research on the relationships between pharmacology and female sexual function is sparse (Schover & Jensen, 1988); however in an earlier report, women on dialysis blamed the masculinizing effects of anabolic steroids for their dysfunction as the steroids accentuated body image changes and further diminished the women's sense of femininity (Golden et al., 1978).

Considering the emphasis society places on physical appearance, it is plausible that changes in body image might foster changes in self-concept and self-esteem. Galpin (1992) stated that, "Patients [on dialysis]...experience disintegration of their former self-images without the simultaneous development of equally valued new ones" (p.21). Alleyne et al. (1989) reported significant differences between hemodialysis patients' self-image before illness in comparison to after starting hemodialysis (p.<0.001). Mlott (1976) noted that women on hemodialysis exhibited lower levels of self-esteem than their male counterparts. The meaning of these changes for women have not yet been studied.

While high levels of family adjustment and satisfaction have been found in hemodialysis patients (Ferrans & Powers, 1993; Muthny & Koch, 1991; Rickus, 1987), other studies have documented impairment and disruption of family functioning (Kaplan De-Nour, 1982; Simmons & Abress, 1990). In particular, Chwanec and Binik (1989) found more women than men manifested problems with marital role strain.

Kaplan De-Nour's (1982) study of 102 Jewish patients on hemodialysis found that women experienced more difficulty than men

adjusting to social, vocational, domestic and psychological domains of life, especially in the latter two areas. Rickus (1987) noted that 32% of women reported sensing resentment from their husbands because of the changes illness made to their roles and personal lives. The implications of this finding for women, however, were not elaborated on by Rickus.

#### **Reproductive Aspects of Sexuality**

Knowledge of the relationships between female gonadal abnormalities and sexual dysfunction remains limited and controversial at this time (Campese & Liu, 1990; Finkelstein & Finkelstein, 1981; Schover & Jensen, 1988). Nonetheless, chronic renal failure and hemodialysis undoubtedly contribute to abnormal ovarian, menstrual, and reproductive function, and in some cases cause these functions to cease. It is unusual for women on hemodialysis to have normal menstrual function and even rarer for them to conceive, even though there are documented cases of successful pregnancy and birth (Barri, Al-Furayh, Qunibi, & Rahman, 1991; Hou, 1994). Nonetheless, recent studies have reported pregnancy rates of 1.5% (Hou, 1994), 5.0% (Holley, Schmidt, Bender, Dunler, & Schiff, 1997) and 7.0% (Milde et al., 1996) among women on dialysis. Rickus (1987) reported that more than 50% of women on hemodialysis experienced early menopause. Some women expressed concern about changes in fertility and reproductive function resulting in a premature loss of the ability to bear children, as well as a loss of their womanhood (Rickus, 1987).

### **Conclusions from the Literature**

As is evident from the literature review, the majority of studies were descriptive and had underpinnings in the biomedical reductionistic model of sexuality. Thus, much of what is known about women on hemodialysis and sexuality relates mostly to one aspect of sexuality (e.g., the extent of women's sexual activity and changes in their sexual responses before and after starting dialysis). While this approach provides information on the kinds of changes women encounter in their sexual responses, sexual function has been decontextualized or isolated from the whole context of women's sexual lives because the topic has been studied from the perspective of the researcher and not women. Clearly, what is missing from this body of literature is understanding of the human experience associated with these changes and, for that matter, other aspects of sexuality. By conceptualizing sexuality more broadly and studying women's perspective of their sexuality in view of the whole context of their lives, the meaning of such changes might help to clarify some of the complex relationships between hemodialysis and various aspects of sexuality, including sexual function.

### **Purpose of the Study**

The immediate purpose of the study was to describe the experience and impact of hemodialysis on female sexuality from the perspectives of women undergoing routine hemodialysis for a minimum of one year. Exploring the experiences of women was expected to contribute to our understanding of the sexual issues which women

living with chronic illness appraise as important. Such an approach may lead to the suggestion of nursing approaches which may be more effective in meeting the sexual health care needs of women on hemodialysis.

#### **Research Question**

The research question guiding this study is: What are women's experiences, thoughts, and feelings concerning their sexuality while they are living with hemodialysis? The study was undertaken on the assumption that the experience of hemodialysis may have an impact on women's experience of sexuality and that they will be willing and able to articulate their experiences.

## CHAPTER II

### METHODS AND PROCEDURES

#### Design

The methodology chosen for this study was qualitative. Qualitative designs seek to "document and interpret as fully as possible the totality of whatever is being studied in particular contexts... ." (Leininger, 1985, p.5). This study sought to gain a better understanding of the sexuality of women on hemodialysis by giving them an opportunity to share their perceptions of how hemodialysis has affected their sexuality. A qualitative design was considered an ideal approach to address the research question of this study because it provides the researcher with access to the empirical world from the perspective of the women.

#### The Qualitative Approach

A qualitative approach provides access to the study of human beings and their behaviour in a way that is different from the traditional quantitative scientific approach. Knowledge of human phenomena resides in the lived experience and particular circumstances of individuals and their interpretation of that experience (Polit & Hungler, 1993). Thus, "The...researcher [strives] to understand the...subjective perspective of the person who has the experience and the effect that perspective has on the lived experience or behaviour of that individual" (Morris, 1977; as cited in Omerly, 1983, p.50). Human beings are studied in context, "as it is only there that what a person values and finds significant is visible" (Leonard, 1989, p.46). For these reasons, a

qualitative approach provided an appropriate means to gather rich descriptions from women about the ways in which being on hemodialysis had had an impact on their experience of sexuality in the whole context of their lives.

The goal of qualitative research is to comprehend the experiences of the persons being studied, and "...interpret [phenomena] in terms of the meaning people bring to them" (Denzin & Lincoln, 1995, p.2). It is through the medium of language that the researcher begins to understand the meaning that a particular lived experience has for individuals (Giorgi, 1975). Using the inductive method, the researcher analyzes the data in an attempt to arrive at an understanding of the experience which the participants find accurate.

The role of the researcher is to facilitate the interview while listening keenly to the participants' descriptions. The researcher should attempt to maintain the "natural spontaneity" of the experience as told by the participants (Jasper, 1994). Researchers must remember that "participants are the authors of their biographies and experiences" (Munhall, 1988, p.23).

#### **Sample and Setting**

The sample consisted of ten women on hemodialysis in four dialysis facilities located in the City of Toronto. The settings included three teaching hospitals and one self-care dialysis unit. Because the researcher has a clinical practice with renal dialysis patients, participants were selected only from settings unfamiliar to the researcher to avoid the threat of researcher bias (Munhall &



Oiler, 1986).

### **Approach to Potential Participants**

Data gathering procedures commenced once ethical approval was obtained from the Office of Research Services (ORS) at the University of Toronto and from the Research Advisory Committees of the agencies from which the participants were chosen. The Nurse Manager or delegate of each dialysis unit assisted in identifying prospective participants for the study (Appendix A) and made the initial approach to them (Appendix B). Those patients who were interested in hearing more about the study were then contacted by the researcher by telephone. The researcher provided the potential participants with an oral description of the study (Appendix C) and answered any questions raised by the women. If individuals expressed interest in participating in the study, an interview was arranged, at which time written consent was obtained (Appendix D).

### **Generation of Data**

Data were gathered through in-depth, unstructured, face-to-face interviews, which were recorded on audiotape. Demographic data were obtained prior to beginning the tape recorded session (Appendix E).

The interviews (Appendix F) began with a broad, open-ended question so that the participants were at liberty to discuss what they recognized to be important in their experience with the phenomenon. The interview began with the question: "In thinking about sexuality, please try to describe to me, in as much detail as possible, what your experience of sexuality has been like since

receiving hemodialysis. I would like you to share all the experiences, thoughts, insights, and feelings you have, as fully as possible, until you have nothing more to say about sexuality. There are no right or wrong answers. I am interested in knowing about what your experience has been like for you as a woman on hemodialysis".

Once the participant had answered this broad question fully, the researcher then asked a series of probing questions. This was done because of the researcher's belief that women might describe sexuality narrowly and thus reflect on their experience of sexuality only in terms of sexual function and sexual relations. Thus, these subsequent questions focused on the topics of body image, self-concept, self-esteem, intimate relationship, family and social relationships, and career and/or employment. However, as some women experienced confusion about the relationship between sexuality and employment, or sexuality and family or social relationships, the researcher eliminated the term 'sexuality' in the above series of questions with some women.

Following this series of topic questions, the researcher asked, "Out of all the changes that you have described to me what has been the most difficult for you manage or deal with and why"?, and the final question, "Is there anything that you would like to add or elaborate on from the interview"?

A second interview occurred following the transcribing of the first interview and within eight to twelve weeks of the initial interview. During the second interview a general summary of the

first interview was shared with the participants. Participants were asked to provide feedback regarding the summary to help validate the researcher's impressions of the initial interview. The participants were asked: (a) "Do you feel that my summary of our interview accurately describes your experiences?"; (b) "Is there any part of your experience that you feel was not covered in this summary?"; (c) "Is there any part of this summary which surprised you because it did not reflect your experience"? and; (d) "Is there anything that we did not discuss that you feel is part of your experience with sexuality since being on hemodialysis"?

All pertinent impressions and observations regarding the researcher's relationship to women and the participants' non-verbal body language and reactions to particular questions during the interviews were recorded following each interview.

#### Method of Data Analysis

The data consisted of interviews, which were transcribed verbatim, and information from the researcher's field notes. These field notes contained information about the investigator's impression of the interview session and the women's responses to the interview questions. All identifying names were removed from the transcripts and a code number was assigned to each participant. Transcripts were then analyzed using a method similar to Giorgi's (1975) psychological phenomenological method.

During the analysis the researcher tried to remain fully open to the data by bracketing out any known information and preconceptions about the phenomenon. Speigelberg's (1976)

operational processes of intuiting, analyzing, and describing were utilized throughout the analysis (as cited in Munhall & Oiler, 1986).

The first step involved the researcher familiarizing herself with the data by reading and re-reading the full naive description (interview transcript) to grasp a sense of its whole and reading the field notes for each participant. The notes provided assistance in remembering what had happened during the interviews (e.g., a context for the exchange and thus were not included in the data analysis directly). During the second step, the verbatim interview transcripts were re-read with the purpose of identifying distinct topics and commonalities among the interviews. Each content topic was identified and marked in each verbatim transcript.

Subsequently, the phrases or sentences from all participants reflective of a particular topic were gathered and written together on a single page of paper. For example, any of the phrases or sentences concerning the topic of physical act of intercourse were written together, no matter when the participants shared them during the interviews. The resulting list of topics provided a direct reflection of what the women in this study shared during the interview.

During the third step, the researcher refined the topic list with the intent of identifying and refining content categories. The content categories were not predefined but resulted from reviewing the topic list generated in step two of the analysis, the data under each topic, and grouping related or similar topic areas. For

example, the topics of physical act of intercourse and desire for sexual intercourse were grouped under physical sexual activity. This work was completed by gathering the data for each related topic together manually on one large scrolled page of paper. Category labels were selected to reflect the nature of the primary content contained within the grouped topic data. Those content categories that related to the research focus (sexuality) were separated from those that were not.

The final step involved re-checking the content categories against the original data to establish that the categories exhaustively reflect the totality of the women's experiences concerning sexuality and hemodialysis. The presentation of data will reflect the range of ideas captured under the content categories.

#### **Methodological Rigour**

The importance of maintaining rigour in qualitative studies cannot be overstated. Qualitative studies must strive to establish a high level of methodological rigour in order that the results generated by such studies will be trustworthy and accurate. The merit of qualitative studies is judged by the extent to which they address and meet the precise evaluation criteria which are established by the scientific community.

To achieve rigour during all phases of the research process, the researcher addressed notions of internal and external validity, reliability and objectivity as defined by the four qualitative evaluation criteria outlined by Sandelowski (1986): credibility,

fittingness [or transferability], auditability, and confirmability.

Credibility is the measure against which the truth value of a qualitative study is evaluated. Truth value is "subject-oriented rather than researcher-defined" (Sandelowski, 1986) because an understanding of the phenomenon begins and ends with the concrete lived experience and descriptions given from the participant's perspective (Van Manen, 1990, p.36). For this reason, participants and their narratives are one of the most fundamental sources of credible data.

The vividness and faithfulness of the descriptions and interpretations presented in the study constitute the measure of credibility. The test for credibility is met if; (a) those who have had the experience are able to recognize and verify their own descriptions as true (Sandelowski, 1988) and; (b) if "... [other readers or researchers], adopting the same viewpoint as articulated by the researcher, can also see what [the] researcher [sees], whether or not [they] agree with it" (Giorgi, 1975, p.96).

Threats to credibility were minimized by seeking expert consensual validation from the advisor overseeing the study. As well, the process of having participants review summaries before the second interview limits the influence of researcher bias on these interpretations.

A strategy that assisted in reducing researcher bias was the production of field notes which documented the researcher's relationship to the patients as well as the data. By doing this, the researcher becomes aware of her own role in the whole research

process (Kahn, 1993). This technique dealt with the concern that the researcher might "go native", meaning that her involvement with the participants becomes so profound that she is unable to distinguish the participants' experiences from her own (Beck, 1993).

Bracketing was also used to enhance credibility. The researcher consciously bracketed out or set aside preconceptions, beliefs, or suspicions regarding the phenomenon under study. This activity helped the researcher to grasp what truly appeared from the data during collection and analysis.

