INDIVIDUALS' EXPERIENCES WITH END STAGE RENAL DISEASE AND HEMODIALYSIS TREATMENT: IMPLICATIONS FOR QUALITY OF LIFE

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Individuals' Experiences with End Stage Renal Disease and Hemodialysis Treatment: Implications for Quality of Life

by

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Abstract

A descriptive correlational design was used to investigate how individuals living with end stage renal disease (ESRD) and hemodialysis perceive illness and treatment experiences, social supports, adjustment to a new normal, and quality of life. The interrelationships among the key study variables (illness and treatment experiences, social supports, adjustment to a new normal, personal characteristics, overall quality of life) were also examined. The Living with End Stage Renal Disease and Hemodialysis (LESRD-H) model was used as the framework for this study.

The convenience sample consisted of 112 individuals who were receiving hemodialysis at four centers located in the province of Newfoundland and Labrador. A response rate of 87.5% was achieved. The majority of participants were male (55.4%), living with a spouse (66.1%), and fifty years of age and over (65.2%). The mean age of the sample was 57.9 (*SD* ± 16.7). Most participants had been receiving hemodialysis for less than three years (79.5%), with a mean time of 21.95 months (*SD* ± 18.9). As well, most participants had one or more comorbid illnesses (85.7%), and experienced low to moderate illness severity (58%). Data were collected via face-to-face interviews between July, 1998 and February, 1999.

Study findings indicated that most participants were generally positive about illness and treatment experiences, social supports, and adjustment to a new normal. Participants were most positive about social supports, followed by adjustment to a new normal and illness and treatment experiences, respectively. As well, most participants were quite satisfied with their overall quality of life and each life domain. Specifically, participants were most satisfied with the family, psychological/spiritual, social and economic, and health and functioning domains, respectively.

Most of the illness and treatment experiences (i.e., physiological stressors, knowledge about the illness and treatment, performance of activities of daily living (ADL), and self-health management) and social support (i.e., family, nursing, physicians, and allied health) variables depicted significant, positive relationships with the adjustment variables (i.e., psychosocial distress and emotional well-being). As well, most experience, support, and adjustment variables depicted significant, positive relationships with overall quality of life, family life, health and functioning, psychological and spiritual well-being, and social and economic conditions. Several personal characteristics (i.e., living arrangement, gender, age, time on dialysis, number of comorbid illnesses, and illness severity) were found to exert variant and minimal effects on the adjustment and quality of life variables.

Study findings provided partial support for the major assumptions of the LESRD-H model. Consistent with model predictions different combinations of experience and support variables exerted a direct effect on the adjustment variables (i.e., psychosocial distress and emotional well-being), and overall quality of life. In partial support of model predictions, emotional well-being was the dominant predictor of quality of life, and moderated the impact of experience and support variables. Counter to expectations age emerged as the second most important predictor variable for quality of life.

Study findings provide some support for previous research and suggest that illness and treatment experiences, social supports, and adjustment to a new normal have significant implications for quality of life. However, due to study limitations, generalizability of the findings to other individuals receiving hemodialysis is cautioned. There is a need for future research to develop a greater insight into the impact of similar and different illness and treatment experiences, social supports, and adjustment to a new normal on the overall quality of life of individuals living with ESRD and hemodialysis.

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CHAPTER 1

Introduction

End stage renal disease (ESRD) is a chronic illness where the kidneys experience permanent damage and fail to perform normal life sustaining functions (Canadian Institute for Health Information [CIHI], 2001). Individuals who have this illness are faced with long-term dependence on renal replacement therapy (i.e., dialysis or renal transplantation) for survival. Although life can be prolonged with treatment, the occurrence of sporadic critical events (i.e., negative or positive) can either amplify or diminish the challenges posed by illness and treatment experiences, social supports, and adjustment to a new sense of self.

There has been a marked increase in the number of Canadians requiring renal replacement therapy, with actual numbers doubling over the past decade (CIHI, 2001). The average age of treatment initiation also evidenced a steady increase (i.e., 55 to 61 years), with males dominating all adult age groups. Hemodialysis (i.e., blood filtered through an extracorporeal dialyzer to remove toxins, electrolytes, and fluids) has been the dominant treatment modality, followed by successful renal transplant and peritoneal dialysis (i.e., the peritoneal membrane acts as the filter between the dialysate fluid and blood in the abdominal vessels), respectively (CIHI).

Despite significant medical advances in recent years, only slight improvements have occurred in survival rates. Clinicians and researchers have long recognized the importance of focusing on additional outcome parameters (i.e., quality of life and health-related quality of life), besides survival time, as indicators of health care effectiveness (Harrison, Juniper, & Mitchell-Dicenso, 1996; Kimmel, 2000a; Kutner, 1994). It has been argued that the provision of quality care is highly dependent on developing an in-depth understanding of the process involved in attaining optimal short- and long-term quality outcomes (Anderson & Burckhardt, 1999; Harrison et al.; Kimmel; Rettig et al., 1997; Tarlov et al., 1989).

The empirical evidence suggests that illness and treatment experiences, perceived usefulness of social supports, and successful adjustment to a new normal are important determinants of overall quality of life. Several components of these factor groupings are subject to modification and would benefit from timely interventions from health care providers. It is not only important to identify and describe influencing factors but also to evaluate their separate and interactive effects on overall quality of life.

The current study is part of a national project designed by Parfrey and colleagues[1] to develop a feasible method for comprehensively assessing individuals' perceptions of ESRD and hemodialysis and monitoring change over

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[1] The Kidney Foundation of Canada funded a prospective, longitudinal study, *Testing the Patient Perceptions of Hemodialysis Scale (PPHS)*, by Parfrey, Hutchinson, and Way (1999).

time. The purpose of the current study is to document how individuals experience the illness and treatment, perceive social supports, experience changes to the self and adjust accordingly, and perceive their overall quality of life. A second study purpose was to examine the separate and interactive effects of illness and treatments experiences, social supports, and adjustment to a new normal on overall quality of life.

Background and Rationale

Most individuals with ESRD are unprepared for the tremendous challenges confronting them when survival is dependent on long-term hemodialysis treatment. Several authors have documented the pervasive changes that individuals are forced to endure in all aspects of their lives (e.g., Faber, 2000; Gregory, Way, Hutchinson, Barrett, & Parfrey, 1998; Kutner, 1987; Lev & Owen, 1998; Nagle, 1998; O'Brien, 1983; White & Grenyer, 1999). Meaningful adjustment to a new sense of normal is greatly dependent on how well one regains and maintains acceptable levels of independence and control over important life domains (e.g., Faber; Gregory et al.; Jones & Preuett, 1986; Kutner; Nagle; O'Brien; Rittman, Northsea, Hausauer, Green, & Swanson, 1993). The challenge facing clinicians and researchers is to develop greater insight into how illness and treatment experiences and social supports impact adjustment to a new normal and, ultimately, overall quality of life.

Research findings have documented that individuals with ESRD and hemodialysis experience variant levels of physical and psychosocial stressors (e.g., Baldree, Murphy, & Powers, 1982; Bihl, Ferrans, & Powers, 1988; Gurklis & Menke, 1988, 1995; Killingworth & Van Den Akker, 1996; Klang & Clyne, 1997; Lev & Owen, 1998; Lok, 1996; Parfrey, Vavasour, Bullock, Harnett, & Gault, 1989; Welch & Austin, 1999), functional limitations (e.g., Killingworth & Van Den Akker; Kimmel et al., 1996; Kimmel et al., 2000; Klang & Clyne; Kovac, Patel, Peterson, & Kimmel, 2002; Lev & Owen; Patel, Shah, Peterson, & Kimmel, 2002), illness severity (Barrett et al., 1997; Beddhu, Bruns, Saul, Seddon, & Zeidel, 2000; Kimmel et al., 2000; Kovac et al.; Sacks, Peterson, & Kimmel, 1990), and negative illness and treatment effects in various life domains (Devins et al.,1990; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Sacks et al., 1990; Patel et al.). As well, there is a developing qualitative research base on the importance of being informed about and actively involved with illness and treatment related practices in order to achieve an optimal level of adjustment (Jones & Preuett, 1986; Kutner, 1987; Gregory et al., 1998; Gurklis & Menke, 1995; Nagle, 1998). Significantly, the limited findings on the interrelationships among the factors defining illness and treatment experiences remain inconclusive.

Several studies were identified that explored the availability and usefulness of social supports for individuals on long-term hemodialysis. The findings were fairly consistent on important members of social networks (i.e., family, health care providers, and friends) and the perceived usefulness of formal and informal supports (e.g., Christensen, Smith, Turner, Holman, Gregory, & Rich, 1992; Cormier-Daigle & Stewart, 1997; Ferrans, Powers, & Kasch, 1987; Gregory et al., 1998; Gurklis & Menke, 1995; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Kovac et al., 2002; Kutner, 1987; Patel et al., 2002; Siegal, Calsyn, & Cuddihee, 1987; Tell et al., 1995; Weil, 2000; White & Grenyer, 1999). Conflicting findings exist on the mediating role of supports for functional levels, illness severity, and illness intrusiveness despite the commonalities of methodology and population base (Kimmel et al., 1996; Kimmel et al., 2000; Sacks et al.). Furthermore, no studies were identified in the current literature review that assessed the effect of supports on stressor frequency or severity.

Studies have also demonstrated that individuals adjust well to the multiple losses associated with long-term dependence on hemodialysis. The qualitative data base suggests that coming to terms with multiple and cumulative losses requires accepting the uncertainties inherent in living with the illness and its treatment and developing an adaptive, hopeful approach, as opposed to a reactive, defeatist one (Gregory et al., 1998; Gurklis & Menke, 1995; Jones & Preuett, 1986; Kutner, 1987; Nagle, 1998; O'Brien, 1983; Rittman et al., 1993). Comparatively, quantitative studies have provided further evidence for the importance of these factors in facilitating effective coping (Baldree et al., 1982; Cormier-Daigle & Stewart, 1997; Gurklis & Menke, 1988; Lok, 1996) and psychosocial adjustment and emotional well-being (Keogh & Feehally, 1999; Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Kimmel et al., 2000; Klang & Clyne, 1997; Kovac et al., 2002; Lev & Owen, 1998; Patel et al., 2002; Sacks et al., 1990; Siegal et al., 1987).

Importantly, few studies have considered the separate or interactive effects of illness and treatment experiences, social supports, and personal characteristics on adjustment to a new normal. There is some evidence from quantitative studies documenting the influence of illness and treatment experiences (i.e., stressors, functional limitations, illness severity, and illness intrusiveness) and social supports on psychosocial adjustment (Devins, Beanlands, Mandin, & Paul, 1997; Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Kimmel et al., 2000; Kovac et al., 2002; Patel et al., 2002; Siegal et al., 1987) and emotional well-being (Cormier-Daigle & Stewart, 1997; Devins et al.; Gurklis & Menke, 1988; Keogh & Feehally, 1999; Lok, 1996; Patel et al.). Finally, personal characteristics (i.e., demographics and medical risk factors) seem to have no to minimal impact on either adjustment (Devins et al.; Killingworth & Van Den Akker; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Klang & Clyne, 1997; Kovac et al.; Patel et al.; Sacks et al., 1990; Siegal et al., 1987) or well-being (Baldree et a., 1982; Cormier-Daigle & Stewart;

Devins et al.; Gurklis & Menke, 1988; Keogh & Feehally; Lok, 1996).