These various techniques employed by the researcher, while aimed at addressing slightly different concerns, also performed one common function. They acted as "anchors" to help the researcher maintain a balance between her personal relationship with the participants and the need to remain unprejudiced and impartial.

Fittingness is the criterion used to evaluate the study's range of applicability. The test for fittingness in qualitative studies is not so much whether the findings can be generalized to other populations but rather whether the data are sufficiently descriptive and detailed so that the readers can determine whether or not the findings apply to other contexts outside the study parameters (Polit & Hungler, 1993). Sandelowski (1986) explains, "A study meets the criterion of fittingness when its findings can 'fit' into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experiences" (p.32).

The criterion of auditability was attended to by concisely documenting the sequence of events which occur during the study, thereby leaving a clear "decision trail" which can be easily followed by a reviewer. The final criterion of confirmability combines all of the above criteria. Confirmability is secured when credibility, auditability and fittingness are established (Sandelowski, 1986). Qualitative research values subjectivity both in the researcher's relationship to the participants as well as the participants' interpretation of their own experiences. Confirmability, however, is concerned with the neutrality of the data because it is essential that independent reviewers, when interpreting the data, be able to arrive at a consensus about that data's meaning or relevance (Polit & Hungler, 1993). In other words, the reviewers should be able to follow the researcher's trail of logic, beginning with the question formulated, going next to the data collected, and finally arriving at comparable analysis of that data.

The researcher will achieve confirmability by describing the kind of evidence relied upon, the techniques used when collecting the data, and the method of analysis used when interpreting the data (Sandelowski, 1986).



## CHAPTER III

### FINDINGS

Data were collected over a five month period from August, 1997 to January, 1998. The sample was accrued through dialysis units in three Metropolitan teaching hospitals and one self-care dialysis unit in the City of Toronto. The total number of women screened for this study by the nurse managers is not known. However, of the 17 known potential participants referred to the researcher for this study, two did not meet the study's inclusion criteria (Appendix A), the researcher failed to make contact with one woman, and four women declined to participate. Thus, the data in this study were generated by ten women, who provided two interviews each.

#### Characteristics of the Women in the Study

The ten women in the study had been treated with hemodialysis for a minimum of one year as a result of chronic renal failure. Five women ranged between 20 and 45 years of age, four were between 46-75 years old and one was 76 years old. At the time of the first interview, five women were married, one was in a stable common-law relationship, one was divorced and three were single. Although one single woman lived with her partner at the time of the first interview, they were no longer living together at the time of the second interview. Three women had completed high school and one woman had completed grade ten in addition to some other courses. Three women each had either attended or completed college or university. The length of time women were on dialysis ranged between one and eight years, with a mean of 4.1 years. A summary of

the demographic information of the women appears in Table 1.

The experience of three women was limited to in-centre hemodialysis. All other women had had previous experience with a combination of self-care dialysis, home or hospital peritoneal dialysis in addition to their in-centre hemodialysis. Three women had received previous kidney transplants. In addition to using many prescribed medications, all women were receiving recombinant human erythropoietin (R-HuEPO). Also, four women were known to be taking prednisone and three women were on hormone replacement therapy. Of the nine women that fully completed the demographic data sheet, it was noted that 7 women were taking at least one anti-hypertensive medication.

The length of time required for initial interviews ranged between 45 and 120 minutes. Five initial conversations were carried out at the participant's house and the remaining five women chose to conduct the initial interviews following their dialysis treatment in a private office at the site of where they received their health care. The second interviews occurred between eight and twelve weeks following the initial interviews and were carried out either at the participant's house (N=2), post-dialysis in a private office at the treatment site (N=5), or while undergoing hemodialysis (N=3). Second sessions averaged 30 minutes in length and were also tape recorded.

There were few, if any, technical or nursing care interruptions while carrying out conversations with the three women who were interviewed while they underwent dialysis. Issues related

Table 1.

Sample Characteristics of the Women

Participant	Age Range (yrs)	Marital Status	Education Level
Anna	20-45	Married	College
Barb	20-45	Common-law	University
Carol	20-45	Single	High school
Dot	20-45	Single	High school
Elley	46-75	Married	College
Fran	46-75	Married	High school
Hanna	20-45	Single	College
Joan	> 76	Married	University
Karen	46-75	Married	University
Sarah	46-75	Single	Grade 10

\* The names of the participants are fictitious.

to confidentiality were addressed beforehand with the charge nurse and the interviews were subsequently carried out in a private room or in a quiet corner of the dialysis unit out of the hearing of other patients.

#### **The Experience of Being on Hemodialysis and Sexuality**

While the interview questions directed the women to reflect on their experiences related to sexuality, in actuality they spoke more broadly about their illness, about dialysis as a treatment, about many other aspects of life with which they contended, as well as about sexuality. In fact, their comments about sexuality represent a relatively small part of the interview data. The broader responses provided a context which helps the reader understand more fully these women's experience of sexuality since being on dialysis.

The results of the data analysis are presented in two sections: (I) Findings related to sexuality, and (II) Other findings. The findings related to sexuality fall into three categories: a) Physical sexual activity, b) Relationship factors, c) Body image/self concept/self esteem. Each category will be described and illustrated with excerpts from interviews. The section on 'other findings' consists of data obtained from women about the importance of health care professional support, as well as data obtained about the impact of the disease and treatment on other aspects of the women's lives. These findings are interlinked with women's sexuality and thus provide further context to women's full experience of being on hemodialysis and sexuality.

### **Findings Related to Sexuality**

Women's physical sexual relationship represented a meaningful aspect of sexuality, but sexuality also included having a particular kind of closeness and understanding with one's partner. In addition, it included how women saw themselves as women and as persons. These three dimensions of sexuality are closely interlinked, but they will be separated in the presentation of findings to follow, to allow for fuller examination and clarity. However, in a few instances, some quotes appear in more than one category because of the close inter-relationship between categories.

Physical sexual activity. The types of topics grouped under this category included women's definition of sexuality, the kinds of changes that occurred in women's physical sexual relationship, the factors that interfered with their sexual relationship, and women's feelings related to physical sexual activity. In response to the initial broad question about sexuality, all but one woman talked about their physical sexual relationship or the lack of it in their lives. For three women, being on dialysis had no apparent negative impact on their sexual relationship. Two of these women commented that they were sexually inactive prior to starting dialysis and continued to be so at the time of the study (Dot & Fran). The third woman, Joan, remarked, "Our sex life isn't as active, I haven't found dialysis to make a difference." Although these three women shared some thoughts on the subject matter, for the most part data in this section comes from the remaining seven

women. The responses of four women were limited to descriptions regarding their physical sexual relationship.

Some women's responses also embodied a vitality for life that extended beyond their sexual relationship. As Hanna said, "...to me sexuality...isn't just having sex in the first place. It's about me, my whole...self...I remember what it's like to be sexual and maybe sexuality is not about sex..."

Nearly all women compared different aspects of their sexual life to the time before they had started dialysis and four women commented about the differences between their partner's sexual desire and their own. All but two women (Joan & Sarah) experienced decrease in their overall sexual desire and sexual activity since starting dialysis. One woman denied any change in the patterns or extent of her sexual activity since being on dialysis (Joan). One woman experienced a general increase in her sexual activity since being on dialysis (Sarah). As Joan explained, "Our sex life isn't as active at our ages as it was but I haven't found dialysis to make a difference. Over the years the pattern changes and diminishes but um, that happens automatically with age...I just think in general over the last ten years or so there hasn't been any sudden change in activity [or] interest."

Eight of the ten women in this study were sexually active. Six of these women indicated that dialysis had had a negative impact on different aspects of their sexual life and sexual relationship. As Elley stated, "I'm not [turned on easily] and I think this made it even worse. My poor husband is exactly the opposite so you can

imagine how wonderful that is for him...[I have] no desire at all." She continued, "Before being sick I was normal I suppose. I've noticed more as the years go by there's nothing there...it's more ...and more subdued...I don't feel anything right now sometimes... sometimes once we get going it sort of wakes something up...[it's] not very often, but it does...it's like harder and harder to enjoy ...I can take it or leave it...I also find it even hurts sometimes ...That's just not a very enjoyable time...you're tired all the time and when you go to bed, you just want to sleep."

Sarah, who experienced overall improvements in the quality of her sexual response and quantity of sexual activity since starting dialysis, also noticed an unusual decrease in her regular amount of sexual activity. She said "...I only have sex once a week. But the truth of the matter is just recently maybe once a week...before, and that's in the past month or two, there was nothing stopping us two, three times a week."

Hanna mentioned, "I'm not going to say I don't have sex but I remember what it's like to be sexual...I have sex maybe once a week ...There are times when I want it. That time is not very often when I'm feeling really peppy and strong...But there are times when I don't and that's a lot of times...And there are times when I will have and I don't really want it but because [my partner] wants it then I'll say yes."

Similarly, Barb said, "Your sexual drive does change because physically and mentally you're going through a lot." She compared her sexual drive to that of her partner's and said, "He's healthy

and I'm not so he has the normal drive and I don't...I do have a sex drive or whatever you want to call it but it's not like it used to be. I could go for a month and be fine."

Anna and Karen also described decreased sexual activity. Anna shared, "Having intercourse isn't something that happens often... maybe once a week. My desire is mostly dampened by the fact that you're tired all the time. Occasionally [I have the] desire...It's hard to get enthusiastic about it because I'm so tired." Karen said, "I don't have as much interest in sexual relations that I used to have...It's not to say you're not interested. It's just not to the same extent that you were before, but then who knows. Sometimes it's just not there."

Women identified a number of factors that further diminished their desire to participate in sexual activity and that triggered subsequent adjustments or changes in their sexual relationship. Seven of the eight sexually active women mentioned that their hemodialysis schedule and the fatigue that followed dialysis treatments were two factors that had had a negative impact on their sexual desire. Because these factors diminished women's sexual desire and the number of available opportunities for sexual activity, they also introduced changes in couples' sexual relationship patterns.

Aside from dialysis treatments and the fatigue brought on by dialysis, the most often cited factors related to women's diminished sexual desire and changes in their sexual relationship included the lingering physical symptoms of fatigue and low energy.



As a result, almost all women mentioned they avoided having sexual activity on dialysis days and shortly before and following their dialysis treatments.

Thus, the permanent nature of dialysis and ongoing fatigue often left little remaining opportunity or time for women to have sexual activity. As Anna said, "Even making arrangements to have sex can be difficult because I'm always tired. Morning is usually a better time than evening for sex but three days a week [I go to] dialysis early in the morning and it's not very conducive to a lot of sex...I go to bed at nine o'clock at night and read, then usually take a sleeping pill every night...and nine o'clock isn't always the time that my husband chooses to go to bed."

Similarly, Hanna commented that evening scheduled dialysis treatments were not conducive to having sex afterwards, "I mean, to have sex takes a lot of energy and sometimes you need some concentration and I'm so drained, I can't perform...By night time, I go to bed, I...have no energy. On dialysis days I feel terrible." Even following day time dialysis treatments Sarah said, "There are times I would say I was tired...I wouldn't probably want to go [and have sex] right after dialysis."

Carol also thought sexual activity needed to be organized around her treatment days. She said, "I get my treatment three days, Monday, Wednesday, Friday, and I don't have sex on those days. I like to have sex on a Tuesday or Thursday or maybe on a Saturday or Sunday. On dialysis days I feel sick, I feel weak, I feel exhausted, really weary...so I don't have sex those days... So

if I have sex on the day before dialysis it wouldn't affect me in any way or make me sick."

Tiredness was a strong factor influencing sexual activity. Aside from working full time, Karen mentioned that she was not sure whether her tiredness was related to her blood pressure medicine or dialysis. Nonetheless, she remarked, "If you're tired you just don't have the energy that you used to have so it affects [sex] the same as it does anything else that you may not be as interested [in] as you used to be...you're just too tired most of the time [and so] you go to bed and fall asleep."

Likewise, Barb emphasized the depletion of her energy as she carried out her daily activities and her subsequent absence of any reserves at the end of the day. As she said, "...if you're busy, all your energy goes to just getting through the day, doing what you have to do. Then when it comes to wanting...sex it's the last thing on your mind because you don't have much of a sex drive." She later added, "In your mind you think differently, but when it comes to physically doing it, being close and that, sometimes you don't have the energy...Just thinking about wanting to have something sexual or some sort of intimacy...is, 'oh, I can't possibly do that'."

As well, unexpected health problems also added an additional layer of complexity to women's sexual relationship. Unexpected medical situations and surgeries thwarted sexual desire. As Anna explained, "...when you're healing from the surgeries and it's sore and you're getting used to the idea of having the tubes in your

body and being worried about the infection--that certainly interferes with how often you want to have sex or what kind of sex you want to have."

Some women referred to several interrelated factors that had sometimes surrounded their lack of sexual desire and interest in their sexual relationship. Barb stated, "Living with dialysis and having problems with your partner and low self-esteem all play into having sex and having the intimacy." Anna described, "[In addition to an open lung biopsy] I've had...surgeries along the way that have kind of made things a bit difficult too. I had a repair of a prolapsed uterus and...an umbilical hernia repair too...So it's been a lot of things--not just hemodialysis and not just peritoneal dialysis. It's been one thing causing another sort of thing." Elley remarked, "If you don't feel good about yourself and that person doesn't make you feel good about yourself, you don't want to go to bed with them. It's not just the disease, it's the disease and all these things going on."

Anna described the process of finding out what can be done without harm. "I had to learn to live with them (lines) and figure out exactly how much or how little they would interfere with me. At the beginning you're very leary about the movement of it or you don't want to get infection...Once it healed reasonable and I was used to the feeling of having the tubes up there...it was fine. It's a question of experimentation. You try to do things so that it's not going to hurt, get caught, or pulled, torn or anything like that."

Regardless of the kinds of dilemmas women encountered in their physical sexual relationship, nearly all women possessed comparable thoughts and feelings about having sexual activity. Almost all sexually active women indicated that sexual activity was not very important to them, especially since they had been on dialysis. As well, these women also mentioned that they were usually not interested in having sexual intercourse and in fact, stated they often participated in the activity because they felt either obligated or guilty. Thus, almost all women revealed that they engaged in sexual activity for reasons other than being sexually interested or aroused. While the majority of women were not unreasonably bothered by the sentiments they harboured, they could not as easily overlook their partners' unsatiated sexual needs as a result of their own disinterest or unwillingness.

Elley explained, "I'm not turned on easily...sometimes you just do it out of guilt because you...feel sorry for him. It's not that I don't love him. I just don't...have those emotions...its just me...the way I am...if somebody said to me, you have a choice between having sex or doing something else, I'd probably pick something else. It makes me upset sometimes because...that's what marriage is and...what makes a marriage, keeps it going and makes it more interesting...another good thing is that, he's been with me for so many years...and being the way I am with sexuality I know most men would either have somebody on the side or they probably would have left...[but] it just doesn't appeal to me...I can take it or leave it...and it makes me feel guilty because it shouldn't

be like that..."

Elley also explained, "It's suppose to be a part of your life ...It's not suppose to be a struggle for him all the time with me. It should be an enjoyable time, at least, when you're in bed together. Sometimes it is but I would say most of the time it isn't either because I'm tired or don't have any desire...so my poor husband has to suffer..."

As Anna said, "Occasionally [I have the] desire but...most of the time it's just something I feel I should participate in. It's hard to get enthusiastic about it because I'm so tired... it's not something I desperately desire. I've learned to live with less sexual activity because I just can't do more."

Barb acknowledged why she sometimes felt responsible for the existing difficulties in her sexual relationship. Although Barb remarked that sex was the last thing on her mind at the end of a day she also said, "I feel I'm letting him down. I'm not trying hard enough." Later she revealed that the source of her guilt related to her conscious attempts to avoid sexual activity. As she said, "I feel it's my fault so I try to avoid it...the whole thing; the closeness basically the sex because usually you're feeling bad because you don't have the energy." She later added, "You feel badly about it because I know exactly what I'm doing...It's unfair ..."

Karen also felt guilt related to her sexual life, "You kind of feel guilty sometimes because my husband is so good about everything and you kind of feel you want to be able to be good to

him. Yet, sometimes you're not in the mood whereas you might have been before. So it makes you feel guilty. Sometimes it's just not there...you kind of worry that he thinks it's him when you think it's yourself."

For Hanna sex was not a high priority. She explained, "...sex is irrelevant. It's something I do...for whatever reason, but it's meaningless. It's nothing to me. Because I have this illness... it's nothing." Later she added, "You don't feel the same way. I don't feel like I want to have sex. I don't feel as if I'm missing anything...I just feel like I want to go to my bed...going to sleep is more appealing than having sex. I'm so drained...when your body's not up to something you don't feel as if you're missing it."

Although Sarah's sentiments towards sexual activity were different than most women in the study, she too remarked about the importance of being able to please her partner sexually and how she had at times questioned her ability in this area. As she said, "I relate more as a person through my sexuality. So it was still important to me...Sex is not work for me. It's not an effort. At times I thought it would be because when you're in a relationship you don't want to displease the person."

In contrast to the mentioned women above, being on hemodialysis did not influence the importance that Joan and Sarah placed on sexual activity. For different reasons, these two women were not bothered by feelings of guilt or obligation like other women. As Joan stated, "At my age [76] sexuality isn't a major thing." However, compared to Joan and the other women in the study,

Sarah's sentiments towards the importance of sexual activity differed. She explained, "Like we have a hard time saying we're going to go out for dinner. Before we know [it] we've spent so much time talking or cuddling or kissing or just laughing and then the sex part, that there's no time to do anything else...It's become like a routine on certain days because those are the days that I'm not on dialysis."

**Summary:** For all women in this study, sexuality included having a physical sexual relationship. Although sexual activity was not of central importance for the majority of sexually active women, they all experienced feelings of guilt and obligation related to their sexual relationship. As well, all sexually active women experienced interference with, and changes in their sexual relationship due to a number of factors (e.g., decreased sexual desire, hemodialysis and fatigue).

**Relationship factors.** The types of topics included under this category are the interpersonal factors that influenced the process of women re-establishing a mutually acceptable physical sexual relationship with their partner, partners' reactions to changes in sexual activity and partner role support. The women in this study described how various interpersonal factors influenced the process of them feeling comfortable with their sexual self and whether or not they were able to re-establish a mutual and feasible sexual relationship with their partner. Several women referred to the exchange process that took place between couples in resuming or maintaining their sexual relationship after starting dialysis, or

the difficulty or absence of that process between partners, and how that experience had subsequently (or, initially) turned out to be either different, difficult, meaningless, or uncomfortable for them. While some couples had overcome their initial difficulties, the problems experienced by other couples continued to persist. The following three women described the initial difficulties they encountered in re-establishing their sexual relationship before eventually overcoming or managing their dilemmas.

Anna referred to her and her partner's willingness to experiment in the whole context of their relationship. She remarked, "We're managing...nicely, much as before, except recognizing the limitations and the tiredness and the things we have to get used to in the process. It's like learning to do something over again that's different. Not the rules but different, factors just are different."

As well, Anna had noticed she and her husband had developed a different appreciation towards their marital relationship or one another. As she said, "...I think in some ways we appreciate each other more than we did before because you do take things for granted. It's not until something like this happens that you realize how precarious everything is."

Carol recalled that she initially experienced personal difficulty in re-establishing her sexual relationship after beginning dialysis but eventually had overcome the strangeness associated with her thoughts about having sex when she considered herself ill. She explained, "When I...started dialysis it was



difficult,...having sex...and having dialysis. It was like you wasn't normal to do that. Your body was saying no to it. Your body keeps saying no to it but you...you have to tell your mind you're going to do it...So it was hard on both of us. [Things are] great [now]. I'm a lot better...in mind, body and soul."

Sarah also experienced changes to which she had to adjust. Aside from the overall improvements in her sexual relationship and her satisfaction with it since starting dialysis, she also indicated that there had been some changes in the relationship that made it initially different for her. As she explained, "...the passion wasn't as strong as it was when I was on peritoneal...He was more accommodating and...careful and showing more love I guess because he saw my illness...he was more passionate. I could feel more emotion coming from him. When I went on hemo that sort of died a little bit but the sexuality got better in other aspects because I was more physical."

Three other women primarily focused on the ongoing difficulties in their sexual relationship and how they continued to struggle at trying to achieve and maintain a mutually acceptable sexual relationship. Elley articulated, "The relationship... suffer[s] ...mostly for me...in the bedroom..., it just doesn't appeal to me...and it makes me...feel guilty because ..., I shouldn't be like that but...I try to change sometimes and I say, 'I'm going to do it' but it always comes back to that I make it hard on my husband and I struggle and all that."

Elley also said, "...the way I am, it gets to be boring and

it's frustrating for my husband...He'd like me to have the incentive sometimes...I don't know what I could do to improve it ...It definitely would make the marriage a little bit more satisfying for both of us especially, my husband."

Hanna described the ongoing difficulty and strife in her sexual relationship that emerged as a result of the impact of physical factors on her well-being and a discrepancy between the expectations both she and her husband had about her as a sexual partner and her ability to live up to these expectations. As she explained, "My partner doesn't really like to have sex with me because he says...I don't have any energy...He says I'm not with it and I don't have the energy. It makes me feel bad...I don't make a very good partner...right now because he has needs that I can't fulfil...There are times when he wants to get sexual and I say, 'No, I'm tired. I can't. I don't want to.' I don't feel as if I'm losing anything but he is because I can't perform. I'm too tired. If I try to, the next day I'll feel the stress and strain on my body."

For Barb, maintaining a healthy relationship with her partner either in general or sexual terms represented an ongoing process. As she said, "It's important to try. It's..., very hard. We've had our problems. But you have to work at it." During her second interview she referred to the process that continued to occur in her relationship. "...being on dialysis is a process and you're always learning and...realizing, okay, someone has to change... something has to change...it's...not black and white...It's always

changing and you're always making compromises and you may not realize the problems right away, but as long as you realize it and do something about it..."

Despite Barb's struggles with her relationship, she recognized the importance of having a kind of closeness with her partner that was not necessarily limited to sexual intercourse because it gave her a sense of healthiness. She explained, "Even I as a sick person need that, [it's] important to try. It's any sort of intimacy, it doesn't have to be consummation...it's any kind of closeness. [Closeness] keeps you together. It keeps you healthy."

Almost all sexually active women mentioned that their partners had either tried to be understanding about the limitations imposed on their sexual relationship or had sometimes experienced frustration or difficulty understanding the reasons for refraining from sexual activity. The following women only remarked about their partners' demonstrated understanding or sensitivity towards them. As Sarah indicated, "The type of person that I'm with has that kind of understanding and he's able to understand you", and Anna stated, "...my husband was very careful...He's been very patient and hasn't let himself be turned off by the whole thing and so it works."

A number of women mentioned that their partners had experienced either initial, occasional, or ongoing difficulty understanding the circumstances of their sexual relationship. Although Carol said, "My boyfriend doesn't push me", she also recalled that her partner had initially exhibited frustration due to her lack of interest in sex. She said, "When I was first on

dialysis, I couldn't do it. It was very hard [and] my boyfriend had problems too because whenever he wanted to have sex I wasn't in the mood."

Similarly, Barb said, "He finds it difficult and it's difficult but he tries to be understanding but he wants to believe it's not my illness...[that] it's something else so he can fix it and he can't. So it's difficult." And in Hanna's experience, "...he doesn't understand [how I feel]. I thought he did but he doesn't. It doesn't matter how much I try to explain to him the hemodialysis process [and] what it does to my body...I don't think he understands or doesn't want to understand. I guess it's frustrating for him too."

In addition to having understanding from their partners about their sexual relationship, women also mentioned the importance of, and their appreciation of having ongoing role support from their partners. Women either referred to presence of role support or the inadequacy of this kind of support in their relationship.

Unlike most participants, Anna and Joan spoke about the ongoing comprehensive support they received from their partner since being on dialysis and how instrumental that support had been to them in terms of their ability to move ahead or carry on with their lives. Anna said, "I couldn't have gotten more support...My husband has been wonderful to me through all of this. He's not been very demanding and has been very understanding. He gets frustrated sometimes but he's been great and very helpful and supportive... Even for me coming down here, my husband usually drops me off in

the morning...on his way to school...In the summertime he usually drops me off and picks me up so it's very good."

Similarly, Joan talked about the extensive practical and emotional support that she received from her husband. "I've been blessed with a very good husband who tries to maintain things as I did...He was always good at doing dishes but he never did anything [with] food. He does now, because quite often I can't face preparation of food...You know,...every day...my husband takes me down and finds something to do while I'm on dialysis and then comes back and brings me home. That's a big commitment."

Karen and Sarah also referred to the presence of support and understanding from their partner. Karen indicated that she was lucky because her, "...husband's very supportive and good about all of this..."

Although Fran admitted that she had a "...husband that [wasn't] interested in warmth", she valued his instrumental (tangible) and practical support. In addition to providing her with a drive to dialysis everyday she stated, "...as far as I want anything or [to] do anything I always get it done like that" [as she snapped her fingers].

Elley referred to her partner's practical support when she said, "...my husband can manage...on his own. He's a better cook than I am. He's a neater person in cleaning the house...he's good at that...Like he helps around the house and stuff and he does a lot."

On the other hand, some women talked about the inadequacy or

absence of support from their partners' and indicated that their relationship had either been trying, or become strained and difficult at times, or even collapsed completely.

Even though Barb stated, "[My partner] has helped me as much as he can but he can only do so much...", she frequently referred to the lack of support and understanding he gave her. In fact, one of the most difficult items for her to deal with related to the issue of emotional support. She explained, "He does give a lot,... [but] at the same time he's not doing it when I need it. He gives when that's not what I want. I want him to give when I need you, not when it takes him a while...I want to be the one that's taken care of. I damn well still take care of him even when I'm on dialysis and doing all of this. I still take care of him and I resent that. I want him to take care of me. I don't want financial assistance, I want mental, physical and understanding and assistance and I don't get that." Barb also perceived that her partner failed to understand why she was sometimes unable to accomplish what she had planned to do in a day. As she said, "If I say I'll do something and usually I put too much on...and I usually don't get it all done, he'll get mad at me for that and he doesn't understand that I'm...exhausted."

Carol's effort to find another partner shortly after her former relationship ended revealed the importance of her need to have some kind of support and understanding nearby. As she said, "I lost a boyfriend and my child's father. He walked out on me because of my kidney sickness but I found another person to take care of

me. It's very hard because sometimes he gets moody because he doesn't know what I'm going through...[he] doesn't know much so it's kinda hard for him to understand...He's only been living with me for about a year. So it's very difficult."