Study findings have also documented that individuals tend to give higher ratings to overall quality of life (i.e., quite satisfied with important life domains) (Bihl et al., 1999; Ferrans & Powers, 1993; Killingworth & Van Den Akker, 1996; Lok, 1996). As well, a few studies have provided evidence for the influence of illness and treatment experiences (Killingworth & Van Den Akker; Kimmel et al., 1996; Lok; Patel et al., 2002), social supports (Ferrans et al., 1987; Kimmel et al., 1996; Patel et al.; Tell et al., 1995), psychosocial adjustment (Killingworth & Van Den Akker; Kimmel et al.; Patel et al.), emotional well-being (Lok; Patel et al.), and personal characteristics (Ferrans & Powers; Kimmel et al., 1996; Kimmel et al., 1998; Patel et al.; Tell et al.) on quality of life.

Despite an expanding research base on ESRD and hemodialysis, the literature review highlighted a piecemeal approach to how individuals adjust and maintain an optimal level of quality of life. The absence of a unified theoretical base and use of diverse factors prevents meaningful comparison of study findings. Furthermore, the heavy reliance on cross-sectional designs and bivariate analysis seriously impedes the conclusiveness of the findings. Obviously, further inquiry is needed to facilitate health care providers understanding of key factors influencing overall adjustment and quality of life.

Problem Statement

End-stage signifies a terminal illness, with life on a dialysis machine indicative of "borrowed time" (Kutner, 1987). It is well documented that individuals on long-term hemodialysis are required to adjust to highly volatile illness and treatment experiences, significant losses and lifestyle restrictions, and a changing support base. Emotionally, psychologically, physically, socially, and spiritually these individuals are searching for a sense of normalcy in their lives. As well, there is evidence of a constant struggle to obtain a quality of life standard that can be used as a benchmark for evaluating unpredictable events.

Clinicians and researchers have been interested in how experiences with ESRD and hemodialysis influence the quality of short- and long-term outcomes. Despite the extensive research base, there is a conspicuous absence of well-articulated models outlining the influence of important factors on different outcomes. In particular, most models fail to account for the separate and interactive effects of key aspects of illness and treatment experiences, social supports, and adjustment to a new normal on overall quality of life. The present study was designed to address some of these concerns with the conceptual model on Living with End-Stage Renal Disease and Hemodialysis (LESRD-H) .

The LESRD-H model is based on the findings from a grounded theory study of individuals receiving hemodialysis by Gregory (1998). The model identifies three theoretical constructs (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) that exert separate and interactive effects on quality outcome. Adjustment to a new normal also constitutes an intermediate outcome which exerts a more powerful, direct effect on quality outcome than either experiences or supports. The proposed relationships among the study variables are outlined in the research questions. A more detailed description of the constructs and their interrelationships are presented in Chapter 2.

Research Questions

This study was designed to address the following research questions:

1. How do individuals receiving hemodialysis perceive illness and treatment experiences and social supports?
2. How do individuals receiving hemodialysis adjust to a new normal?
3. Are illness and treatment experiences and social supports significantly related to adjustment to a new normal?
4. How do individuals receiving hemodialysis rate their overall quality of life?
5. Are illness and treatment experiences, social supports, and adjustment to a new normal significantly related to quality of life?
6. Are illness and treatment experiences, social supports, adjustment to a new normal, and quality of life a function of select personal characteristics (i.e., gender, hemodialysis site, age, living arrangement, cause of ERSD,

time on dialysis, frequency and type of comorbid illnesses, and illness severity)?

7. What factors investigated in the current study are the best predictors of adjustment to a new normal and overall quality of life?

CHAPTER 2

Literature Review

The purpose of this review is to examine the literature on people living with ESRD and receiving hemodialysis treatment. The review of relevant literature is divided into three major sections. The first section presents an overview on how individuals adjust to ESRD and hemodialysis treatment. Special consideration is given to illness and treatment experiences, the role of social supports, and the process of developing a new sense of normal. The second section reviews the literature on the quality of life construct and important factors influencing the quality of life of individuals living with ESRD and hemodialysis. The final section presents an overview of the conceptual framework for this study.

Adjusting to ESRD and Hemodialysis Treatment

As normal renal function becomes increasingly compromised, an individual is confronted with a life-threatening illness that must be treated with dialysis or transplantation. The declining physical health status characteristic of ESRD is usually significantly abated following the initiation of dialysis (i.e., peritoneal or hemodialysis). Despite the positive influence of dialysis on physical health and functioning, there are concomitant negative effects on the social, emotional, and psychological aspects of health which have significant repercussions for overall quality of life. With the primary focus on physical health and functional status outcomes, less attention has been given to individuals' subjective experiences with an unpredictable illness course, hemodialysis treatment, social supports, and a new sense of normal. The following discussion summarizes key findings from qualitative and quantitative studies conducted with individuals receiving renal replacement therapy, especially in-center hemodialysis. The discussion is organized according to major constructs (i.e., illness and treatment experiences, social supports, and adjusting to a new normal) believed to significantly impact quality of life outcomes.

Illness and Treatment Experiences

An extensive review of the literature provided useful insights into how individuals' experience ESRD and hemodialysis treatment. It is well documented that these individuals are exposed to many illness- and treatment-related physiological and psychological stressors, experience variant levels of functional abilities and illness severity, and perceive illness intrusiveness in many life domains. There is also some support for the importance attached to being informed about the illness and treatment and involved in self-care activities. As well, there is empirical evidence supporting the interrelationships among frequency and severity of illness and treatment events, functional limitations, illness severity, and intrusive illness effects. The evidence is less convincing on how personal characteristics (e.g., gender, age, time on dialysis, marital status, education, etc.), knowledge, and self-care practices influence illness and treatment experiences.

The following review highlights and discusses relevant research literature. The discussion in the first section is focused on physical and psychosocial stressors. The discussion in the second and third sections is expanded to consider knowledge and self-care practices, and functional levels and illness severity, respectively. In the final section, consideration is given to perceptions of illness intrusiveness, and how such perceptions may or may not influence or be influenced by stressors, functional limitations, and illness severity. The purpose and key methodological aspects of the major studies reviewed are summarized in Table 1.

Physical and psychosocial stressors. There are numerous illness- and treatment-related factors that have been identified as potential stressors for individuals with ESRD and receiving dialysis. Stressors have been subdivided into physiological and psychosocial problems. The frequency and severity of physical and psychosocial stressors are believed to have important implications for one's ability to adjust to the chronicity of the illness and long-term treatment requirements. Despite the importance of stressors for overall adjustment, there are few comprehensive and/or valid measures.

Several self-report scales have been developed to assess the incidence and severity of stressors in the hemodialysis population. Generally, participants are asked to rate the frequency of symptom occurrence on a Likert-type rating scale. The most frequently used scale was the Hemodialysis Stressor Scale (HSS), which is comprised of items dealing with physiological (i.e., muscle cramps, fatigue, itching, etc.) and psychosocial (e.g., fluid and food limitations, future uncertainty, job interference, physical activity limitations, altered body appearance, etc.) stressors. The Stressor Assessment Scale (SAS), comprised of the original HSS and Luby's (1984) scale, also contains items assessing both types of stressors. Additional disease-specific measures of physiological stressors identified from the studies reviewed included the Symptom scale, Leicester Uraemic Symptom Scale (LUSS), Health Index (HI), the Somatic Symptom Distress Scale (SSDS), and researcher-developed checklists of common uremic symptoms. A couple of scales were also identified that focused only on psychosocial stressors, including the disease-specific Affect scale and the generic Fatigue-Inertia subscale of the Profile of Mood States (POMS). While all of these scales have demonstrated good to excellent internal consistency and stability, there have been limited reports of validity. Specifically, the HSS and SAS were content validated, whereas the Symptom and Affect scales demonstrated construct validity, good intra- and inter-observer reproducibility, and discriminant validity (see Table 1).

Table 1

Summary of Health Care Studies Dealing with Select Aspects of Experiences[1]

Study	**Design & Sample**	**Purpose**	**Instruments & Psychometrics**
Baldree et al. (1982)	Descriptive-correlational; 35 HD patients	Examine frequency & severity of stressors	HSS (content valid & stable, *r* = .71 over 2-wks)
Bihl et al. (1988)	Descriptive-correlational; 18 HD patients	Examine frequency & severity of stressors	Modified HSS (α = .80)
Fuchs & Schreiber (1988)	Descriptive-correlational; 30 HD patients	Investigate frequency & severity of stressors	SAS (α = .84 & content valid)
Gurklis & Menke (1988)	Descriptive-correlational; 68 HD patients	Examine frequency & severity of stressors	Modified HSS (α = .90 but content validity problems)
Parfrey et al. (1988)	Descriptive-correlational; 97 dialysis patients	Investigate physical stressor severity & clinical indicators	Researcher-developed scale to assess physical symptoms (content, construct, & discriminant validity; & intra & inter observer reliability)
Parfrey et al. (1989)	Prospective (1-year); 63 dialysis patients	Monitor changes in the frequency & severity of stressors	Symptom & Affect scales (construct validity, good interrater reliability, & sensitivity)

Barrett et al. (1990)	Prospective (1-year); 96 dialysis patients	Examine the effects of psychological & clinical factors on the frequency, severity & duration of somatic symptoms	Symptom & Affect scales
Devins et al. (1990)	Prospective (6 weeks); 65 dialysis (i.e., home, in-centre, and CAPD) and 33 transplant patients	Examine perceived illness intrusiveness & the effects of select factors	IIRS ($\alpha = .81$ to 85, $r = .79$ over 6 wks), uremic symptom checklist, POMS (Fatigue-Inertia subscale), & researcher-developed items for ADL
Sacks et al. (1990)	Descriptive-correlational; 43 HD patients	Examine levels of illness intrusiveness, illness severity, & interrelationships among variables	IEQ ($\alpha = .93$ & stable, $r = .99$) & ESRD severity coefficient
Christensen et al. (1992)	Descriptive-correlational; 78 HD patients	Examine physical functioning	SIP ($\alpha = .74$)
Tell et al. (1995)	Descriptive-correlational; 256 African-American and White HD patients	Investigate physical functioning	KS (objective & subjective) & one item measuring leisure time restrictions
Killingworth & Van Den Akker (1996)	Descriptive-correlational; 48 HD patients	Examine frequency & severity of physical stressors, & levels of physical functioning	LUSS ($\alpha = .93$ & stable, $r = .99$), & ESRF-ADL

Kimmel et al. (1996)	Descriptive-correlational; samples of 99 incident (HD for $\leq$ 6 mos) and 149 prevalent (HD $\geq$ 6 mos) patients	Examine levels of illness intrusiveness, illness severity, physical functioning; & relationships among variables	IEQ, ESRD Severity Coefficient, & KS
Lok (1996)	Descriptive-correlational; 56 HD patients	Examine frequency & severity of stressors	HSS (α = .79)
Cormier-Daigle & Stewart (1997)	Descriptive-correlational; 30 male HD patients	Describe illness- & treatment-related situations	Interview schedule
Klang & Clyne (1997)	Prospective (predialysis, 3 & 6 mos. post-dialysis); 28 uremic patients	Examine health perceptions, uremic symptoms & physical functioning levels	Checklist of physical symptoms, HI (α = .72 to .76), & SIP
Kimmel et al. (1998)	Prospective (baseline, 6 & 12 mos); 295 HD patients	Monitor changes in levels of illness intrusiveness, illness severity; & relationships among variables	IEQ, ESRD Severity Coefficient, & KS
Lev & Owen (1998)	Prospective (baseline, 4 & 8 mos); samples of uremic patients (n = 64,36, & 28)	Monitor changes in somatic symptoms, functional status, illness severity, & self-care self-efficacy	SSDS (α = .73 to .82), SIP (α = .25 to .86), ESRD-SI (α = .51 to .61), & SUPPH (α = .67 to .96)
Welch & Austin (1999)	Prospective (3 mos); 86 HD patients	Monitor changes in frequency & severity of stressors	HSS

Kimmel et al. (2000)	Descriptive-correlational; 174 HD patients	Examine gender differences on levels of illness intrusiveness & illness severity	IEQ & ESRD severity coefficient
Kovac et al. (2002)	Descriptive-correlational; 79 HD patients	Examine levels of illness severity, physical functioning; & relationships among variables	KS & ESRD severity coefficient
Patel et al. (2002)	Descriptive-correlational; 53 HD patients	Examine levels of illness intrusiveness, illness severity, physical functioning, & relationships among variables	IEQ, KS & ESRD severity coefficient

[1] Limited information is provided on the psychometrics of most instruments, especially in the studies reviewed.