Hanna mentioned the emergence of strife in her relationship since being on dialysis and how the presence of discord generated inadequate support and understanding from her partner. In fact, during the second conversation Hanna articulated that she was no longer living with her partner.

**Summary:** The women in this study described various interpersonal factors that influenced their ability to re-establish a mutually acceptable physical sexual relationship. These factors included a positive exchange process of communication, understanding partners and ongoing role support.

Body image/self concept/self esteem. In this category, the types of topics included are women's self-consciousness of body image changes, women's perceptions of themselves, self-confidence, role changes and reactions to role changes. All women talked about changes in their body image since they had started dialysis. Most women commented that they had either gained or lost weight, or noticed swelling or puffiness in different areas of their bodies. However, most women did not dwell on changes in their body image or describe them as particularly troublesome in terms of their intimate relationship. For example, women who had lost weight mentioned that they were pleased because they had needed to lose weight and had been unable to do so before they had started

dialysis. Similarly, women who had lost weight during the early days of dialysis treatment and who eventually regained their weight back were pleased.

Some of their comments included, "I've lost a lot of weight and feel better about my body image now" (Anna); "My body image hasn't changed. It doesn't affect me personally" (Barb); "My body image is very different. It's not a problem with sex...I've put on weight since I started...It's good because I was very skinny" (Carol); "I've gained 45 lbs since last year. I'm growing each day...it definitely affected my body image. I was down to 68 lbs [from] 125-130 lbs" (Fran); "It affects my body to some degree but then again maybe my age [alone] would have changed my body too." (Sarah).

Women talked more about the appearance of their dialysis access and how it had affected them. Nearly all of the women were mindful of feeling self-conscious about how other people viewed them or reacted to the sight of their dialysis access. Most women had discovered ways of dealing with potentially uncomfortable situations. Some women indicated that they had learned to conceal their access from sight. This approach eliminated their need to provide explanations to people and carry on unnecessary, detailed conversations about their dialysis access and physical condition.

The following excerpts illustrated women's self-consciousness of overt changes in their body image, especially their dialysis access. The following excerpt highlights the kind of situation or interaction that most women tried to avoid. Dot referred to some



recent remarks that her brother's friend had said to her and how badly it made her feel. She explained, "...my brother's friend don't like to see me with the tube in my neck...He came yesterday ...and when he see me, he said, 'he can not eat, his appetite is gone...so he can not see me no more'. He doesn't want to look at me no more. It makes me feel bad. I can't do nothing about it."

Karen's fistula was one bothersome change in her body image as she explained, "I always wear long sleeves cause I don't want anybody to have to look at my arm mainly because it's getting bigger all the time and also, maybe people think you're a drug addict or something...[and] that would bother me...People don't really know what it is and it's strangers I don't...want to discuss what it is with. I don't like to stick out in a crowd."

As well, Karen was bothered by other overt changes in her physical appearance. She went on to say, "I just don't like putting clothes on myself, that's all. I don't like going out and I used to love shopping [but] I don't like it any more. I don't like looking at myself in the mirror and seeing the slacks with the stomach coming out. I guess that's the thing that's bothered me the most."

Sarah said, "I'm not so grotesque as far as my fistula goes, [but] it's still there. Well, it's swollen and there's needle marks...I expose my arm in the summer but you know, at times I'm hiding it. I can't wear the sexy outfits as much because that's there...Most of my stuff is all long sleeved."

Hanna explained, "I was really proud of my body...I liked my body...I didn't have any scars on my hands, ...on my tummy and...

There's nothing I can do except accept it because thinking about that would depress me...I can't even wear dresses up here any more ...I don't have smooth arms any more..."

Although Elley used to conceal her access site from others' sight, she now felt different about its presence. As she stated, "I would try to cover it up with long sleeves or whatever for a long time but now I figure this is me. This is part of me and people will look and if they ask, I tell them. Obviously everybody notices and they say, 'Oh, what happened to your arm? How come it's bruised?'" However, Elley also added, "...sexuality to me is, like I'm a very spiritual person...When you're a teenager or young woman you're more into the physical thing. Spiritual is what a person is inside. It's not how you look on the outside...You have to accept me for what I am and I feel good about who I am as a human being... and the way I am with people...I don't look at my physical being because it's scars all over my body..."

In a different way, Barb mentioned how fortunate she was to not look like a person who has kidney disease. As she explained, "My sister looks more like a kidney patient than I do...I see it but other people don't really see the symptoms of the yellow skin or, like, some people just look, you know, by looking at them, that their on dialysis. I think I'm fortunate that I don't look like that or I feel I don't have that."

All women commented in general about their perceptions, thoughts and feelings about themselves. Women either perceived that they were essentially the same person they were before starting

dialysis or that they were not the same person they used to be. However, two of the six women who believed they were the same person as before, also mentioned that, "You do get to feel that you're different and "why me" when you're sick" (Sarah) and "You don't feel as good about yourself as you did before" (Karen).

Apart from all the changes that had happened to women, and the fact that some changes were bothersome, six women perceived that they continued to be the same person they were before they had started dialysis. Dot remarked, "I don't feel no way different about myself." As Joan said, "I don't see that it's changed me as a person and it hasn't changed my opinion of myself as a person. I can't do a lot of things I used to do. I mean I don't go out as much. I don't entertain. We don't socialize the same but when I do, I'm the still the same person I always was."

With the exception of Anna's limitations related to tiredness she explained, "I was always the same person only with a lot less energy at the end of it all...I don't really perceive myself differently. It's just a matter of recognizing the limitations that I have now and didn't have before...I'm the same person as before...I feel pretty good about myself." Similarly, Karen remarked, "I think I have just as many brains as I did before and I have as much to offer as I did before".

Sarah claimed, "I know my life has changed maybe a 100% as far as other things go, you know, finances and how I live and all that, but me as a person, you know, my heart and my brain hasn't really changed. My physical body has changed. Yes, and I've...adapted to

that as well, but me is still me, you know."

Carol eventually realized, "...[dialysis] doesn't do nothing to my body. I only thought in my mind that I was a disabled person because I [lost] a kidney but I'm not a disabled person. I'm okay."

Three women struggled with their perception of changes in themselves. While Barb talked about employment prospects she said, "...I'm as good as anyone else and I think I should be given an equal opportunity...[but] you have to keep in mind that you're not like everyone else. I tend not to and it always back fires and hurts me because I figure I can do what everyone else can do and I can't. It's hard. You have to keep in mind...you're not like everyone else."

In many ways Hanna perceived that she was not the same person she used to be. As she said, "I'm not myself. Since I've had this illness. I have not been me. I have lost myself. Since I've had kidney dialysis,...had this chronic illness...I have lost the person that I was. It's not the real me. This person that you see here talking to you right now, doesn't feel as if it's me. It's not the real me. It's...like I'm waiting for some miracle cure so that I can go back to the person that I was...That person was going somewhere. That person had goals and plans. This person here does not."

Although at the time of the conversation Elley indicated that she felt a lot better about herself, she nonetheless continued to struggle with her self concept. As she said, "...you just don't feel like you measure up to anybody else. Even sexuality wise

because you're half a person. You're not a whole person being sick. Your arm is maimed in such a way that it doesn't make you feel good about yourself. At this point I'm feeling a lot better with it. Part of that problem is that you look at yourself that way,... you're not half of what you're suppose to be." Later she added, "It's still difficult because in the back of your mind you always feel you have this disease and you don't measure up to everyone else. I mean that's how I feel about myself. A whole human being with no problems. You feel like there is always something wrong with you and that doesn't make you see yourself as a whole person."

In talking about sexuality, some women revealed other thoughts and feelings about themselves and how they reflected some measure of their healthiness or normalcy. Four women talked about the normality associated with a sexual relationship and/or reproduction, and one woman mentioned the sense of healthiness related to having a closeness with her partner. As Carol remarked, "If I wake up in the morning and feel like having sex then I have it...I feel like a normal person. I even got pregnant on dialysis. I was so sexually active I [got] myself pregnant." Hanna said, "[It] wasn't until a year ago, [after I had my baby] that I actually [felt] as if I was living. That I was among the living ...It wasn't until I had the baby that I realized hey, [I am] amongst the living. You can do things that other women can do..., if you can have a baby that means you're still alive. If you can reproduce..."

For Elley, maintaining a sexually satisfying relationship was

important for a number of reasons. As she explained, "I'm...with my husband and we're supposedly married and in love. It's suppose to be a part of your life...I feel that's what marriage is, that's what makes a marriage, keeps it going and makes it more interesting...It's not just communication. I think if you have a good sex life and you're satisfied, then it works itself into the whole relationship."

Sarah referred to maintaining her sexual activity as a way of being normal even though she was on hemodialysis. As Sarah said, "It makes a big difference being able to experience that part of life...and it's not always necessarily...intercourse but that bonding of some sort will eventually lead to that...I find it's an important part that does keep you going...if you're reserved on it because of your health then I think your health sort of goes downhill...because uh you see yourself [as] inadequate and uh you don't have that drive, that little pep that uh, you know, says hey I'm okay still. I'm still part of the rest of the world and not different and I'm pretty much the same?"

Nonetheless, the notion of living with a chronic illness and having sex was initially incompatible or incongruous to two women. For example, Carol referred to an internal conflict experienced initially that related to living with an illness and having sex again. As she said, "The only way it troubles your sex life [is if] your mind tells you, "no you can't do it, you can't have sex, you're not allowed to do it because you're sick. Your mind can tell you that and then you don't have it."

Hanna also spoke of feeling that her body was sick and did not need sex. She explained, "When your body's not up [to it], when your body is ill, your body is sick,...it's like you're not missing anything...You're not fretting over it...not depressed over it because your body [doesn't] want it...But if my body was healthy and I was okay, then I would miss it. I would be lonely for it. But my body's not crying out for it, so I don't want it."

Some women mentioned the notion of self-confidence and how it provided a sense of security or limited women's relationships due to its fragility. Sarah talked about self-confidence and attractiveness and said, "Well sexuality sometimes is...sort of a bit of self-confidence in yourself...The other thing that's important about sexuality...[is] the uh, attractiveness that you, you know, can attract somebody and are you going to be discriminated because uh, you have a kidney disease..."

Other women acknowledged that their lack of self confidence imposed limits on their personal lives and the possibility of them being able to establish new relationships. Barb stated, "I'm confident in myself as a person and my abilities but when it comes to a relationship with a man my confidence is not as strong. So that plays into a sexuality thing." And Hanna talked about her lack of self-confidence related to being able to find a new partner that would accept her chronic illness. She said, "I wouldn't try to go out right now and...date somebody or [meet]...somebody. I don't really feel that confident any more...There are not many men out there who would want to venture into a relationship with somebody

who has a chronic illness. So maybe that's one of the reasons why I still see my kids' dad."

In terms of self-appraisal, all but one woman appraised themselves in terms of the roles they assumed and their ability to function in or carry out tasks associated with these roles. Although there was variation in the way women appraised themselves, all recognized changes that created limitations and subsequent dissatisfaction or contentment with such changes in themselves.

Women reacted differently to the changes they perceived in themselves. While some women were not particularly bothered by the changes, some struggled to accept their specific limitations, and others talked about how they had chosen to enjoy different activities or develop themselves in ways that were positive and beneficial to them.

Although Anna indicated that she felt good about the things she could do with her children since she had quit working, she also felt responsible for limiting the scope of activities her family could do together. As she said, "I feel good about the things that I do with them. I help out at the schools if I can. I can't do field trips because I don't have the energy to do that but I can go ...it's something that's turned out positive." However, she also mentioned, "Sometimes I feel that I'm holding back my family because we can't do things as a family,...I feel kind of responsible for my family not being able to have a good time...I'm a wet blanket in terms of uh, enjoyment or you know the things we can do as a family."



Hanna reviewed her performance in a number of roles. She said, "I think I'm a...very good mother...I am there for them. I...meet most of their needs. As for a partner, I don't think I make a very good partner right now...because he has needs...I can't fulfil... I'm not the same person I used to be to my family. I have changed. I'm no longer that role model for my sisters that I used to be... that's the biggest hurt [and] disappointment because I used to be a real go-getter...I just can't be that person any more...I used to be a very strong person."

Elley referred to the difficulty of being a mother and wife when you're sick. She explained, "It's hard to be a complete wife and mother...You still have to do all those...mundane things in life like laundry and...your body is not up to its full potential. Even if you do one thing you're already tired...you can't be Miss Wonderful all the time in bed or it's going to deteriorate somewhere. I keep my house and laundry and stuff up to date but my poor husband has to suffer. It's very hard to do all those things."

Barb illustrated how she struggled with low self-esteem. As she said, "I put [the closeness] last. I put my school and work first then I put that last...It should be first but it's hard when you have school, you have obligations...So it's very difficult to try and juggle it all and try and make your partner first...I feel ...I'm not living up to my expectations of me in the relationship. It's hard because I don't have the energy and so I don't want to deal with it...So it affects me and makes me feel low about myself ..."

While Carol recognized that she struggled with carrying out day to day household activities, she said, "...I look at myself ... very independent because I don't look to anyone to be helping me... I try to be strong for myself,...I do a good job at laundrying my clothes, preparing my meals, doing my shopping and taking care of my apt." However, during the same interview Carol also said, "It's very difficult to continue with...housework, laundry, to cook and cope with the shopping...I think I've had a hard time doing it because it's not easy for a person...without any family or friends."

Karen articulated, "I can't take the stress quite so much as I used to before because I'm more tired. I think I have just as much to offer as a friend as I did before. Maybe not quite as much as an employee because I don't have the ambition...to do any more than I'm doing...I can't take the stress of more responsibility so I've stepped back...So it has affected me that way but I'm happy with that. That's not really bothering me."

Despite the vast changes in Joan's role of a home maker she was not too bothered by the changes in it. As she stated, "It certainly has changed my role because I have no energy. So I do very little. I've always been a very active person...my role is totally diminished. It's gone. It bothers me at times but not a lot because he's so good about it...I don't feel totally useless because I'm not doing those things." She also spoke about her limitations as a grandmother, "I can't do it. But it still doesn't make me feel worthless...a little bit...maybe envious. It's not an

issue. I recognize my capabilities."

Sarah appraised herself in terms of the changes in her sexual life and her ability to be a sexual partner. As she said, "...I feel that I became a real woman...where I...know what it's like to be in love...and feel what sex was meant to be felt like. I never had those experiences before I got sick." Later she remarked, "Maybe having gotten to know my body more allowed me to have this experience in sex that was more fulfilling...I guess I was able to ride with the flow and got the best parts because I had more knowledge of my own body..."

**Summary:** All the women in this study were aware of changes in their body image. Although women were not troubled by the changes in their weight since being on dialysis, they were self-conscious about how others perceived and reacted to them, especially their dialysis access sites. The majority of women possessed positive self-concepts. All women recognized changes in their ability to carry out tasks associated with their roles however women's acceptance of role changes varied.

#### **Other Findings**

This section contains findings related to the support from health care professionals on sexual health topics that women received. Also presented are data on the impact of living with chronic renal disease and its treatment. These findings provide further context to women's full experience of being on hemodialysis and sexuality.

Role of health professionals. Almost all women mentioned the importance of having understanding from health professionals about the issues they lived with as a result of being on hemodialysis. Women described how some health professionals either demonstrated understanding or fell short of doing so. Instances described as lacking or devoid of understanding included problems with follow through on doctors' orders and care planning, and a lack of attention to gynaecologic problems.

Unlike many women, Carol spoke positively about the understanding she received from health professionals. "Even the nurses know what I'm going through because I explain the hardness of it to them...I have the nurses to understand me and sometimes even the doctor will talk to me. They understand."

In comparison to Carol's experience, five other women described situations that were lacking or devoid of basic understanding. Although Hanna perceived that nurses were generally good and knew how to take care of her medically, she explained "...sometimes, they just don't have...certain other skills...Sometimes ...the nurses don't make you feel as if you're human. They just make you feel as if you're a patient...and because of that, well you start questioning yourself [as a woman, as a person]."

Issues with follow through on doctors' orders and care planning was a source of frustration for both Sarah and Elley. Both experienced gynaecologic problems and felt frustrated by the lack of attention to their issues. Elley said "...I was haemorrhaging for about six months...I was getting a transfusion every week if I

was haemorrhaging from there...I thought I was going to go crazy cause nobody would listen to me. They kept trying all different kinds of medication and giving me a needle and it would work for a while but then it didn't...please...I can't go on like this."

Several women expressed the need for explicit information and counselling on reproductive and gynaecologic problems, as well as relationship and sexual problems. Reproductive and gynaecological problems included the event of pregnancy in two women, and menstrual cycle irregularity and hormonal changes in four women, three of whom were middle-aged women. The absence or inadequacy of information and counselling caused frustration for women and grief for one woman.

Some women identified the importance of having information and counselling services readily available to women on dialysis. One woman suggested that having available information about the types of changes women might encounter in their sexuality as a result of being on hemodialysis might prevent women from becoming unnecessarily alarmed by such changes.

Barb and Elley described their difficulty in discussing sexual issues with male doctors and thus the unlikelihood of their initiating conversations of this kind with physicians. For these reasons they suggested that it remains important for health care professionals to address the subject of sexuality with women on dialysis. Barb said, "I'm too shy. I don't think it would be appropriate maybe...I couldn't bring it up to him. I wouldn't feel comfortable asking him. I guess 'cause it's a male doctor...if he

didn't mention it, well then I'm not...I mean stuff like that's very hard to talk about especially when you have to talk to a male doctor. I find it easier to talk with female doctors."

Elley recommended having available information about the types of changes women might encounter in their sexuality as a result of being on hemodialysis. "It's good to have that kind of information available for...someone else...it's good for somebody coming to dialysis to know that...those things are normal and it's nothing [to be] ashamed of...Women have never, I think, been addressed about that...if women feel...embarrassed, it's unlikely they can approach that and talk to a doctor or whatever."

While the outcome of becoming pregnant differed for Carol and Hanna, both women commented they had unknowingly conceived while living with dialysis. Carol indicated that she was unaware of the likelihood of becoming pregnant on dialysis. "...I didn't know that I could get pregnant on dialysis...I didn't know until Dr. [said], '[you're] pregnant' [because] I was still having my period when I was pregnant...I was three months pregnant...then he said..., 'you know, you can't have this baby running a risk with your life so you have to either...give your life or give the baby up.' ...So I chose my life and I gave the baby up. It was...difficult to give a baby up...because I love children."

Hanna delivered a healthy baby boy while living on dialysis but she also was not aware she was pregnant until several months into the pregnancy. As she said, "I was pregnant...for a good amount of time before I realized I was pregnant. I was really sick

and didn't know why I was feeling so bad..."

Three women remarked about the absence of suitable counselling and how it could have helped them to better understand and manage different issues that emerged in their lives since being on dialysis. Counselling would provide an opportunity for women to talk about issues that they might otherwise struggle with alone. Another woman mentioned the need for counselling in conjunction with partners and the apparent absence of this kind of service. As well, the incompleteness of information provided to some women left them to search without guidance for some solutions to their problems.

Hanna commented how she had benefited from her participation in the current study because it had provided an opportunity for her to talk about many different issues that she was struggling with alone. She said, "...maybe it's a good thing that we're doing this because this is the first time that I've actually addressed this to myself...I mean this is an issue that I've never addressed with myself before. I've never had an opportunity to actually sit down and discuss this with anybody so therefore I've never heard myself voice these things that I was...thinking."

Barb spoke about her need for counselling in conjunction with her partner and the apparent absence of such counselling for couples only. "I think...men need counselling so that they understand that we're working with them even though being sick and not having the same sex drive...he's never had to deal with any sort of illness before in his life..."

Furthermore, in another attempt to gain information about her sexual relationship problems Barb explained, "I broached the subject [of sexuality] with the peer support coordinator and she gave me tapes [to watch]...and they were no good...There was nothing of interest...like they just laughed...that's not going to help me. So it's very superficial. It was...like skim of the surface, but you don't really deal with what's going on, you know ...it didn't help me."

Impact of illness and treatment on other aspects of life. An unexpected finding that developed from the current study on sexuality was the amount of data generated about the other experiences associated with living on hemodialysis. Included in this section are findings about the impact of the illness and treatment on women's lives, the fatigue associated with the latter items, and women's subsequent coping efforts with being on hemodialysis. In talking about the experience of living with dialysis, the participants described a treatment procedure that governs their life because of the need to have it performed at regular, designated intervals. Moreover, once dialysis has been initiated, the treatment continues throughout a person's life unless a transplant is possible. Yet, the treatment procedure does not provide assurance that an individual will feel better following its application. Both the treatment and the disease can have a physical impact. For these women the experience of living with dialysis was more than living with the treatment procedure itself. Their illness was present all the time making its presence felt



through symptoms or side effects such as fatigue.

All women talked about the relentless fatigue and tiredness they lived with and the ways in which it permeated and affected most areas of their lives (e.g., sexual relationship, family and social activities, and employment/career), including their day-to-day living and routine household activities. All women claimed that dialysis days were tough or hard days to proceed through, because of the way the procedure physically taxed them, and that they usually returned home following their treatment to rest or sleep to rejuvenate themselves.

In fact, when asked what the most difficult thing was for women to manage or deal with since being on hemodialysis, seven women referred to changes in their physical well-being or stamina that was in some way connected to their fatigue and tiredness. Consequently, these symptoms often impeded and even prevented women from participating and proceeding more fully in their lives as they once had. Most women focused on what they were no longer able to do or participate in rather than the activities in which they continued to join. As a result, women struggled to meet not only their own expectations of themselves but sometimes the implicit expectations that others might have of them.

As women reflected on the experience of living with dialysis, they revealed the strategies that they employed in the process of coping with their lives. The particular strategies women utilized helped to downplay or minimize their experience of major life changes and the hardships they faced day-to-day in their life

situation. The strategies women described most often included downward comparisons, the tendency to normalize their lives, approaching life with a different appreciation, and re-evaluating and/or re-focusing their life priorities. The use of these coping strategies helped women to view their life situation in a slightly different, perhaps more positive way, so that they were better able to move forward with or just carry on with their lives.

Women used downward comparisons and normalizing to highlight differences between themselves and other patients on dialysis or the general populace. Women assured themselves that there were indeed people in far worse predicaments than what they themselves had to contend with in their own life. Women also revealed the inclination to normalize their lives. They cited examples of how what they did was like "normal people" and that such activities helped them to feel positive about themselves.

In spite of the hardships with which these women lived each day since being on dialysis, nearly all women acknowledged that they now appreciated some area of life more than they had before they started dialysis. In general they had developed a different appreciation for life, and had re-evaluated and re-focused their life priorities in terms of what mattered most to them.

Almost all women talked about the extent to which they accepted being on hemodialysis. Whereas some women indicated they had simply come to accept dialysis, other women talked about how they continued to struggle with accepting it more fully. As women talked about their approach to coping they also revealed the

attitude they had adopted in that process. Most women indicated they had tackled being on dialysis by simply accepting what was and pushing themselves to carry on and do the best they could.

## CHAPTER IV

### DISCUSSION

The interviews with women in the current study revealed that the topic of sexuality is rarely broached between women and health professionals, including nurses. When women were asked about the impact of hemodialysis on their sexuality, the researcher noted that initially most women discussed their physical sexual relations. In many cases, it was not until the researcher made specific inquiries about women's body-image, self-concept, self-esteem, intimate relationship, and family and social lives that they began to share or elaborate on their experiences of these aspects of sexuality, which included their interpersonal relationships.

An unexpected finding was the amount of data elicited from women on topics in addition to sexuality, even as broadly interpreted in the current study. One possible reason for this might relate to the fact that the whole experience of being on hemodialysis was so personally traumatic for women, that the interviews actually functioned as a kind of catharsis for women--an opportunity to talk to a sympathetic listener about many aspects of their situation.

Another possible reason is the topic itself. Although most women talked openly about sexual activity and the kinds of obstacles that interfered with such activity, they may in fact have felt uncomfortable talking about this aspect of their relationship or other sexual issues in any further detail and thus chose to

on less threatening topics.

A third possible reason may relate to the actual importance of the topic to the women. Although the researcher assumed that only women genuinely interested in the subject matter would participate in the study, it is possible that the topic of sexuality was actually a relatively unimportant aspect of their lives in comparison to other aspects of life affected by hemodialysis.

The discussion which follows is organized according to the three categories of findings and will include references to related literature. Discussion is also included relevant to women's experience with support and counselling from health professionals about hemodialysis and sexuality, and the impact of illness and treatment on other aspects of life.

### **Findings Related to Sexuality**

#### **Physical Sexual Activity**

The primary focus of the few previous studies on women, has been on the extent of sexual activity in women on hemodialysis. Most of these studies fostered the impression that downward changes in sexual activity or the presence of (dys)function represent an important women's issue. The current study provided a contrasting picture and parallels the findings reported by Ferrans and Powers (1993). Ferrans and Powers, in an exploratory study of quality of life in 349 hemodialysis patients (46% of whom were women), reported that patients ranked their 'sex life' as slightly important and slightly dissatisfying. However, data specific to women were not provided.

While sexual function has been identified as a source of stress for dialysis patients (Eichel, 1986; Fuchs & Schreiber, 1988; Kline et al. 1985), these studies provide little understanding about what patients find specifically stressful in relation to their sexual functioning or why this item even constitutes a stressor. This current study provides some insight why changes in sexual function might be difficult or stressful for women on hemodialysis. Most women perceived that their being on hemodialysis had had some kind of transitory or long-lived impact on their physical sexual relationship with their partner.

The notion of engaging in sexual intercourse for other reasons such as obligation or guilt, has been suggested in previous studies. Despite women's diminished sexual desire and orgasmic ability, Mastrogiacono et al. (1984) deduced that women most likely continued to engage in regular sexual activity as a result of their partner's behaviour and the relationship itself. Rozenman et al. (1990) mentioned that compared to healthy women, women on hemodialysis and peritoneal dialysis avoided their partner's sexual overtures more but did not speculate on the reasons for this. In the current study, almost all sexually active women identified a variety of factors and thus reasons why they simply declined or avoided having sexual activity. The absence of sexual energy or desire likely heightened women's feeling of guilt, as they were mindful of the support and understanding they needed and received from their partner but also of their limited ability to always satisfy or meet their partner's sexual needs. It was evident that

the root of some of women's struggles with feelings of obligation and guilt were primarily related to the disparity between their own meagre levels of sexual desire and their partner's intact, healthy libido. Thus, it is reasonable to suggest that the ongoing presence of this type of dichotomy in couples' sexual desire and sexual expectations could very well contribute to, or even generate stress in women.