The findings from cross-sectional studies indicated that most participants experienced low (Bihl et al., 1988; Fuchs & Schreiber, 1988; Gurklis & Menke, 1988; Parfrey et al., 1988) to moderate (Baldree et al., 1982; Gurklis & Menke, 1995; Killingworth & Van Den Akker, 1996) stressor levels. While some researchers failed to document a significant difference between stressor types (Baldree et al.; Bihl et al.), Gurklis and Menke (1988) and Lok (1996) found that physiological stressors were significantly more troublesome than psychosocial ones.

A few prospective, longitudinal studies also evidenced low stressor levels at variant time intervals (3 months to 1 year) between measurements (Klang & Clyne, 1997; Lev & Owen, 1998; Parfrey et al., 1989; Welch & Austin, 1999). Conflicting findings were reported on the stability of stressor frequency over time. Specifically, Klang and Clyne reported no significant change, while Parfrey et al. documented a slight but significant increase in physical symptoms only. In contrast, Lev and Owen and Welch and Austin reported a slight declining trend in stressor levels.

As well, a few authors found support for a moderately strong correlation between the two stressor types (Barrett, Vavasour, Major, & Parfrey, 1990; Gurklis & Menke, 1988; Lok, 1996). A number of studies also reported on the rankings of various stressors. Although the rank ordering varied across studies, the most common stressors were fatigue and general tiredness, fluid and physical activity limitations, muscle cramps, and hypotensive episodes (Baldree et al., 1982; Bihl et al., 1988; Fuchs & Schreiber, 1988; Gurklis & Menke, 1988, 1995; Killingworth & Van Den Akker, 1996; Klang & Clyne, 1997; Lev & Owen, 1998; Lok; Parfrey et al., 1988; Welch & Austin, 1999).

Several researchers have investigated differences in stressor levels of hemodialysis patients based on key personal characteristics (i.e., demographic and medical risk factors). For the most part, these factors were found to exert minimal or no effect on stressors. The most frequently investigated factors were length of time on dialysis, age, education, marital status, and gender. Most researchers failed to find a significant effect for time on dialysis (Baldree et al., 1982; Bihl et al., 1988; Fuchs & Schreiber, 1988; Gurklis & Menke 1988; Klang & Clyne, 1997; Parfrey et al. 1989), age (Baldree et al.; Klang & Clyne), education (Baldree et al.), and marital status and gender (Baldree et al.; Welch & Austin, 1999). While Lok (1996) found that stressor severity increased with length of time on dialysis, Welch and Austin found the opposite (i.e., decreased over time). As well, Welch and Austin reported that participants who were older and more educated experienced more stressors than their younger and less educated counterparts.

A few of the preceding studies that used the HSS to assess stressor severity also included open-ended questions to elicit information on additional stressors (Baldree et al., 1982; Gurklis & Menke, 1988; Welch & Austin, 1999).

Without exception, participants identified stressors not included in the HSS. In the Baldree et al. study, participants identified 13 additional stressors (e.g., staff attitudes, inexperienced staff, body temperature and blood pressure changes, noise levels in unit, etc.) which were mostly individual specific. Gurklis and Menke questioned the content validity of the HSS, with participants identifying an additional 30 treatment-related stressors (e.g., hypotension, unwell feeling after dialysis, clotting of the fistula, etc.). Additional stressors (e.g., lifestyle changes/modifications, management of multiple diets, fear of infection, clotting of access site, limited expertise of new staff, etc.) were also identified by participants in the Welch and Austin study, reinforcing Gurklis and Menke's concerns about the content validity of HSS.

Qualitative studies designed to investigate the life and experiences of patients with ESRD have also highlighted illness- and treatment-related stressors. While many of these stressors, especially physiological ones, have been incorporated into self-report disease-specific scales, the low to moderate ratings observed across quantitative studies reinforce individual variations in the frequency and intensity of specific stressors over time. The following discussion reviews relevant qualitative study findings.

Gurklis and Menke (1995) used audio taped structured interviews to investigate hemodialysis patients (N = 129) perceptions of stressors. During data analysis, 62 stressors were identified and subsequently categorized as physiological or psychosocial, concerns about starting hemodialysis, restrictions of living with a chronic illness, and kidney transplant concerns. Approximately 54% of the participants experienced one or more physiological stressor. The most frequently reported physiological stressors included fatigue, hypotension, not feeling well after dialysis, cramps, nausea and vomiting, decreased mobility, and bone pain. Psychosocial stressors identified most frequently included compromised social life, length of dialysis treatment, time spent traveling to and from treatment site, costs, work interference, hospital admissions, and food and fluid restrictions.

In the Cormier-Daigle and Stewart (1997) study, the most frequent illness-related stressors included weakness, fatigue, sleep disturbances, and fluid restrictions. Treatment-related stressors included travel difficulties, time management problems, and fears related to surgery and problems with fistula access.

In a grounded theory study, Gregory et al. (1998) used semi-structured interviews to explore patients' (*N* = 36) experiences with and perceptions of ESRD and hemodialysis treatment. The meanings of illness and treatment category was shaped by the unpredictable effects of treatment-related events, variable illness states, and time on dialysis. Although there were notable variations in the frequency and type of stressors for each individual, a few commonalities were noted. The most frequent stressors were fatigue, general weakness, hypotension, muscle cramps, pain and discomfort with needling of access site, decrease in social life, cost factors (e.g., medications, travel to treatment site, etc.), future uncertainty, and food and fluid restrictions.

Using the interview data obtained from 22 dialysis patients, White and Grenyer (1999) used the Husserlian phenomenological approach to explore the biopsychosocial impact of ESRD and treatment regimes. Many of the participants identified problems with fatigue and length of treatment, and were anxious about the uncertainty of their health and the future. A second theme focused on negative emotions (i.e., anger, denial, depression, and fantasy ideation) in response to dialysis requirements.

Faber (2000) used a phenomenological approach to gain an integrated understanding of how individuals (*N* = 4) live with ESRD and hemodialysis treatment. Frequently identified stressors by study participants included fatigue, itching, arterial and venous needling, fluid and food restrictions, physical activity limitations, length of treatment, limit on time and place for vacation, decrease in social life, cost factors, transportation for treatment, and sleep disturbances.

Knowledge and self-care practices. Only one quantitative study was identified from the hemodialysis literature that specifically addressed the use of self-care practices. Lev and Owen (1998) examined time-related changes in the self-care self-efficacy of individuals receiving hemodialysis and its relationship to physical and psychosocial factors. The Strategies Used by Patients to Promote

Health (SUPPH) assessed confidence in implementing self-care measures. Most participants reported moderate confidence in using self-care behaviors to improve coping, reduce stress, and improve decision-making and enjoyment of life. There was also evidence of greater confidence in most domains, with the exception of decision-making, at 7-months than at either baseline or 11-months. Confidence in using self-care behaviors depicted inconsistent associations with physical and psychosocial factors over time, and was not influenced by demographic (i.e., age, gender, marital status, ethnicity, education level, or job type) or medical risk factors (i.e., medications with dosages, days hospitalized, and reasons for hospitalizations) factors.

Several qualitative studies were identified from the literature that investigated the knowledge levels and self-care practices of individuals with ESRD and receiving hemodialysis. The findings from these studies are summarized below.

Jones and Preuett (1986) examined the self-care processes of employed hemodialysis patients (*N* = 25) to deal with the treatment stressors. Qualitative analysis of semi-structured interview data revealed four patterns of self-care (i.e., equalizing, substituting, withdrawing, and guarding). The equalizing process involved making decisions (i.e., weighing, juggling, and shifting) about conflicting demands (i.e., time, energy, finances, desires, and requirements). The substituting process involved searching for suitable alternatives through trial and error (i.e., deal with thirst by trying a variety of beverages until a suitable one was found). The withdrawing process captured participant's ability to choose appropriate measures to avoid increasing stress levels (i.e., not talking about the illness, trying not to dwell on negatives, and restricting activities to conserve energy). Finally, the guarding process captured active participation in monitoring changing health states, treatment effects, and the care administered by health care providers.

Kutner (1987) examined the role played by illness and treatment knowledge in dealing with uncertainties and adjusting to a new normal. The data were collected from semi-structured interviews with 159 individuals, most of whom were receiving hemodialysis. Seeking information about and developing an understanding of short- and long- term physiological changes were seen as important in managing future uncertainties and promoting adjusting to a new normal.

Gurklis and Menke (1995) reported on the information seeking behaviors, activities of daily living, and involvement in health management of hemodialysis patients. The qualitative comments were indicative of active patient involvement in monitoring health and treatment, seeking information and support, coming to know and understand the effects of hemodialysis on the body, and following prescribed treatment plans within personal limitations. As well, study participants were actively involved in a number of self-care activities (e.g., exercising, socializing, housework, etc.).

Gregory et al. (1998) examined how hemodialysis patients implement measures to facilitate understanding and adjustment to illness and treatment stressors. The meanings of illness and treatment category conveyed a heavy reliance on cognitive appraisal techniques. Participants stressed the importance of knowing treatment protocols, developing awareness of treatment effects, and monitoring the activities of health care providers, as well as treatment effects during dialysis. Fianlly, there was a clear struggle between knowing what should be done (i.e., following recommended treatment protocols) and the willingness to accept lifestyle restrictions (i.e., food, fluid, and physical activity limitations).

Using a hermeneutics design, Nagle (1998) examined individuals experiences with hemodialysis (*N* = 11). Participants' experiences with having to rely on technology for survival was captured in three major themes: coming to terms with loss and limitations, abiding with technology, and enduring the treatment environment. All of the themes addressed the importance of knowing about the illness and treatment, participating in routine activities of daily living, and becoming actively involved in managing ones own health. Specifically, developing an increasing awareness of declining physical abilities, coming to know and understand the technical aspects of dialysis, continuous monitoring of illness and treatment effects, being vigilant of health care provider's activities, and having the necessary information and opportunities to participate in decision-making were highlighted as important precursors to acceptance of and adjustment to the illness and treatment.