Aside from the always impending dialysis treatments and the way the treatments physically taxed women and imposed structure in their lives, the presence of ongoing fatigue, low energy reserves, and an awareness of their own sexual limitations and abilities as a partner most likely contributed to or even generated transitory feelings of threat or challenge in women. Lazarus and Folkman's (1984) cognitive theory on coping offers an explanation of why such feelings might have surfaced in women. From women's perspective, it may be that the above listed external and internal demands (ie, hemodialysis routine, fatigue, obligation) that surrounded women's sexual relationship had been appraised by them as threatening or challenging. These types of demands, at times, may tax or exceed their resources (Lazarus & Folkman, 1984).

Consistent with previous studies (Alleyne et al. 1989; Levy, 1973; Mastrogiacomo et al. 1984; Milde et al., 1996; Rozenman et al. 1990; Rickus, 1987), the majority of sexually active women in this study experienced a decline in their sexual desire and sexual activity compared to before they became ill. However, the unimportance of sexual activity to most women in this study is

perhaps best explained by the extent to which women repeatedly emphasized the presence of fatigue, and the depletion of or complete absence of energy on some days. Because fatigue pervaded all aspects of women's lives it is not inconceivable that fatigue played a major role in subduing their sexual desire and shifting the relative importance of sexual activity. Most women viewed sexual activity as a taxing activity because it required the expenditure of valuable energy that was very much needed elsewhere in their lives. As well, all women claimed that dialysis days were tough or hard days to proceed through, because of the way the procedure physically taxed them, and that they usually returned home following their treatment to rest or sleep to rejuvenate themselves. Thus, given the devitalizing effect of post-dialysis fatigue, it is understandable why all that women preferred to do after dialysis was sleep versus entertain thoughts of having sexual activity.

The connection between fatigue and downward changes in dialysis patients' sexual functioning has been reported in two earlier studies. Toorians et al. (1997) did not measure fatigue or the importance of sexual activity quantitatively but, based on the articulation of fatigue during the interviews with subjects, they surmised fatigue and listlessness were largely responsible for the presence of sexual dysfunction in hemodialysis patients. Similarly, Milde, Hart and Fearing (1996) documented that fatigue interfered with the sexual functioning of 41% of patients in their study. Despite the absence of gender specific data in these two studies,



their findings and the same finding in this study support the need for further research on the impact of fatigue on women's sexual functioning as a reasonable next step.

It was interesting that this relatively young group of women were so plagued by fatigue, given they were all receiving r-HuEPO therapy. Because r-HuEPO therapy is expected to alleviate some of the symptoms associated with anemia (e.g. fatigue) and perhaps enhance patients' sexual function (Laupicus, Wong & Churchill, 1991), one might have expected to find less fatigue and better sexual function than what the women in the current study described. Since the current study did not determine if women had perceived improvements in their sexual function since starting r-HuEPO therapy and because data gathered did not include women's hematocrit and fatigue levels prior to starting r-HuEPO or at the time of the study, it is difficult to suggest a purely physiological explanation for women's fatigue, low sexual desire or level of sexual function.

While fatigue is no doubt a common reason why healthy individuals avoid engaging in sexual activity, there were other factors that interfered with women's sexual desire and sexual activity. In fact, the lack or absence of sexual desire was in itself a common reason why women postponed or avoided having sexual intercourse. Moreover, women not only had to consider how they physically felt prior to an opportunity for sexual activity but they were inclined to also think about the implications of the fatigue that usually followed after engaging in sexual activity and

how it would impact on them. As well, the regular intrusion of the treatment regimen and various unexpected physical and psychological factors that were not necessarily related to their underlying kidney illness also limited the opportunity for sexual activity.

### **Relationship Factors**

The notion of closeness described by the women in this study constituted one of the four conditions included in Timmerman's (1991) theoretical definition of intimacy which excluded the necessity for 'physical intimacy' (sexual activity) but included mutual trust, emotional closeness, self-disclosure, and reciprocity. While a meaningful relationship provided the women in this study with a sense of normality, healthiness and/or satisfaction, sexual intercourse was not essential to cultivating closeness in the relationship. Likewise, in Milde, Hart and Fearing's (1996) study, 79% of participants considered intimacy (closeness) to be crucial in their relationship. Unfortunately, the conditions that comprised closeness were not identified by women in either study.

Perhaps more importantly, one of the most influential factors that interfered with woman's ability to regain, re-establish and maintain an acceptable sexual relationship was both themselves and the underlying general nature (condition) of their relationship with their partner. Thus, it was clear that the process of finding an acceptable level of sexual activity for both partners was different among couples. Whereas most women focused on the initial hurdles they faced in re-establishing an acceptable sexual

relationship, a few women underscored the difficulties they consistently faced in securing their sexual relationship.

Although the majority of women described their initial sexual experiences as difficult, experimental and challenging, unusual or not 'normal' compared to the time before starting dialysis, overcoming all of these factors involved not only self-reflection and time, but an understanding partner. The ease and comfort of re-establishing an acceptable sexual relationship for both partners was also dependent on ongoing understanding from the women's partners. It was evident that effective communication and understanding with one's partner not only facilitated smoother adjustments in their sexual relationship but also, in other areas of their lives in comparison to women who perceived that they received little understanding from their partner.

Data in this study have provided insight into the areas and ways women have struggled to recover and regain their sexual relationship while living with hemodialysis. Apart from case reviews, there have been no empirical studies examining how women re-approach their sexuality in the context of their sexual relationship or re-establish a sexual relationship that is acceptable for both partners.

The current study also substantiated the importance to women on hemodialysis of having different types of support available to them from their partners. In view of women's pronounced fatigue and low energy levels, it is understandable why tangible support (assistance with domestic tasks and dialysis routine) and emotional

support (understanding and care) was needed by them. Based on women's descriptions, it was evident that the presence of support helped to mitigate or counterbalance some of the chronic burdens that the women in this study had to live with daily. While information relevant to women on hemodialysis and support is notably limited, Burton, Kline, Lindsay, & Heidenheim (1988) reported a similar finding in their study of older subjects receiving peritoneal dialysis. The elderly group of peritoneal dialysis patients reported that support helped them to contend with the daily annoyances and routine with their dialysis regime (Burton et al., 1988). It would seem that the women who had reliable, comprehensive support managed living with the intrusiveness of hemodialysis and their fatigue more easily than women who had less dependable support available. It is important to note that, since most of the women in the current study were involved in a steady relationship that had pre-dated their initiation of hemodialysis, it is possible that these couples had already established functional support patterns in their relationship. Therefore, there may be differences for women who are single and living on hemodialysis and women who have formed more recent relationships prior to starting dialysis.

Further analysis of this study's data revealed that the quality of support women received from their partners varied considerably. While most women mentioned how helpful their partners were, a couple of women were dissatisfied with the support shown to them by their partners since being on dialysis. Emotional

understanding was the most often cited missing component of support in women who were dissatisfied. The importance of emotional support was also reported by Wolcott, Nissenson and Landsverk (1988) in their study of peritoneal and hemodialysis patients and support. Furthermore, this study's finding on women's perceived quality of support and their satisfaction with such support bears some resemblance to the findings of Siegal, Calsyn and Cuddihee (1987) and Goodenow, Reisine and Grady (1990). These studies reported a significant relationship between the quality versus the quantity of support and hemodialysis patient's psychological adjustment (Siegal, Calsyn & Cuddihee) and similarly, arthritic women's social and psychological functioning (Goodenow, Reisine & Grady).

Although marital role strain and distress was not the focus of this study, it was apparent that discord existed in couples where partners were less involved in helping with domestic tasks and/or with the dialysis regime (drives to and from dialysis), and who showed a limited understanding of the nature of, and impact of the dialysis treatment on women's physical limitations and well-being. Women's perception of a supportive partner offset the extent of their perceived intrusiveness of dialysis by enhancing both their own well-being and the couple's ability to adapt more successfully to dialysis. These findings are in keeping with those of Binik, Chowenac and Devins (1990) in which they concluded that the patients' well-being and their marital adjustment was adversely affected by increased marital role strain and marital distress because of the way such situations augment levels of illness

intrusiveness.

One possible reason why some relationships survived and others failed may relate perhaps to the finding that supportive relationships for women in this study seemed to evolve from pre-existing positive relations that were in place before starting dialysis. These relationships may not only be more capable of withstanding the impositions or changes that result from dialysis but may also, subsequently be strengthened from the experience. A lack of understanding and consideration were most often attributed to the existence of troublesome relations that deteriorated. Based on Siegal, Calsyn and Cuddihee's (1987) finding on the importance of primary support (e.g., partner and family) to patients' psychological well-being, it was not surprising that women who had less support from these primary sources expressed sometimes feeling hopeless and depressed compared to women who had ample support. Similarly, a significant relationship between spousal support, that included elements of encouragement, sensitivity and involvement in the patient's care, and the morale of home and in-centre hemodialysis patients was documented by Dimond (1979).

#### **Body Image/Self Concept/Self Esteem**

Women were clearly aware of body image changes that had occurred to them since being on hemodialysis. However, it is important to note that the body image changes they described were not seen by them as issues that affected their relationships, at least, at the time of the current study. Body image changes have been identified as one of many sources of stress for hemodialysis

patients (Baldree et al. 1982; Eichel, 1986; Rickus, 1987). Ferrans and Powers (1993) reported that physical appearance was both valued by, and considered moderately important to, patients. Rickus (1987) documented that surgical scarring and weight gains were more disturbing to women on hemodialysis, peritoneal dialysis and those who had transplants than their fistula or weight loss. This present study provides understanding as to why women personally viewed specific body image changes more or less troubling. In fact, weight gains or losses were not especially disturbing to most women in this study because many women thought their body image had been somewhat enhanced by their subsequent change in weight. Changes in weight were generally viewed favourably by women depending on their own personal circumstances with weight before starting dialysis.

While several women acknowledged their access sites were unattractive, the sites were not an issue for sexually active women in terms of their sexual relationship. What troubled women more about their access site was how others might view it and react to them because of the site. The unattractiveness of access sites, including related bruising and scarring, represented one of the most visible or tangible symbols of the women's illness. However, concealing tactics helped to minimize or eliminate unwanted attention and misinterpretations of access sites by others and enabled women to preserve their valued body image, and thoughts and feelings of themselves. These data emphasize that body image remained important to these women on hemodialysis.

Self-concept has rarely been examined in hemodialysis

patients, much less sexual self-concept. Despite the number of changes that transpired in women's lives since being on dialysis, the data indicated that the majority of women in this study possessed a relatively positive self-concept. Although a couple of women struggled with some thoughts and feelings about themselves, essentially all women believed they were the same person in terms of character and intelligence compared to before they started dialysis. In contrast to this study's findings, Alleyne et al. (1989) reported that patients' self-concept had worsened significantly ( $P < 0.001$ ) at the time of their study compared to the time before patients started on dialysis.

However, it is difficult to draw comparisons between these two studies given that gender data in the Alleyne et al. study (1989) were collapsed and females were underrepresented in the study sample. Also, only one item was included related to self-concept in Alleyne et al.'s (1989) study. It is interesting that most of the women in this study focused on more positive aspects of their self-concept, devoting limited if any attention on their thoughts and feelings of themselves in terms of their sexual self-concept. While it is possible that women simply overlooked reflecting on their sexual self-concept, considering the sentiments held by most women on sexual activity and their diminished sexual lives, perhaps this finding might not come as much of a surprise. What is interesting however is that most women didn't necessarily recognize or acknowledge the conceptual link between body image, self concept and self esteem in terms of their sexuality.



Considering women's attitude and personal thoughts on sexual activity, it was not surprising that almost all women overlooked evaluating this aspect of themselves. Only a few women commented briefly on their perception of themselves as a sexual partner and most of these assessments were negative. Although most women focused on the shortcomings and limitations of themselves in the various roles they assumed and how their fatigue and hemodialysis had negatively affected their roles and abilities, a couple of women did acknowledge positive influence in some roles they continued to carry since going on dialysis. Unfortunately, no studies were located in the literature on self-esteem in either general or sexual terms and women on hemodialysis with which to compare this finding.

#### **Other Findings**

##### **Role of Health Professionals**

The women interviewed in this study articulated that they had not relied extensively on health professionals for any particular kind of support. However, it was apparent that when the need arose they expected to receive support and understanding through information and counselling on dialysis related issues; relationship, personal and sexual matters; and on reproductive and gynaecologic issues. While a couple of women gave positive accounts about the support they received from health professionals on some of these topics, the actual support that the majority of women received on these topics fell short of what they expected for a few identified reasons.

Several women expressed dissatisfaction with the actual support they received from health professionals on these topics simply because the information lacked comprehensiveness and caused subsequent frustration. This finding parallels Milde, Hart and Fearing's (1996) findings in which, more than one-third of subjects who received education on sexual and fertility issues viewed it as unhelpful and 20% of patients communicated interest in having further information on sexual matters. The finding of frustration was also articulated in women with physical disabilities because of their perceptions of insufficient care and a lack of relevant information (Becker, Stuijbergen, & Tinkle, 1997).

While several women believed they might have benefited from talking to health professionals about their concerns, they decided not to broach conversations on sexuality because they felt embarrassed, shy or uncomfortable doing so. This dilemma was not surprising since women who failed to obtain adequate support through information and counselling about one health problem or concern may be less inclined to raise other concerns or questions they might have had to health professionals. Also, as some women had sensed at one time a demonstrated lack of sensitivity and interest in their problems from health professionals, this situation might have also contributed to their inability to broach more personal problems. These situations, in addition to the finding that sexual function did not emerge as an important issue for the majority of women, perhaps further our understanding of why the women in this study did not seek advice or information from

health professionals on the changes in their sexual activity and why the self-referral rates among the women in Rozenman's et al.'s (1990) study were low despite having problems in their sexual function. Regardless of the above findings, women were still receptive to their health professionals' initiating conversations on a variety of sexual health care topics with them.

The finding that women received what they thought was less than optimum or exemplary support on sexual health matters was not unexpected. For years, literature has documented that patients on hemodialysis receive little, if any, education and counselling on sexuality and the sexual changes related to their illness, including reproductive and gynaecologic matters (Holley et al. 1997; Milde et al., 1996; Rickus, 1987). Besides, related work has documented that nephrology workers lacked adequate knowledge on sexuality (Ulrich, 1987), and that sexual health care issues were not only poorly addressed by nephrology workers (Binik & Mah, 1994; Dailey, 1998; Holley et al., 1997; Milde et al., 1996; Rickus, 1987; Schmidt & Holley, 1998; Schover, Novick, Steinmuller & Goormastic, 1990) but, also by health professionals in diverse practice settings (Baggs & Karch, 1987; Becker, et al., 1997; Jenkins, 1988; Matocha & Waterhouse, 1993; Richards, Tepper, Whipple & Komisaruk, 1997; Wilson & Williams, 1988).

Despite the absence of a comparable Canadian study, further evidence on the scope of this issue and finding was located in Milde et al.'s (1994) survey in which only 33% of the 36 participating dialysis centres included education on sexuality and

fertility issues in their patient education programs. Thus, the likelihood of nurses receiving and thus possessing suitable knowledge and education material that support and encourage the inclusion of these topics in their practices seems somewhat unlikely.

The women in this study indicated the need to have accessible and comprehensive information on reproductive and gynaecologic matters in a timely manner from health professionals. Since many of women's illness-related symptoms on hemodialysis mimic the symptoms associated with pregnancy, it was understandable why the two women in this study had difficulty discerning that they were pregnant until several months into their pregnancy. Although fertility in women on hemodialysis is uncommon, conception nonetheless remains a possibility as some women continue to have menstrual cycles, though many are irregular (Holley et al. 1997). Recent studies have reported that pregnancy rates range between 1.5% and 7% in women after commencing dialysis (Hou et al., 1994; Wilde et al., 1996). Despite the relative low incidence of pregnancy in women on dialysis, the provision of educational material is necessary because of the high fetal and maternal risks associated with women on dialysis.

Moreover, several of the women experienced gynaecologic problems or changes commonly encountered by perimenstrual or post-menopausal aged women. In fact, one of the sample participants was post-menopausal and three of the women had had a hysterectomy since being on hemodialysis. Similarly, while the majority of women in

Rickus' (1987) study were between 35-39 years of age, 18 women encountered menopause despite the fact that only nine of the women were between 45-55 years old. As revealed by the women in this study, gynaecologic issues not only intensify women's already diminished interest in sexual activity but further compromise their general well-being. The finding that the women in this study desired support on middlesence matters is sufficient evidence for the need for health professionals to provide support to women on these sexual health matters. Menopausal and post-menopausal aged women not only comprise the largest growing proportion of women starting hemodialysis, but they are prone to degenerative changes like osteoporosis from the loss of estrogen and its protective mechanisms and fluctuations in calcium/phosphorous balance that occur secondary to chronic kidney disease.

#### **Impact of Illness and Treatment on Other Aspects of Life**

Most of the women in the present study characterized their fatigue as highly intrusive because of the way in which it introduced widespread changes in their lives and continuously affected and regulated their lives. For several reasons, it comes as no surprise that women talked about persistent generalized fatigue and tiredness. The women in this study referred to fatigue as a chronic and pervasive physical and emotional condition of weariness or exhaustion induced by the illness and treatment related factors. Thus, women lived with little if any reprieve from fatigue and the features that comprise the nature of the dialysis experience for them. It is beyond the scope of this discussion to

review the extensive literature documenting the prevalence of fatigue among this illness population, the kinds of limits it can impose on day-to-day living, and the importance of assessing patients' subjective levels of fatigue regularly, but a few examples are Brunier & Graydon (1993, 1996), Cardenas & Kutner (1982), Killingworth & Van Den Akker (1996), Sklar, Riesenber, Silber, Waqar Ahmed & Amir Ali (1996), Srivastava, 1986, 1989).

Fatigue was appraised by the women in this study as a major inconvenience because of the extent to which it interfered with and compelled them to modify or change the way they lived and conducted their day-to-day lives. This finding was not surprising since fatigue or weakness has been consistently ranked by patients on hemodialysis as one of the top five stressors in their lives (Baldree et al. 1982; Eichel, 1986; Fuchs & Schreiber, 1988; Gurklis & Menke, 1988; Kline, Burton, Kaplan De-Nour & Bolley, 1985; Lok, 1996).

Throughout the interviews, the women in the present study referred to their coping efforts and use of different strategies to help them to better cope with their endless need for dialysis, the intrusiveness of the illness and its treatment regimen, and the many life changes they had faced since being on hemodialysis. Given the finding that life on hemodialysis had been trying, and at times overwhelming for women, the volume of data amassed on coping was not surprising.

The ongoing, dynamic and evaluative nature of women's coping efforts paralleled the coping process described by Lazarus and

Folkman (1984). Women used types of coping strategies which coincided with the findings of earlier studies (Baldree et al. 1982; Blake & Courts, 1996; Gurklis & Menke, 1988; Gurklis & Menke, 1995; Lok, 1996). While some women mentioned they had attempted to cope with specific sexual health matters in the absence of adequate support from health professionals, overall very little data on coping pertained to the ways in which women had dealt with changes in their sexual lives in comparison to coping with the overall demands placed on them by their illness and its treatment regimen. The finding that women devoted little attention to coping with their sexual lives should not come as a surprise given that their illness and its treatment regimen consumed so much from them in terms of their physical, emotional, and psychological well-being.

## CHAPTER V

### SUMMARY, LIMITATIONS AND IMPLICATIONS

#### Summary

The purpose of this study was to describe the experience of and impact of hemodialysis on female sexuality from the perspective of women living with this treatment modality for a minimum of one year. It was also hoped that the experiences of women would impart understanding of the sexual issues that women consider to be important and lead to the suggestion of useful nursing approaches that would meet the sexual health care needs of women.

Interviews with ten women were carried out using a relatively unstructured format. Findings related to sexuality were presented under the categories of physical sexual activity, relationship factors, and body image/self concept/self esteem. While sexuality has not been previously studied from the perspective of women living with hemodialysis, the data from this study provided support for earlier findings specific to the changes in women's sexual function and frequency of sexual activity. For all women in this study, sexuality included having a physical sexual relationship. Although sexual activity was not of central importance for the majority of sexually active women, they all experienced feelings of guilt and obligation related to their sexual relationship. All sexually active women identified a number of factors that interfered with, and generated changes in their sexual relationship since being on dialysis (e.g., decreased sexual desire, hemodialysis and fatigue). Also, the women in this study described



various interpersonal factors that influenced their ability to re-establish a mutually acceptable physical sexual relationship. These factors included a positive exchange process of communication, understanding partners and ongoing role support. All the women were aware of changes in their body image. Although women were not particularly troubled by the changes in their weight since being on dialysis, they were self-conscious about how others perceived and reacted to them especially, their dialysis access sites. The majority of women possessed positive self-concepts. All women recognized changes in their ability to carry out tasks associated with their roles however their acceptance of role changes varied. In addition, the study identified the importance of the women having support and counselling from health professionals. The interview also became a vehicle for women to express their thoughts on matters besides sexuality.

#### Limitations

The sample size was a limitation of this study as it included only ten women dependent on hemodialysis from four dialysis facilities located in one city. A larger sample might have contributed additional data or understanding on some findings that began to emerge from the data collected. In view of the fact that the dialysis population consists of women from diverse cultural backgrounds, the inclusion of only English speaking women was another limiting factor in this study. A more heterogenous sample of women from various ethnic groups might reveal different attitudes, beliefs, and values towards sexuality and chronic

illness, and thus a different experience. Because the sample included only women who had been on hemodialysis for more than one year, it excluded the experiences of women in the very early stages of treatment.

Lastly, the researcher recognizes that the women who agreed to participate in this study might have been more comfortable discussing their experiences, feelings, and thoughts about sexuality than women who declined to participate. It is possible that the subject matter was perceived by women who declined to participate in this study as a topic much too personal for discussion.

#### Implications for Nursing

##### Practice

It is essential for nurses to be aware of the kinds of changes that women undergoing hemodialysis may experience in their physical sexual relationships and other aspects of sexuality, so that they are better able to anticipate problems and provide support. Some such factors and problems uncovered in this study were the influence of fatigue, and the impact of the quality of the relationship with one's partner. Women have a right to expect to receive support, understanding and information from nurses. Furthermore, nurses have an obligation to meet the standards of practice on sexual health care as set out by the World Health Organization in 1975 and the American Nephrology Nurses Association in 1988. As this study highlighted, nurses' failure to address women's sexual health care issues can cause at a minimum,

frustration for women and at the other end of the continuum, its absence can leave women vulnerable to the threatening physical and psychological sequelae related to reproductive and gynecologic matters.

In addition, it is important that nurses recognize a conceptualization of sexuality broader than that currently provided by the conventional bio-medical model of sexuality. Unlike the bio-medical model of sexuality, a broader conceptualization of sexuality captures the breadth and complexity of factors related to women's sexuality as it facilitates the exploration of issues that might matter to women. In comparison to narrower perspectives, a broad conceptualization of sexuality provides a more unabridged version and thus understanding of women's experience of sexuality in the context of their whole lives because it encourages women to talk about issues they perceive as important. Utilization of a more holistic perspective on sexuality might help nurses to explore issues beyond women's physical sexual relationship.

Nonetheless, use of a broader perspective does suggest that nurses might overlook the usefulness of findings that emerge from the biomedical perspective in relation to the measurement of bio-physical or bio-chemical factors and women's sexual functioning. Thus, it is important for nurses to consider the kinds of hormonal changes that typically occur over time in women, and the impact that some medications exert on women's sexual function. While many medications have a negative impact on sexual function, drugs such as erythropoietin might be expected to enhance women's sexual

function or relationship and therefore require monitoring.

Additionally, a broader perspective on sexuality might also help alleviate patients' feelings of discomfort that often arise when broaching conversations of this type because its sole focus is not on women's sexual function or sexual activity but rather on issues that women view as important or problematic. Unlike the biomedical perspective of sexuality, there is no expectation that such conversations must begin and end with the topic of sexual activity. Broader perspectives on sexuality provide the necessary latitude that encourage nurses to begin asking women questions about the least sensitive areas on sexuality and then proceeding to more sensitive topics, if women indicate an interest.

In order for nurses to be able to counsel and support women in sexual health care issues, they themselves must have comprehensive and up-to-date information. Because women on hemodialysis receive dialysis related care in a variety of settings, such as pre-dialysis clinics and nephrology units, it is important that all nurses who provide direct care to women receive consistent and relevant educational material. Initially nurses could receive information on sexuality in departmental orientation manuals. Subsequently, information and support could be acquired through staff inservices, patient care conferences, and published literature left available to nurses in their respective units. To supplement nurses' practice efforts on sexuality, it is recommended that written information on a variety of topics be readily available to women so they can review the material at their leisure

or at a later date, if necessary. The latter approach to educating women is supported by the fact that people have different learning styles.

Given the findings of previous studies on nurses' lack of comfort in discussing sexual matters with patients, practice conducting conversations of this nature could be included in preparing nurses to broach conversations of this kind. Role modelling and role playing may be useful devices in practicing. A comprehensive sexual health care assessment form may also aid the nurse in approaching this topic more comfortably. Nurses' practices related to counselling women about sexual health care also requires multi-disciplinary support. Clearly, the absence of such support would only be counterproductive to the efforts expended by nurses, and also detrimental to women especially in situations that require the expertise of other key team members.

It is also important that nurses give careful thought to the ways in which they approach helping women to deal with changes in sexuality or for that matter, other life areas of significant change. While it is important for nurses to inform women about the kinds of changes they might encounter as a result of being on hemodialysis, it is equally important to provide opportunity to discuss how such changes and problems might be viewed differently and perhaps better managed. As evidenced in this study, women had little difficulty identifying what they were no longer able to do in their lives. Although it is important to acknowledge the losses and changes women have experienced, rather than emphasizing the

things women can no longer do or participate in, it might be more constructive to shift the focus of conversations to the kinds of things women might be fully capable of doing.

Because of the complexity of issues in women's lives and their struggle in living day-to-day, it is essential that nurses provide women with many opportunities to talk about the issues they confront. The women in this study seemed to have the impression that nurses did not fully appreciate their concerns as they spent little time talking with them. The activity of nurses 'knowing the patient' is one means of enhancing patient care outcomes (Radwin, 1996) because knowing patients allows nurses to tailor their care to patients' individual needs. Knowing the patient also fosters a trusting therapeutic relationship between the nurse and patient. Since consistent contact with patients is one vital factor in nurses knowing their patients (Jenny & Logan, 1992; Radwin, 1996), hemodialysis nurses are in a favourable position because these patients typically receive dialysis treatments thrice weekly.