Functional levels and illness severity. While several studies have examined individuals' perceptions of stressors as defining components of illness and treatment experiences, fewer studies have focused on functional limitations and illness severity in this manner. Functional status has been used vicariously as an indicator of physical health status and quality of life. Comparatively, illness severity has been solely used as an indicator of physical health status. In addition, both subjective and objective measures of functional status have been used with the hemodialysis population. In contrast, only objective ratings were used to assess illness severity in the literature reviewed.

The disease-specific End Stage Renal Function Activities of Daily Living Scale (ESRF - ADL) and a researcher-developed scale by Devins et al. (1990), as well as the standardized Sickness Impact Profile (SIP), are examples of subjective measures used to assess functional limitations in terms of everyday activities (e.g., mobility, domestic tasks, self-care, social activities, etc.). The Karnofsky scale (KS) provides subjective and objective ratings of physical functioning (i.e., ability to perform normal activities of daily living). The SIP and KS have been used extensively with the hemodialysis population and are reported to have strong reliability and validity (Edgell et al., 1996). The ESRF - ADL is reported to have fairly strong internal consistency, as well as concurrent validity with the SIP (Julius et al., 1989). Comparatively, standardized measures have been used to assess illness severity within this population. The most frequently used measures in the studies reviewed were the ESRD severity coefficient (i.e., age *x* risk of additional medical illnesses) and the End-Stage Renal Disease Severity Index (ESRD-SI) which is a composite of risk scores for common illness and disease conditions for patients with ESRD, as well as select personal characteristics (i.e., demographics and medical risk factors) (see Table 1).

Cross-sectional study findings have repeatedly documented minor impairments in physical functioning (Christensen et al., 1992; Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Kovac et al., 2002; Patel et al., 2002; Tell et al., 1995) and low levels of illness severity (Kimmel et al., 1996; Kimmel et al., 2000; Kovac et al.; Sacks et al., 1990) in the hemodialysis population. Only Kimmel et al. (1996) reported on the relationship between functional status and illness severity (i.e. higher levels of illness severity with lower levels of physical functioning). As well, only a few studies examined correlates of functional and severity status. The most frequently investigated personal characteristics were length of time on dialysis, age, gender, and race. While researchers failed to find a significant effect for time on dialysis (Christensen et al.; Kimmel et al., 1996; Sacks et al.), older individuals were found to have greater impairments in physical functioning (Kimmel et al., 1996; Patel et al.; Tell et al.) and greater illness severity (Kimmel et al., 1996; Sacks et al.) than their younger counterparts. In contrast, while Kimmel et al. (2000) reported that women had significantly lower levels of illness severity than the men, other researchers failed to document such an effect for illness severity (Sacks et al.) or physical functioning (Christensen et al.; Patel et al.; Tell et al.). Finally, while Tell et al. found that Caucasians had lower physical functioning and greater restrictions with leisure time activities than African-Americans, these authors failed to find a significant effect for education, employment status, or marital status.

Few studies were identified that examined variations in functional status and illness severity over time. While Kimmel et al. (1998) and Klang and Clyne (1997) reported that functional disabilities and illness severity were in the low range and remained relatively stable, Lev and Owen (1998) documented slight improvements in functional areas but inconsistencies in illness severity (i.e., increase followed by a decrease). Limited attention was given to the effects of personal characteristics in these studies. While Kimmel et al. found that older participants were significantly more likely to have greater illness severity than younger ones, Klang and Clyne failed to document a significant effect for age on functional status.

Perception of illness effects. Subjective perceptions of lifestyle disruptions are believed to be greatly influenced by the frequency and severity of physical and psychosocial stressors due to the illness or treatment. It is also conjectured that functional disabilities and illness severity exert an important influence on perceived intrusiveness. The literature review revealed a few studies that investigated perceptions of the intrusive effects of ESRD and treatment, and how these perceptions were affected by stressors, functional limitations, and illness severity.

Self-report scales have been developed to assess illness intrusiveness in the hemodialysis population. Generally, respondents are asked to rate perceived negative illness effects on a Likert-type scale. The most frequently used scale was the Illness Effects Questionnaire (IEQ) which is comprised of items dealing with perceptions of illness interference with personal and social behaviors, physical functioning, family and personal life, and fears about illness consequences. One disease-specific measure of intrusiveness was identified, the Illness Intrusiveness Ratings Scale (IIRS), which assessed the intrusiveness of ESRD in five life domains (i.e., physical well-being and diet, work and finances, marital and family relations, recreation and social relations, and other activities, including self expression, religious expression, and community and civic activities). The IEQ and IIRS have had extensive reliability and validity testing, with study findings demonstrating excellent internal consistency and stability, as well as construct validity (Wise, Mann, Jani, Kozachuk & Jani, 1994; Devins et al., 2001; respectively).

Devins et al. (1990) found that the illness and treatment were perceived to have low to moderate intrusive effects in all life domains. Although the various dialysis groups did not differ significantly from each other, the transplant group had significantly lower levels of perceived intrusiveness than each group. These group differences were primarily attributed to negative effects in the physical well-being and diet and work and finances domains, followed by recreation and social relations, marital and family relations, and other activities, respectively. In addition, the burden of illness intrusiveness across the life domains and modes of treatment (i.e., hemodialysis, CAPD, and transplant) did not vary between baseline and follow-up. Finally, greater illness intrusiveness (i.e., total perceived intrusiveness and the intrusiveness of each life domain) was significantly correlated with greater uremic symptoms, greater fatigue, greater difficulties in performing daily activities, and more treatment time requirements.

In studies using the IEQ, most participants rated their illness as slightly intrusive (Kimmel et al., 1996; Kimmel et al.,1998; Kimmel et al., 2000; Patel et al., 2002; Sacks et al., 1990). Inconsistent findings were reported on the association between illness intrusiveness and illness severity or functional status. For the most part, illness intrusiveness failed to correlate with illness severity (Kimmel et al., 1996; Kimmel et al., 1998; Sacks et al.). The exception was the significant association found between greater illness intrusiveness and greater illness severity for women but not men in the Kimmel et al. (2000) study. While Patel et al. found that greater illness intrusiveness was significantly correlated with greater impairments in physical functioning, Kimmel et al. (1996) failed to document a significant relationship. Finally, neither age (Kimmel et al., 1998; Patel et al.), gender (Patel et al.; Sacks et al.), nor length of time on dialysis (Kimmel et al., 1998; Sacks et al.) were found to affect illness intrusiveness.

Summary. Numerous studies have examined the illness and treatment experiences of individuals with ESRD and on hemodialysis. Predominantly low to moderate ratings were documented for physical and psychosocial stressors, functional limitations, illness intrusiveness, and illness severity. As well, high value was placed on being informed about the illness and treatment and involved in self-care practices.

Few studies assessed the relationships among variables. There is some evidence suggesting that physical and psychosocial stressors are correlated, as well as illness severity and physical functioning levels. Although greater levels of perceived intrusiveness significantly correlated with a greater frequency of physical stressors, it has not been consistently correlated with either illness severity or physical functioning levels. As expected, personal characteristics had minimal effects on stressor severity, functional levels, illness severity, and illness perceptions. In fact, there were notable inconsistencies across studies for length of time on dialysis, age, gender, and education level.

Low ratings of physical and psychosocial stressors, functional limitations, illness intrusiveness, and illness severity may be attributed, in part, to the cross-sectional designs and small samples comprised of relatively stable patients. While the longitudinal study findings were similar to those from cross-sectional studies, they also relied on populations of stable patients and, more importantly, used a short-term follow-up period. More research is needed to develop a clearer understanding of how these parameters change in response to critical illness and treatment events, the interrelationships among the factors comprising illness and treatment experiences, and the mediating role of personal characteristics.

Social Supports

The illness and treatment experiences of individuals with ESRD are continuously being redefined in response to others (i.e., spouse, family, friends, fellow patients, and health care providers). Family members have been consistently identified as the most important sources of support. There is also some suggestion that social support has a positive impact on how individuals view various aspects of the illness and treatment experience. The studies highlighted in this section address how formal and informal support systems are perceived by individuals with ESRD and on dialysis, as well as their influence on individual' perceptions of illness and treatment experiences.

The multidimensional nature of social support has stimulated the development of similar and variant operational measures. While some scales address only structural (i.e., network size and frequency of contact) or functional (i.e., emotional, informational, tangible, and affirmation) aspects, other scales incorporate both components. Generally, respondents are asked to identify the number of network members and frequency of contact with them, and use a Likert-type scale to rate items addressing types of support.

Self-report scales used with the hemodialysis population may be grouped according to their primary focus (i.e., informal network members only, health care providers only, or both informal and formal network members). In the studies reviewed, several standardized scales were used which assessed only informal supports, including the Family Relationships Index of the Family Environment Scale (FES), Lubben Social Network Scale (LSNS), the Interpersonal Support Evaluation List (ISEL), and the Dyadic Adjustment Scale (DAS). In contrast, the Satisfaction With Care Questionnaire (SCQ) and the Patient Satisfaction Questionnaire (PSQ) were restricted to an assessment of formal supports. Several scales were also used to assess overall supports, including Interpersonal Relationship Inventory (IPRI), Multidimensional Scale of Perceived Social Support (MSPSS), and a researcher developed measure. The FES, LSNS, ISEL, DAS, SCQ, PSQ, IPRI, and MSPSS have demonstrated strong validity and reliability (Moos & Moos, 1986; Lubben, 1988; Cohen, Mermelstein, Karmack, & Hoberman, 1985; Spanier, 1976; Ferrans et al., 1987; Dimatteo & Hays, 1980; Tilden, Nelson, & May, 1990; Zimet, Dahlem, & Zimet, 1988;

respectively). The purpose and key methodological aspects of studies using these scales with hemodialysis patients are summarized in Table 2.

In general, study participants gave high ratings to the support received from informal network members, especially family (Christensen et al., 1992; Cormier-Daigle & Stewart, 1997; Siegal et al., 1987; Tell et al., 1995). Kimmel et al. (1996) and Kimmel et al. (2000) also documented high levels of satisfaction with marital or partner relationships. Kimmel et al. (2000) and Cormier-Daigle and Stewart found support for a moderate level of conflict in family relationships, similar to levels derived from normative samples.

Several researchers also examined hemodialysis patients' perceptions of health care providers. For the most part, providers were perceived to be very helpful (Cormier-Daigle & Stewart, 1997; Ferrans et al., 1987; Kovac et al., 2002; Siegal et al., 1987). Although not addressed in most studies, individuals seem to be more satisfied with the support received from physicians than other dialysis staff (Ferrans et al.; Kovac et al.).

As well, most study participants were quite satisfied with their overall social supports, with levels approximating those from healthy populations (Cormier-Daigle & Stewart, 1997; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al. 2000; Kovac et al., 2002; Patel et al., 2002). With regard to time-related changes, Kimmel et al. (1998) found that overall perceived social support

Table 2

Summary of Health Care Studies Dealing with Social Supports[1]

Study	**Design & Sample**	**Purpose**	**Instruments & Psychometrics**
Ferrans et al. (1987)	Descriptive-correlational; 416 HD patients	Examine level of satisfaction with health care	SCQ (α = .94, content valid, & criterion related validity, r = .78)
Siegal et al. (1987)	Descriptive-correlational; 101 HD patients	Investigate the support base & the helpfulness of supports	Researcher-developed scale
Christensen et al. (1992)	Descriptive-correlational; 78 HD patients	Examine perceived supportiveness of family environment	FES (α = .87)
Tell et al. (1995)	Descriptive-correlational; 256 African-American and White dialysis patients	Examine perceived & actual social support, & their associations with physical functioning	ISEL& LSNS
Kimmel et al. (1996)	Descriptive-correlational; samples of 99 incident (HD for ≤ 6 mos) and 149 prevalent (HD ≥ 6 mos) patients	Examine levels of supports & dyadic satisfaction	MSPSS & DAS
Cormier-Daigle & Stewart (1997)	Descriptive-correlational; male HD patients	Describe social networks	IPRI (α = .73 to .82)

Kimmel et al. (1998)	Prospective (baseline, 6 & 12 mos); 295 HD patients	Monitor changes in supports satisfaction	MSPSS
Kimmel et al. (2000)	Descriptive-correlational; 174 HD patients	Examine gender differences in supports, & dyadic adjustment	MSPSS & DAS
Kovac et al. (2002)	Descriptive-correlational; 79 HD patients	Investigate support levels & satisfaction with physicians & staff	MSPSS & PSQ (α = .82 to .94, test-retest r = .63)
Patel et al. (2002)	Descriptive-correlational; 53 HD patients	Examine levels of depression, supports, satisfaction with physicians & staff, religious involvement, spirituality; & relationships among variables	MSPSS & PSQ

[1] Limited information is provided on the psychometrics of most instruments, especially in the studies reviewed.

remained relatively stable over a 12 month period. Finally, despite the variations in support rankings in the studies reviewed, participants identified the family as the most important source (Cormier-Daigle & Stewart; Siegal et al., 1987).

Qualitative studies investigating individuals' experiences with ESRD and hemodialysis also highlighted the importance attached to informal and formal support systems. Without exception, the family was identified as the most helpful support source. These studies also provide meaningful insight into the specifics of the dual role of supports (i.e., helpful but also a source of strain). The following discussion reviews relevant qualitative study findings.

Kutner (1987) examined the importance of different social worlds for the dialysis population. Many study participants identified their families as the primary source of support. While family members provided encouragement and understanding and helped facilitate adherence to treatment regimes, friends were seen as less supportive due to reduced social contact. With reduced participation in the workforce and a reluctance to discuss the illness because of wanting to appear normal, co-workers were relied on less frequently for support. On the positive side, the dialysis social world emerged as an important source of support (i.e., dialysis peers and health care providers were sources of social, emotional, and informational support). Dialysis peers reassured individuals that they could cope with their unique situation and survive, gave invaluable knowledge about the illness and treatment, and provided socializing opportunities. Dialysis peers were often seen as more important supports than health care providers (i.e. physician, nurse, social worker, dietician, and dialysis technicians). Finally, participants emphasized the important role of health care providers in providing emotional support, being attentive to care needs, and addressing the "whole" person.

Gurklis and Menke (1995) examined hemodialysis patients' perceptions of different sources of support. Most participants (90%) identified one or more immediate family members, with spouses or significant others and adult children the most frequent sources. Additional sources of support, in order of frequency, included extended family members, dialysis nurses and technicians, friends and neighbors, the self, home health service providers, physicians, social workers, God and church members, and dieticians. Informal and formal social network members provided variant types of support. Family and friends provided tangible assistance (i.e., home management, health care, transportation, and financial), emotional support, and companionship. Health care providers helped with problem-solving, and were sources of health care, information, and emotional support. Home health care service providers assisted with home management, transportation, personal care, and health care. With regard to support ratings, most participants (89%) felt positive about the support received from relatives and friends, while only 38% felt this way about the dialysis staff. Overall, 31% of participants felt that they were still alive because of the supportiveness of friends, health care providers, and home health care services, especially during serious illness episodes.

Gregory et al. (1998) examined how individuals receiving hemodialysis experienced informal and formal support systems. High value was placed on the support of family and friends, especially for emotional support and assistance with managing treatment regimens. At times family and friends were seen as promoting greater than desired dependence. With increased awareness of the impact of the illness and treatment requirements on others (i.e., spouse, family, and friends), participants felt the need to protect them from the burden of care. Participants also spoke about the benefits derived from the family-like atmosphere present on the dialysis unit, and the provision of emotional and informational support by fellow patients and their families. On the downside, watching others suffer and/or experiencing the death of fellow patients were viewed as negative consequences of developing close relationships. Finally, participants were generally satisfied with the quality of health care received and gave high ratings to nurses' and physicians' technical and interpersonal competencies. Dialysis nurses were more likely to be recognized for treating participants in a humanistic manner (i.e., caring, valuing, and acceptance as persons) than physicians or other members of the health care team (i.e., dieticians and social workers).

White and Grenyer's (1999) study also revealed themes about partner relationships. While many positive comments were made about the caring and supportive nature of relationships, the downside was the growing sense of indebtedness (i.e., increased awareness that the illness and treatment imposed extra demands).

Weil (2000) used audiotape interviews to identify the sources of hope in patients with ESRD receiving chronic hemodialysis (*N* = 14). The most frequent source of hope was the family. Additional sources of hope included friends, spirituality, technology, control (i.e., freedom to decide when to quit dialysis, being informed, and participation in decision-making), and dialysis staff.

There is some evidence linking social support and satisfaction with marital or partner relationships to perceptions of illness intrusiveness. Kimmel et al. (1996) found that greater perceived support and satisfaction with marital or partner relationships depicted low, but significant, correlations with lower illness intrusiveness. However, the presence of a stable dyadic relationship was not significantly correlated with illness intrusiveness. In addition, Kimmel et al. (2000) found gender differences in how marital or partner satisfaction, but not social support, was related to illness intrusiveness. Specifically, greater marital or partner satisfaction was moderately associated with less perceived illness intrusiveness, while greater marital or partner conflict was moderately associated with greater illness intrusiveness for the women but not the men.

The interactive effects of supports and the quality of relationships with functional limitations and illness severity are less clear. Tell et al. (1995) documented low, significant associations between greater perceived social support and better physical functioning and less leisure time restrictions. In the Kimmel et al. (1996) study, perceptions of supports, presence of a stable dyadic relationship, and satisfaction with marital or partner relationships did not significantly correlate with illness severity or physical functioning. Similarly, in the Kimmel et al. (2000) study, illness severity was not found to significantly associate with perceived support and marital or partner satisfaction regardless of gender status. Finally, Kovac et al. (2002) failed to find a significant association between satisfaction with physicians and staff and illness severity and physical functioning.

Only a few studies were identified from the literature that examined the effects of personal characteristics on individuals' perceptions of supports. The most frequently investigated characteristics were length of time on dialysis, age, education, marital status, and gender. While Christensen et al. (1992) and Tell et al. (1995) failed to find a significant effect for any personal characteristic on family supports, Ferrans et al. (1987) did find that lower education and less time on dialysis were predictive of greater satisfaction with health care. As well, Kimmel et al. (2000) found that female participants did not differ significantly from the men on perceived levels of social support, overall satisfaction with marital or partner relationships, or level of dyadic positivity. However, the women did report significantly higher levels of conflict in dyadic relationships.

Summary. Qualitative and quantitative study findings reinforce the importance of a supportive environment for individuals receiving dialysis. In general, the support received from informal network members was given high ratings, with families emerging as the most important source. Although the degree of satisfaction with formal supports varied across studies, most participants identified health care providers as important and helpful sources of informational, tangible, and emotional support.

Few studies were identified from the literature that examined the effects of perceived social support, satisfaction with marital or partner relationships, and satisfaction with physicians and dialysis staff on functional limitations, illness severity, or perceived illness intrusiveness. The studies by Kimmel and colleagues provide some evidence for the positive impact of overall supports and quality relationships on perceptions of illness intrusiveness. However, satisfaction with physicians and dialysis staff failed to correlate with illness intrusiveness. As well, perceived social supports, marital or partner satisfaction, and satisfaction with physicians and dialysis staff failed to correlate with illness severity or functioning levels.

It has also been conjectured that interaction between social supports and illness and treatment experiences influence how well individuals adjust to a new normal and, ultimately, attain an acceptable quality of life. The moderating effect of supports on the stress of the illness and its intrusiveness is crucial to understanding how to improve psychosocial adjustment and overall quality of life for individuals requiring long-term hemodialysis.

Adjustment to a New Normal

Illness and treatment experiences evolve over time in response to changing circumstances and can only be understood in terms of how the person adapts to a new normal as an extension of the old self. There is some evidence linking reduced emotional well-being and greater psychosocial distress with increased stressor severity, lower knowledge levels, limited self-care, greater functional limitations and illness severity, and enhanced perceptions of illness intrusiveness. Importantly, changes within the self also influence and are influenced by the availability and quality of social supports. The ability to maintain definite roles (and hence identity) within the family, to interact with friends, and participate in work situations is challenged by a chronic illness like ESRD. Nevertheless, the supportiveness of family and friends has been identified as an integral force in illness acceptance and overall adjustment.

The following review highlights study findings on adjustment to ESRD and a long-term treatment regime. The discussion in the first section is focused on how individuals forge new identities as they struggle with multiple losses. In the second section, the discussion examines how individuals cope with the challenges of illness and treatment experiences. In the final section, the review considers study findings on psychosocial distress and overall well-being. The purpose and key methodological aspects of quantitative studies conducted with hemodialysis patients are summarized in Table 3.

Forging new identities. When confronted with a chronic illness that requires long-term dependence on technology and health care, individuals struggle to make sense of what is happening to their physical selves and the resulting implications for their self-concept. Several authors have provided insight into how individuals transcend the old self and forge new identities while learning to manage positive and negative illness and treatment effects. Study findings suggest that a number of similar and disparate factors help individuals with ESRD adjust to a new sense of normal.

In a qualitative, longitudinal study, O'Brien (1983) examined the emotional reactions of ESRD patients (N = 126) to illness and treatment regimes. The findings indicated that self-perceptions fall along a sickness to wellness continuum, with three identifiable modes (i.e., sickness, chronic illness, and wellness). Select attitudinal and behavioral states separate one mode from the other. The sickness mode is characterized by dependency, anxiety, and withdrawal, among others. In contrast, the chronic illness mode is characterized by acceptance, trust, and social interaction with family and friends. Finally, the wellness mode is dominated by independence, control, and involvement in work or career. While some patients move back and forth between the various modes in response to changing health status (i.e., positive or negative physical and psychological events), others never move beyond the sickness mode. O'Brien noted that the chronic nature of the illness and treatment makes it more difficult for patients to maintain the wellness perspective over time in the face of prolonged uncertainty about the future and social isolation.

Applying a Heideggerian phenomenological approach to the interview transcripts of six dialysis patients, Rittman et al. (1993) examined how individuals' experienced living with chronic renal failure. Taking on a new understanding of being, maintaining hope, and dwelling in dialysis emerged as the dominant themes. The new sense of being evolved as individuals accepted illness- and treatment-related stressors and major lifestyle interruptions as normal aspects of living. Maintaining hope for a better future was an integral force behind coping with daily living. Dwelling in dialysis reflected meaningful understanding of dependency on technology for survival, and ultimate adjustment to and acceptance of the situational context of the dialysis world. The unifying thread connecting the three themes was control: the meaning of technology (i.e., attempting to regain control while experiencing a distant or objectified relationship with the physical self and depending on technology and medicine for normal body functions).