As well, it would be beneficial for health care professionals to include more partner centered care in their practices given the importance of women having ongoing support from their partners and the fact that many women in this study mentioned their partners had at sometime experienced frustration about their life situation. It seems only reasonable that we consider examining partners' issues, so that women continue to receive adequate support from their partners over time. Likewise, it is necessary to include the significant others of women who do not have the support of a

partner.

### Research

There are methodological considerations worth heeding in the event that this study is repeated. Although the present study deliberately conceptualized sexuality more broadly than any known previous study on women on hemodialysis and sexuality, its breadth likely contributed to the data amassed on topics beyond the study's original purpose. While it was clear that sexuality included physical sexual activity for women, the data also emphasized that there were other important aspects to their intimate relationship than sexual activity. Such factors included having a closeness with their partner and support and understanding from their partner. Thus, in considering future research projects on sexuality, it would be beneficial to include these specific components of women's intimate relationship along with physical sexual activity in future conceptualizations of sexuality.

The interview format was troublesome to some women due to the ordering of some questions and the language or terms used in some questions. Given the ordinary, close association of the terms self-concept and self-esteem, it is not advisable to ask consecutive questions related to these two concepts as some of the women in this study talked about both terms concurrently or failed to understand the meaning of or differences between the two terms. It might be more practical to select less academic terms that the general populace are more familiar with.

To ensure that women receive adequate information and support

on the sexual health care issues that are important to them, research is needed to measure the outcome associated with care provided to women in this area. An interesting study for a nephrology nurse researcher might include assessing women's satisfaction with such care on a variety of topics related to their sexual health. Prior to developing sexual health care educational material for women, it would be useful to determine what kinds of information women might like to have and to have women rank the importance of different topics or issues. It is also necessary to investigate nurses' knowledge of and comfort in carrying out conversations of this nature. As there were no studies located on this matter, it would be interesting to conduct a study on nurses both prior to and after incorporating the content in dialysis programs and nurses' practices. This type of study might also uncover the effectiveness of teaching material for nurses.

Given the importance of the women in the current study having a closeness with their partner and support from them, it would be interesting to study this concept further in order to identify the factors that constitute closeness for women. This kind of information would be useful to nurses when they provide family centered care to women's partners. It would also be interesting to examine the congruency between couples' experience of changes in their physical sexual relationship and each partner's satisfaction with their relationship.

Since the dialysis population includes women from a variety of cultures it would be useful to explore these women's experience of



being on hemodialysis and sexuality. Because sexuality carries different meanings across cultures, the definition of a normal and satisfying sexual relationship, along with perceptions and meanings of sexual dysfunction might be different from those described by the women in this study.

As well, there is room for further exploration of women's experience of being on hemodialysis and sexuality. A phenomenological study would capture another level of understanding about the meaning of women's experience of being on hemodialysis and sexuality.

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**APPENDIX A**  
**Sample Criteria**

Inclusion criteria for participants include:

1. Women who have been receiving either in-centre or self-care hemodialysis therapy for a minimum of one year.
2. Women who are able to comprehend English and communicate in English.
3. Women who are medically stable.

## APPENDIX B

### Nurse Manager's Introduction of Study to Participants.

Hello Ms./Mrs. \_\_\_\_\_.

Debbie Harkness, a registered nurse and graduate student, in the Faculty of Nursing at the University of Toronto is conducting a study entitled "Women's Experience of Hemodialysis and Sexuality: A Phenomenological Study". She is interested in learning about what life is like for women living with hemodialysis and the influence that has on sexuality. She would like to explain more about her study to you and then ask if you would be interested in participating in the study.

She hopes that the information obtained from the study will help nurses understand what women experience in relation to sexuality when living with hemodialysis. Hearing more about the study does not obligate you to participate. Would you be interested in learning more about the study?

If individual responds "no", say; Thank-you for your time today.

If individual responds "yes", ask; Would it be all right to give your name and telephone number to Ms. Harkness so she can arrange a time to telephone you and to tell you more about the study?

What would be a convenient time to reach you at home?



## Appendix C

### Telephone Explanation of Study Given to the Participants

Hello Ms./Mrs. \_\_\_\_\_.

My name is Deborah Harkness. I am a graduate student in nursing at the University of Toronto. Thank-you for agreeing to speak with me to learn more about my study. The title of my study is "Women's Experience of Hemodialysis and Sexuality". I am very interested in learning more about the experiences of women living with hemodialysis and its influence on sexuality. I would like to learn more about what this experience is like for you. The study will be supervised by Dr. Margaret Fitch, Head of Oncology Nursing at Toronto Sunnybrook Regional Cancer Centre.

The study would involve talking to me about your experiences, thoughts, and feelings about sexuality since starting hemodialysis. I will also ask some questions about your age, the medications you take, your marital status, the length of time you have been on dialysis, and your education. I would like to speak with you on two separate occasions. Although the length of each session will depend on how much or how little you want to share with me, I expect that the first session will take a minimum of one hour or more if required and that the second session will take approximately one hour. The second session will take place approximately three weeks following the first session. Both sessions will be conducted in privacy at a time and place convenient to you.

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I would like to tape record the sessions so that I can listen fully to what you say. If you prefer not to have something you say recorded, the tape recorder will be turned off. Even though you might agree to participate, you are free to withdraw from this study at any time without consequence to your ongoing health care. You may refuse to answer any questions asked during the tape-recorded session. If you are unwilling to have the sessions tape recorded I cannot consider you further for the study.

The tapes will be erased at the end of transcribing. The transcriptions and study consents will be kept for six years in a locked file cabinet at my home and will be destroyed after this time period. I will not share any specific information of our conversation with the unit or hospital staff. The master list of code numbers and names will also be kept at my home in a locked file cabinet for the duration of the study and destroyed after the analysis is completed.

Your name or any other identifying information will not appear in any report of this study. Although I may use excerpts from the conversations to illustrate particular points for the thesis analysis and educational presentations regarding the thesis, any identifying information will be removed or disguised. You might recognize your own words but it is unlikely that others would be able to identify you in the report.

Although I would like you to participate in my study, the decision is entirely up to you. There are some known potential

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risks and benefits to being involved in the study. There is the risk that you may become emotionally upset from your participation in the study. If you should become upset during the interview, I will do one or all of the following: turn the tape recorder off, suggest a temporary break, offer support, and eventually ask whether you are able or willing to continue with the session.

Although some people may find the subject difficult to talk about, you may benefit indirectly by the opportunity to express your feelings. In addition, your involvement might help nurses to understand what women, like yourself, experience in relation to sexuality and living with hemodialysis. Ultimately this may influence the health care women receive from health professionals.

If you would like to participate in the study, I would be happy to make arrangements for our first session at a convenient time and place for you.

Do you have any questions?

If yes, answer questions.

If no questions are voiced ask; Are you willing to take part in the study?

If yes, ask; What would be a convenient time and place to arrange our first session?

If no, thank you for your time Ms./Mrs.\_\_\_\_\_.

**APPENDIX D**

**Participant's Consent Form**

**Study Title: "Women's Experience of Hemodialysis and Sexuality: A Phenomenological Study".**

**Student Researcher: Deborah Harkness, RegN., BScN**

**Phone Number: (416) 932-3993**

I \_\_\_\_\_ consent to participate in a study described to me by Deborah Harkness, a graduate student in the Department of Nursing Science at the University of Toronto, concerning the experience of women living with hemodialysis and its influence on sexuality. The study will be supervised by Dr. Margaret Fitch, Head of Oncology Nursing at Toronto Sunnybrook Regional Cancer Centre.

I understand that I will be asked to talk about my experiences, thoughts, and feelings concerning my sexuality and what this aspect of life is like for me when living with hemodialysis. I will also be asked some questions about my age, medications, marital status and education, and the length of time that I have been on dialysis. I have been asked to participate in two conversational sessions. The initial session will take a minimum of one hour or more if required and the second session will take approximately one hour. The second session will take place approximately three weeks following the initial session. Both sessions will be conducted in privacy at a time and place convenient to me.

I understand that the conversational sessions will be tape

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recorded and I agree to have each session recorded. If you prefer not to have something you say recorded, the tape recorder will be turned off. You may refuse to answer any questions asked during the tape recorded session. Even though you might agree to participate, you are free to withdraw from this study at any time without consequence to your ongoing health care.

After each conversational session the tape will be transcribed and then erased. The transcriptions and the study consents will be retained for six years in a locked file cabinet at the researcher's home and will be destroyed after this time period. The master list of code numbers and names will be kept in a locked file cabinet at the researcher's home for the duration of the study and destroyed after the analysis is completed.

Your name or any other identifying information will not appear in any report of this study. Although excerpts from the conversations may be used to illustrate particular points for the thesis analysis and educational presentations regarding the thesis, any identifying information will be removed or disguised. You might recognize your own words but it is unlikely that others would be able to identify you in the report.

I understand the potential risks and benefits to being involved in the study. I understand that I may be at risk for becoming emotionally upset from my participation in the study. I understand that if I should become upset during the interview, the researcher will do one or all of the following: turn the tape

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recorder off, suggest a temporary break, offer support, and eventually ask whether I am able or willing to continue with the session. Although some people may find the subject difficult to talk about, I may benefit indirectly by having the opportunity to express my feelings.

Lastly, I understand that while I may not benefit directly from this study, the findings may help nurses to understand the importance of women's experience concerning sexuality and thereby affect the future care that women receive.

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Date

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Participant's signature

Researcher's signature: \_\_\_\_\_

Print Name: \_\_\_\_\_

Researcher's Phone Number: \_\_\_\_\_

**APPENDIX E**

**Demographic Data Questionnaire**

Code Number: \_\_\_\_\_

Date of Data Collection: \_\_\_\_\_

1. What is your current age:

20 - 45 years \_\_\_\_

46 - 65 years \_\_\_\_

66 - 75 years \_\_\_\_

76 years old and greater \_\_\_\_

2. Are you: 1. single

2. married

3. divorced

4. widowed

5. separated

3. Which of the following medications are you currently taking?

1. erythropoietin (EPO)

2. list any other medications you are taking

4. How long have you:

1. been on hemodialysis? Years \_\_\_\_

Months \_\_\_\_

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5. Have you ever been: (circle those applicable)
1. on in-centre hemodialysis
  2. on self-care hemodialysis
  3. on home hemodialysis
  4. on hospital peritoneal dialysis
  5. on home peritoneal dialysis
  6. a "living-related" transplant patient
  7. a "cadaveric" transplant patient
6. What is your highest level of education?
1. Elementary school
  2. High school
  3. College
  4. University
  5. Other



## **APPENDIX F**

### **Format for Interview Sessions**

Before beginning the interview, the researcher will briefly discuss the purpose of the study to participants.

Opening Question: The initial open-ended question will ask:

"In thinking about sexuality please try to describe to me, in as much detail as possible, what your experience of sexuality has been like for you since living with hemodialysis? I would like you to share all the experiences, thoughts, insights, and feelings you have, as fully as possible, until you have nothing more to say about sexuality. There are no right or wrong answers. I am interested in knowing about what your experience has been like for you as a woman living with hemodialysis."

Based on the content of the participant's initial description of their experience of sexuality, the researcher will then ask a series of probing questions. These questions will be asked if the topics have not previously been discussed by the participant: (a) "Some women find that hemodialysis affects their sexuality in terms of their body image. You may or may not have found this. Could you tell me about this?"; (b) "Some women find that dialysis affects their sexuality in terms of their self-concept. The term self-concept refers to your perception of yourself and the thoughts and feelings that you have about yourself. You may or may not have found this. Could you tell me about this?"; (c) "Some women find that dialysis affects their sexuality in terms of their self-esteem. The term self-esteem refers to your appraisal or

evaluation of yourself. You may or may not have found this. Could you tell me about this?"; (d) Some women find that dialysis affects their sexuality in terms of their intimate relationship. You may or may not have found this. Could you tell me about this?"; (e) Some women find that dialysis affects their sexuality in terms of their family and social relationships. You may or may not have found this. Could you tell me about this?"; (f) Some women find that dialysis affects their sexuality in terms of their career/employment. This may or may not be true for you. Could you tell me about this?"

Following this series of questions the researcher will ask, "Out of all the changes that you have described to me what has been the most difficult for you manage or deal with and why"? The final question will ask, "Is there anything that you would like to add or elaborate on from the interview"? This final question will provide an opportunity for the participants to talk about anything they feel is important to the interview and/or elaborate on any part of their description.

At the end of the initial session the participants will be reminded that the researcher will meet with them in approximately three to four weeks for the second session.

The researcher will bring to the second session a general summary of the first interview. The participants will then be asked to carefully read this summary and provide feedback in order to help validate the researcher's impressions.

The participant will be asked the following questions: (a)

"Do you feel that my summary of our conversation (i.e. interview) accurately describes your experiences?"; (b) "Is there any part of your experience that you feel was not covered in this summary?"; (c) "Is there any part of this summary which surprises or puzzles you because it does not reflect your experience?" and; (d) "Is there anything that we did not discuss that you feel is part of your experience of sexuality since being on hemodialysis?"

Information obtained from both interviews will comprise the data for final analysis.