Gregory et al. (1998) also reported on how individuals receiving hemodialysis experienced significant changes in the self over time. The evolving "new self" was seen as an interactive process contingent upon current levels of illness and treatment and the "remembered old self". Although dependence on a dialysis machine impaired confidence in the physical self, it became easier to accept illness and treatment requirements with notable improvements in health and physical functioning. Following a decline in health due to disease progression or treatment ineffectiveness, individuals experienced more difficulties in maintaining a positive attitude and a strong sense of normalcy. Adaptation to a "new normal" was defined in terms of the degree of frustration with treatment routines, changing health states, social restrictions, and alterations in roles and responsibilities at home and work. Maintaining control and testing the boundaries of treatment restrictions were important facilitators of acceptance.

Nagle (1998) explored the meaning of technology for individuals receiving hemodialysis. The essence of the experience was interpreted as a necessary but reluctant partnership with the dialysis machine for survival. The transformation experienced by participants was captured in three major themes (i.e., coming to terms with loss and limitations, abiding with technology, and enduring the treatment environment). Coming to terms was defined as accepting the reality of the loss and adjusting to a new sense of normal (i.e., accommodating illness and treatment restrictions and loss of "old self"). The struggle to maintain a sense of wholeness and normalcy led to a redefinition of personhood. Abiding with technology was described as developing an alliance with, while trying to dissociate the self from, dialysis treatment. As well, while partnering with technology, there was an increased awareness of body deterioration, a greater tendency to monitor body changes and health care providers' activities, and a growing uneasiness or uncertainty about survival while struggling to maintain hope for alternate treatments. The final theme, enduring the treatment environment, reflected a desire for health care providers to involve them in decision making (i.e., information about health status and treatment plans, and wishes listened to and incorporated into plans of care). This theme also dealt with participants desire to be seen as different from fellow dialysis patients, while acknowledging the benefits of giving and receiving support and the importance of a conducive environment (i.e., physical, social, and cultural) for facilitating treatment acceptance.

Faber (2000) explored how individuals come to know, understand, and accept the new self. The findings revealed that these individuals confront enormous challenges daily while trying to maintain a semblance of a normal life. The process of identifying the self "as a patient" was problematic because participants did not consider themselves unhealthy. Despite disliking various aspects of their illness and treatment, participants were able to adapt for the most part. As well, there were indications of negative views of the dialysis environment (e..g, watching others become ill, cluttered and unkept physical space) and struggles to maintain control over their emotions. The use of new behaviors or practices to deal with daily stressors (i.e., reducing thirst by sucking on ice cubes) was seen as essential in facilitating adjustment. It was also very important to have flexible dialysis times to help support a normal life. Although aware of the importance of following illness and treatment regimens, there were times when participants chose to disregard fluid and diet restrictions, as a way of maintaining some control over, rather than being controlled by, the illness.

Coping resources. As individuals struggle to forge new identities, adjustments are required in the emotional, psychological, physical, and social realms. An important initial step in coming to terms with the illness is accepting the uncertainties inherent in living with ESRD and hemodialysis, maintaining a positive attitude, and achieving a sense of personal control. The availability and use of appropriate coping resources for dealing with illness and treatment stressors have far-reaching implications for overall psychosocial distress and emotional well-being. A few studies were identified from the literature that investigated the use of problem-oriented (i.e., directed toward problem solving or handling stressful situations) and emotional-oriented (i.e., directed toward managing the emotions associated with stressful situations) coping strategies to buffer the impact of illness and treatment stressors and facilitate adjustment (see Table 3).

Table 3

Summary of Health Care Studies Dealing with Adjustment to A New Normal[1]

Study	**Design & Sample**	**Purpose**	**Instruments & Psychometrics**
Baldree et al. (1982)	Descriptive-correlational; 35 HD patients	Examine coping methods & their effects on stressor severity	JCS (content valid & stable, r = .71 over 2-wks)
Siegal et al. (1987)	Descriptive-correlational; 101 HD patients	Investigate the effects of supports on adjustment	BSI
Gurklis & Menke (1988)	Descriptive-correlational; 68 HD patients	Examine coping methods & their effects on stressor severity	JCS (α = .86)
Sacks et al. (1990)	Descriptive-correlational; 43 HD patients	Examine levels of depression & role disruptions; & interrelationships among study variables	BDI, CDI, & SAS-SR
Kimmel et al. (1995)	Descriptive-correlational; 149 prevalent patients	Examine the effect of illness intrusiveness, support, & illness severity on adjustment	BDI, CDI, & PAIS
Killingworth & Van Den Akker (1996)	Descriptive-correlational; 48 HD patients	Examine depression/anxiety & adjustment levels; & relationships among variables	HADS & PAIS

Kimmel et al. (1996)	Descriptive-correlational; samples of 99 incident (HD for ≤ 6 mos) and 149 prevalent (HD ≥ 6 mos) patients	Examine levels of depression & dyadic adjustment	PAIS
Lok (1996)	Descriptive-correlational; 56 HD patients	Examine coping methods & their effects on stressor severity	JCS (α = .86)
Cormier-Daigle & Stewart (1997)	Descriptive-correlational; 30 male HD patients	Describe coping strategies	WOC (α = .32 to .76)
Devins et al. (1997)	Descriptive-correlational; 101 ESRD patients	Examine predictive effects of select factors on emotional distress & psychosocial well-being	SEI, MMPI-K, CES-D, SNI, ABS, LHR, researcher developed items on self-concept (semantic-differential technique)
Klang & Clyne (1997)	Prospective (predialysis, 3 & 6 mos. post-dialysis); 28 uremic patients	Monitor changes in distress levels	STAI
Kimmel et al. (1998)	Prospective (baseline, 6 & 12 mos); 295 HD patients	Monitor changes in levels of depression	BDI & CDI
Lev & Owen (1998)	Prospective (baseline, 4 & 8 mos); samples of uremic patients (n = 64, 36, 28)	Monitor changes in distress levels	POMS (α = .94 to .96) & DSS (α = .87 to .91)

Keogh & Feehally (1999)	Descriptive-correlational; 113 dialysis patients	Examine adjustment levels & the effects of personal characteristics	AIS
Kimmel et al. (2000)	Descriptive-correlational; 174 HD patients	Examine gender differences in with depression	BDI & CDI
Kovac et al. (2002)	Descriptive-correlational; 79 HD patients	Investigate depression levels	BDI & CDI
Patel et al. (2002)	Descriptive-correlational; 53 HD patients	Investigate depression levels	BDI & CDI
Walters et al. (2002)	Prospective (baseline data); 422 incident HD patients	Describe prevalence of depressive symptoms	DIS (3-items assessing presence of depressive symptoms)

[1] Limited information is provided on the psychometrics of most instruments, especially in the studies reviewed.

Generally, study subjects were asked to rate the frequency of using different coping strategies on a Likert-type scale. The Jalowiec Coping Scale (JCS) was the dominant self-report method. Additional measures included the Ways of Coping (WOC) questionnaire and a VAS scale (i.e., rating of coping effectiveness in dealing with illness-related difficulties from very bad to very well). Psychometric testing of the JCS and WOC have provided evidence for the reliability (stability and internal consistency) and validity (content and construct) of these instruments with hemodialysis and chronically ill populations, respectively (Jalowiec, 1990; Folkman & Lazarus, 1988).

In general, study findings indicated that most participants rarely to sometimes used coping strategies to solve problems or manage the emotions emanating from stressful situations (Baldree et al., 1982; Gurklis & Menke, 1988). As well, there was a significantly greater tendency to use problem-oriented over affective-oriented strategies by most study participants (Baldree et al.; Cormier-Daigle & Stewart, 1997; Gurklis & Menke; Lok, 1996). Although the rank ordering of different strategies varied across studies, optimism or hope, trying to maintain control, and distancing or taking an objective stance were the more common approaches (Baldree et al.; Cormier-Daigle & Stewart; Gurklis & Menke; Lok).

A few qualitative studies were also identified from the literature that investigated how individuals with ESRD and receiving hemodialysis treatment coped with illness-and treatment-related stressors. The findings by Kutner (1987), Gurklis and Menke (1995), and Weil (2000) are summarized below.

Kutner (1987) examined the interaction between the illness experience and the social worlds of individuals. Whether the loss of kidney function was sudden or insidious, uncertainty about the future and the many adjustments made it difficult to cope with the chronicity of the illness. Accepting the situation was not easy and many questioned whether or not they wanted to go on living. Managing the uncertainties associated with longevity, the effectiveness of the selected treatment modality, the potential adverse effects of dialysis, and the physiological erosion of body functions was a constant struggle. Family members were also a source of psychosocial distress. Participants articulated concerns about becoming too dependent, role reversal, and the burden assumed by significant others. Additional areas of concern included compromised sexual activities, resentment, over or under caring, fear of loss, communication barriers, and restrictions on travel, vacation, and social activities.

Gurklis and Menke (1995) investigated how hemodialysis patients coped with treatment-related stressors. Content analysis of the interview transcripts generated 48 coping methods which were collapsed into six major categories (i.e., accepting being on dialysis, maintaining control of health care, maintaining a positive outlook, staying active, self-mastery, and using support networks). The data defining the categories highlighted the importance of accepting the treatment, knowing the treatment regime and potential benefits and consequences, implementing recommended treatment plans while maintaining some personal control, maintaining a positive outlook and being as normal as possible (i.e., active in various life domains), being as independent as possible, and seeking support from others as needed. The researchers concluded that the coping strategies identified were very similar to those comprising the JCS.

Weil (2000) explored the meaning of hope for patients struggling to adapt to ESRD and chronic hemodialysis. The construct of hope was defined as seeing positives in the future (i.e., improved health, something to keep one going, and being able to do things one wants to do), anticipating a good quality of life (i.e., acceptance, perseverance, and avoidance of complications), and having strong spiritual beliefs. With regard to factors increasing hopefulness, participants highlighted diversional activities, socializing with family and friends, and feeling useful. In contrast, not feeling well, death of fellow patients, and the presence of co-morbidities decreased hopefulness.

A few studies also examined the association between coping strategies and stressor types. While Baldree et al. (1982) and Cormier-Daigle and Stewart (1997) failed to find a significant association between stressor type (physiological or psychosocial) and coping method, Gurklis and Menke (1988) found that greater use of problem-oriented strategies accompanied increases in both physiological and psychosocial stressors. Gurklis and Menke also found increased use of affective-oriented strategies in response to increased psychosocial stressors. Comparatively, Lok (1996) only documented a significant correlation between physiological stressors and problem-oriented coping. The study differences could be a function of the small sample sizes.

Only a few of the studies reviewed examined the effects of personal characteristics on different types of coping strategies. The most frequently investigated factors were length of time on dialysis, age, education, marital status, and gender. Baldree et al. (1982) failed to find a significant effect for any of these factors. While Gurklis and Menke (1988) found that participants on dialysis for longer periods of time were significantly more likely to use problem-oriented than affective-oriented strategies, Lok (1996) failed to document a significant difference. Similar to Baldree et al., Cormier-Daigle and Stewart (1997) did not find that type of coping style was a function of age or marital status.

Distress and well-being. Several studies were identified from the literature that examined the psychosocial distress and emotional well-being of ESRD and hemodialysis populations as indicators of adjustment. Distress and well-being are often viewed as opposite ends of a continuum, with greater distress indicative of less well-being. While some authors use psychosocial distress and emotional well-being labels to reflect mental health functioning, others prefer emotional distress and psychosocial well-being. The following discussion reviews study findings on both aspects of adjustment. For the most part, many of these studies also focused on the impact of diverse factors (i.e., physical symptoms, illness severity, physical functioning, perceived illness intrusiveness, quality of supports, marital adjustment, type of dialysis, age, and time of dialysis) on psychosocial distress and emotional well-being (see Table 3).

Several standardized measures have been used to assess the overall adjustment of individuals with ESRD and receiving hemodialysis in terms of psychosocial distress and emotional well-being. Global scales include the Brief Symptom Inventory (BSI), Beck Depression Inventory (BDI), Cognitive Depression Index (CDI), Diagnostic Interview Schedule (DIS), Social Adjustment Scale-Self Report (SAS-SR), Psychosocial Adjustment to Illness Scale (PAIS), Hospital Anxiety and Depression Scale (HADS), Center for Epidemiologic Studies Depression (CES-D), Profile of Mood States (POMS), State-Trait Anxiety Inventory (STAI), Self-Esteem Inventory (SEI), Affect Balance Scale, (ABS), Life Happiness Rating (LHR), and Acceptance of Illness Scale (AIS). The BSI, BDI, CDI, DIS, SAS-SR, PAIS, HADS, CES-D, POMS, and STAI have been subjected to extensive reliability and validity testing, and frequency used as clinical screening tools in the mental health field. The SEI, ABS, and LHR have demonstrated strong validity and reliability (Devins et al., 1990; Devins et al, 1997), as well as the AIS (Johnson, Wright, & Weinman, 1995). When Devins et al. (1997) combined items from the SEI, CES-D, POMS, ABS, and LHR and subjected them to factor analysis, two factors were generated, emotional distress and psychological well-being, which accounted for 66% of the total variance. Finally, a disease-specific measure for ESRD and dialysis patients, the Dialysis Stress Scale (DSS), has also demonstrated reliability and validity (Burton, Lindsay, Kline, & Heidenheim, 1989).

Studies focusing on adjustment in terms of psychosocial distress used variant empirical indicators for this construct (i.e., depression, anxiety, mood states, and psychosocial maladjustment). Study findings were very similar to general population norms, with most participants reporting mild overall depression and cognitive depression (Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Kovac et al., 2002; Patel et al., 2002; Sacks et al., 1990) and mild anxiety (Klang & Clyne, 1997). Similarly, Lev and Owen (1998) found that most participants experienced mild mood disturbance and low distress with the chronicity of the disease and hemodialysis from baseline through 8-months. In contrast, Walters, Hays, Spritzer, Fridman, and Carter (2002) found that 45% of an incident cohort screened positive for depression. Killingworth and Van Den Akker (1996) also reported that approximately one-half of their participants had borderline or clinical signs of anxiety and depression. As well, Siegal et al. (1987) found that most study participants reported significantly more psychological symptoms than the normal population, with somatic complaints, depression and anxiety the most common.

In addition, Sacks et al. (1990) found that most participants experienced minor social maladjustment or role disruptions (i.e., employment, social and leisure activities, and marital, family and parental roles). Although Kimmel et al. (1996) found that both incident and prevalent group participants were adjusting quite well in the vocational and social spheres, the incident group had better family and sexual relationships than did the prevalent group. Finally, Killingworth and Van Den Akker (1996) found that most participants (74%) were experiencing difficulties with overall adjustment, with 29% evidencing significant psychosocial maladjustment. Vocational environment and sexual relations were highlighted as the most difficult areas.

Several researchers also investigated the effects of illness and treatment experiences and social supports on various indicators of psychosocial distress. Only Killingworth and Van Den Akker (1996) examined the effects of stressors on anxiety, depression, and psychosocial maladjustment. Specifically, increased severity of physical symptoms was strongly correlated with greater anxiety and depression and increased psychosocial maladjustment. Other researchers investigated the effects of negative illness events on depression and psychosocial maladjustment. Study findings supported the presence of significant moderate to strong correlations between greater perceived illness intrusiveness and greater overall depression and cognitive depression (Kimmel et al., 1996; Kimmel et al., 1998; Sacks et al., 1990). In addition, a low, significant association was documented between greater perceived illness intrusiveness and greater role disruptions (Sacks et al.) and greater maladjustment in the social, extended family and sexual relations, and vocational spheres (Kimmel et al. ,1996).

Study findings were inconsistent on the effects of physical functioning capabilities on depression and psychosocial maladjustment. Killingworth and Van Den Akker (1996) found that greater difficulties with activities of daily living were moderately associated with greater depression and greater overall psychosocial maladjustment. While Kimmel et al. (1996) failed to document a significant association between physical functioning levels and depression levels and extended family and sexual maladjustment in either the incident or prevalent group, decreased physical functioning was significantly correlated with greater social maladjustment in the prevalent but not the incident group. In contrast, decreased physical functioning significantly correlated with greater vocational maladjustment in the incident but not the prevalent group.

As well, study findings were inconsistent on the effects of illness severity levels on depression and psychosocial maladjustment. Sacks et al. (1990) found that greater illness severity demonstrated a low, significant correlation with greater overall depression and greater role disruptions, but not cognitive depression. While Kimmel et al. (2000) found that greater illness severity depicted a low, significant correlation with greater overall depression for women but not the men, Kimmel et al. (1996) and Kimmel et al. (1998) failed to document a significant effect. Kimmel et al. (1996) reported notable group differences in the associations between illness severity and psychosocial maladjustment. Greater illness severity depicted low to moderate correlations with greater social maladjustment and compromised extended family and sexual relationships in the prevalent but not the incident group. Finally, illness severity failed to correlate with vocational maladjustment in both groups.

With regard to the effects of social supports on depression levels, Kimmel et al. (1996) found that greater perceived overall support and greater satisfaction with marital or partner relationships depicted low, significant correlations with lower levels of overall depression and cognitive depression. Similar findings were reported by Kimmel et al. (1998). As well, in the Kimmel et al. (2000) study, greater dyadic satisfaction and lower levels of dyadic conflict depicted low to moderate correlations with less overall depression and cognitive depression for the men and women, respectively. Finally, Kovac et al. (2002) failed to find a significant association between satisfaction with physicians and staff and depression.

With regard to the effects of social supports on psychosocial maladjustment, Siegal et al. (1987) found that greater perceived quality of informal supports (i.e., family and friends) depicted significant, moderate correlations with higher levels of psychological adjustment. Kimmel et al. (1996)

found that reduced perceived social support evidenced significant low to moderate correlations with increased vocational maladjustment and greater social maladjustment, respectively, in the incident and prevalent groups. As well, a low, significant association was found between reduced satisfaction with marital or partner relationships and compromised extended family and sexual relationships in both groups. However, only the incident group evidenced a low, significant association between reduced satisfaction with marital or partner relationships and greater social maladjustment.

Only one study was identified from the literature that investigated the best predictors of depression. Sacks et al. (1990) used regression analysis to determine the predictive power of key factors for depression. Greater perceived illness intrusiveness emerged as the best predictor of overall depression (i.e., accounting for 43% of the explained variance), followed by greater illness severity (8.5%) and being female (6.9%). Finally, greater perceived illness intrusiveness emerged as the best predictor of cognitive depression (i.e., accounting for 22.9% of the explained variance), followed by being female (9.8%) and greater illness severity (6.4%).

Three studies were identified from the literature review that investigated the best predictors of adjustment. Siegal et al. (1987) used regression analysis to determine the predictive power of key factors influencing psychological adjustment. During regression analysis, several social support variables (i.e., more helpful friends and relatives, more social services, more positive staff evaluation of social support networks, less frequent contact with friends and relatives, greater desire for strenuous activities, more helpful confidants) combined to explain 29.5% of the variance in adjustment. Two personal characteristics contributed an additional 19.4%, including active employment and on dialysis for a shorter period of time.

As well, Kimmel et al. (1995) and Devins et al. (1997) used regression analysis to determine the predictive power of key factors influencing social adjustment and emotional distress, respectively. In the Kimmel et al. study, lower disease severity emerged as the best predictor of improved social adjustment (8%), followed by lower perceived illness intrusiveness (5%) and greater social support (5%). In the Devins et al. study, increased illness intrusiveness was predictive of greater emotional distress in individuals with high perceived similarity to the chronic kidney patient, but not for those who viewed themselves as dissimilar.

A few of the studies reviewed examined the effects of personal characteristics on psychosocial distress. The most frequently investigated factors were age, gender, length of time on dialysis, marital status, and employment status. With regard to anxiety and depression levels, most researchers failed to document a significant effect for age (Killingworth & Van Den Akker, 1996; Kimmel et al., 1998; Klang & Clyne, 1997; Patel et al., 2002), gender (Killingworth & Van Den Akker; Kimmel et al., 2000; Kovac et al., 2002), time on dialysis (Killingworth & Van Den Akker; Kimmel et al., 1998; Sacks et al., 1990), or marital status (Kimmel et al., 1996). Sacks et al. found that older participants were significantly more likely to have higher levels of overall depression than younger ones, and women were found to have significantly higher cognitive depression levels than men. In contrast, Patel et al. found that men had significantly higher levels of cognitive depression and overall depression than the women.

In addition, Sacks et al. (1990) and Kimmel et al. (1996) found that older age was significantly associated with greater role disruptions and greater family and sexual maladjustment, respectively. As well, Siegal et al. (1987) found that participants who were actively employed and on hemodialysis for longer periods of time were adjusting better than those unemployed or on hemodialysis for less time. Siegal et al. failed to find a significant effect for age, gender, or marital status on adjustment. Finally, Kimmel et al. did not find that presence of a committed relationship influenced psychosocial maladjustment.

Studies focusing on well-being used variant empirical indicators for this construct (i.e., illness acceptance and well-being). In the Keogh and Feehally (1999) study, participants reported moderate levels of illness acceptance. As well, younger persons, Caucasians, and employed individuals had significantly higher illness acceptance levels than those who were older, from ethnic minority groups, or unemployed. The authors caution that the effects of age, ethnic group, and employment status only accounted for a small proportion of the differences in acceptance levels. Finally, gender, marital status, or number of years on renal replacement therapy had no effect on illness acceptance levels.

Devins et al. (1997) investigated the moderating effects of age and self-concept as a chronic kidney patient on the emotional impact of illness intrusiveness. Greater perceived similarity with the chronic kidney patient was significantly associated with a greater number of comorbid illnesses and weekly hours of treatment, fewer hours worked, fewer positive life events, and increased uremic symptoms, tiredness, and somatic symptoms of distress. As well, increased similarity to the chronic kidney patient was significantly associated with greater illness intrusiveness and a greater tendency to appraise the self as inactive and weak. While increased illness intrusiveness was predictive of greater psychosocial well-being in younger individuals with high similarity to the chronic kidney patient, the opposite effect (i.e., decreased psychosocial well-being) was observed for older individuals. Finally, increased illness intrusiveness was predictive of less psychosocial well-being in younger individuals who perceived themselves as dissimilar to the chronic kidney patient.

Summary. An extensive review of the literature provided significant insights into how individuals struggle to adjust to ESRD and hemodialysis. The sense of living an artificial existence due to long-term dependence on a dialysis machine threatens one's identity. Physically, emotionally, psychologically, socially, and spiritually these individuals are searching for a sense of balance in their lives. Despite the many adjustments required, the findings suggest that most individuals cope with the challenges confronting them.

A few researchers have examined the role played by coping strategies and psychosocial factors in helping individuals adjust to the illness and dialysis treatment. While qualitative and quantitative findings suggest that coping and adjustment are fairly high, scales designed to measure these constructs do not seem to be sensitive and specific enough to identify important strategies used to deal with problems or manage emotional responses. Despite the limited and contradictory evidence on the influence of illness and treatment experiences across studies, there is a greater tendency toward use of problem-oriented coping strategies, less psychosocial distress, and increased overall well-being when physical impairments, illness severity, and illness intrusiveness are low. Significantly, the evidence is much stronger for the positive influence of support systems on reducing psychosocial distress and improving emotional well-being.

Summary

The preceding literature review highlighted the diverse factors influencing an individual's ability to adjust to ESRD and hemodialysis treatment. The uncertainties associated with variable health states and treatment effects were constant threats to maintaining a sense of normal living. The empirical evidence suggests that successful adjustment to a new normal is a complex, convoluted process with multiple factors (e.g., frequency and severity of physical and psychosocial stressors, functional limitations, perceived illness intrusiveness, available and useful supports, etc.) exerting separate and interactive effects on the individual. Given the use of different instruments to measure study variables and small convenient samples, it is not surprising that the findings are inconclusive. This warrants the need for future studies with more disease-specific instruments and larger representative samples to grasp a greater appreciation of the key factors facilitating acceptance and adjustment.

Quality of Outcomes for Individuals with ESRD and on Dialysis

Quality of life is increasingly recognized as an important outcome for individuals with a chronic illness. While technological advances are important for increasing survival time, equal consideration should be given to ways to improve quality of life. The design and implementation of health care must not take place in a vacuum. An important initial step is to develop a greater understanding of how individuals who are continuously being confronted with the uncertainty of an illness course and dependence on dialysis technology for survival perceive their quality of life.

Quality of life is a multidimensional construct that is the end-result of a complex process. The theoretical and research literature suggest that a number of diverse factors (e.g., symptoms of illness, psychological states, functional status, perceptions of illness intrusiveness, quality of supports, psychosocial adjustment, etc.) exert a direct and indirect effect on perceptions of quality of life. These same influencing factors are often used interchangeably with individuals' level of satisfaction with life domains (i.e., physical and material well-being, relations with others, social interactions and recreational activities, and personal achievements) as indicators of quality of life.

The following review briefly discusses variant conceptualizations of the quality of life construct and the resulting proliferation of methodological approaches to measurement. Consideration is also given to research findings on quality of life for individuals with ESRD and hemodialysis, and the many factors affecting it.

Quality of Life: Conceptual and Operational Approaches

While there is much controversy about the specific indicators defining quality of life, there is a general consensus on its multidimensional nature. Satisfaction with important life domains, functioning levels (i.e., physical, psychological, emotional, role, and social), and well-being encompass the dominant content domains. Authors who distinguish quality of life from functional status, well-being, and health status argue that this construct should reflect satisfaction with important life domains (Anderson & Burckhardt, 1999; Ferrans, 1996; Ferrans & Powers, 1992; Gill & Feinstein, 1994; Haas, 1999). In contrast health-related quality of life is seen as being more reflective of functional outcomes and well-being (Gill & Feinstein; Harrison, Juniper, & Mitchell-DiCenso, 1996; Kimmel, 2000b; Kutner, 1994).

An important aspect of the satisfaction-based versus function-based debate is the controversy over the use of subjective or objective indicators for quality of life. It has been argued that any assessment of quality of life should include subjective ratings (i.e., individuals' perceptions of their overall quality of life and satisfaction with life domains deemed to be important) (Dijkers, 1999; Gill & Feinstein, 1994; Haas, 1999; Kimmel, 2000b). However, these authors also note that there may be instances where objective measures (i.e., health care provider or family ratings of physical, social, psychosocial, and emotional status) are believed to have equal or greater utility, especially when monitoring outcomes of clinical interventions.

Given the broadness and complexity of the quality of life concept, it is not surprising that numerous instruments have been proposed as operational measures. Both generic and disease-specific instruments have been used with ESRD Patients. Generic versions have equal applicability across different population groupings, illnesses, and treatment modalities (Edgell, Coons, Carter, et al., 1996; Harrison et al., 1996; Kutner, 1994). In contrast, specific measures are used to assess problem areas associated with diseases, groups, or functional levels. Some authors assert that a combined approach might provide more useful and insightful information about the quality of life of ESRD patients (Edgel et al.; Gill & Feinstein, 1994; Harrison et al.; Kimmel, 2000b; Kutner).

In the studies reviewed, the only disease-specific measure used to assess life satisfaction was the QLI-D. In contrast, several generic versions were used to assess overall satisfaction and general well-being, including subjective (Campbell's indices of General Affect [IGA], Well-being [IWB], and Life Satisfaction [ILS]; Satisfaction With Life Scale [SWLS]; Padilla et al.'s Quality of life Index [QLI]; Spitzer subjective QL-Index, Feinstein QOL score [FS] from the McGill QOL questionnaire; and researcher-developed items) and objective (Spitzer concise QL-Index) measures.

The IGA, IWB, and ILS have been used extensively in ESRD studies and are reported to have strong validity and reliability (Edgell et al., 1996). The Spitzer QL-index was found to have strong reliability and validity following extensive psychometric testing with healthy populations, cancer patients, and chronically and terminally ill patients (Spitzer et al., 1981). The SWLS is also reported to have strong validity and reliability and has been used in several studies by Kimmel and colleagues (Kimmel et al., 1995; Kimmel et al., 1996; Kimmel et al., 1998; Patel et al., 2002). Although Padilla et al's (1983) QLI and the FS (Patel et al.) are reported to be reliable and valid, these scales have been used infrequently with the ESRD population. Following an extensive review of the quality of life research literature on individuals receiving dialysis, Cagney et al. (2000) concluded that many researchers failed to adequately evaluate the psychometric soundness and/or relevancy of instruments as clinical monitoring tools with the ESRD population. The purpose and key methodological aspects of studies reviewed using the quality of life scales with hemodialysis patients are summarized in Table 4.

Research Findings on Quality of Life Outcomes

An extensive research base exists on quality of life outcomes with the hemodialysis population. While some studies addressed overall satisfaction with important life domains, other studies were more focused on overall health status. The following discussion is limited to a brief overview of findings from studies that reference either satisfaction ratings with important life domains or subjective and objective ratings of quality of life.

In general, study participants were satisfied with the areas of life considered to be most important (Bihl et al., 1988; Ferrans & Powers, 1993; Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Kimmel et al., 1998;

Table 4

Summary of Health Care Studies on Quality of Life[1]

Study	Design & Sample	Purpose	Instruments & Psychometrics
Bihl et al. (1988)	Descriptive-correlational; 18 HD patients	Examine overall quality of life	QLI
Ferrans et al. (1987)	Descriptive-correlational; 416 HD patients	Examine the relationship between satisfaction with care and quality of life	QLI-D
Parfrey et al. (1989)	Prospective (1 year); 63 dialysis patients	Examine subjective and objective quality of life	IGA, IWB, ILS, KS, & Spitzer QL-Index
Barrett et al. (1990)	Prospective (2 year); 96 dialysis patients	Examine indices of affect and quality of life	IGA, IWB, ILS, KS, & Spitzer QL-Index
Fox et al. (1991)	Descriptive-correlational; 71 HD patients	Examine overall quality of life	Spitzer QL-Index
Ferrans & Powers (1993)	Descriptive-correlational; 349 HD patients	Examine overall quality of life	QLI-D

Kimmel et al. (1995)	Descriptive-correlational; 149 prevalent (HD >6 mos) patients	Examine the effect of perception of illness intrusiveness, support, adjustment, illness severity on physical functioning & overall quality of life	SLSW
Tell et al. (1995)	Descriptive-correlational; 256 African-American and White HD patients	Examine the effect of supports & select demographics on quality of life	2-items assessed feelings about life as a whole and life satisfaction
Killingworth & Van Den Akker (1996)	Descriptive-correlational; 48 HD patients	Examine the effect of stressors, adjustment, anxiety & depression on quality of life	QLI-D
Kimmel et al. (1996)	Descriptive-correlational; samples of 99 incident & 149 prevalent HD patients	Examine the effect of select factors on overall quality of life of the incident and prevalent groups	SWLS
Lok (1996)	Descriptive-correlational; 56 HD patients	Examine the effect of stressors, coping methods, & length of time on dialysis on quality of life	Padilla et al.'s QLI (α = .71)

Kimmel et al. (1998)	Prospective (baseline, 6 & 12 mos); 295 HD patients	Examine the effect of illness severity and age on quality of life	SWLS
Patel et al. (2002)	Descriptive-correlational; 53 HD patients	Examine the effect of select factors on overall quality of life	SWLS & FS

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[1] Limited information is provided on the psychometrics of most instruments, especially in the studies reviewed.

Lok, 1996; Patel et al., 2002). Significantly, most of these researchers, with the exception of Lok, noted that participants' ratings were very similar to those obtained from normative samples. Ferrans and Powers speculated that the close parallel between the quality of life scores of the study population and healthy persons from the general population could be attributed to the long-term adjustment of living with ESRD.

Only two studies highlighted the rank orderings of life domains. Ferrans and Powers (1993) found that participants were most satisfied with the family, followed by psychological/spiritual, socioeconomic, and health and functioning domains, respectively. While Bihl et al. (1988) reported similar findings on the two top domains, the socioeconomic domain received the lowest ranking.

Besides satisfaction ratings of important life domains, other researchers focused on the subjective and objective ratings of well-being and quality of life by dialysis patients. Parfrey et al. (1989) documented moderate to high levels of subjective well-being and quality of life. As well, both Parfrey et al. and Fox et al. (1991) found that objective measures revealed high overall quality of life. While subjective ratings of quality of life by dialysis patients remained relatively stable over a one year period, objective ratings evidenced slight, significant improvements (Parfrey et al.).

Several studies were identified from the literature that examined the influence of select factors (i.e., stressors, illness severity, physical functioning, perception of illness intrusiveness, social supports, coping methods, psychosocial distress, well-being, and personal care characteristics) on the quality of life of hemodialysis patients. The following review highlights select study findings.

There is some evidence linking individuals perceptions of medical risk factors with various quality of life indicators. Killingworth and Van Den Akker (1996) and Lok (1996) documented significant, moderate to strong correlations between lower levels of physiological stressor severity and greater overall quality of life. Comparatively, Barrett et al. (1990) found that greater physical symptom severity depicted a moderately strong correlation with reduced well-being (i.e., less overall life satisfaction and general affect) and lower subjective quality of life (i.e., Spitzer subjective QL-Index). As well, Lok found that lower levels of psychosocial stressors depicted low, significant correlations with greater life satisfaction and overall well-being. Finally, greater overall life satisfaction demonstrated significant low to moderate correlations with lower perceived illness intrusiveness (Kimmel et al., 1996; Patel et al., 2002).

There was also empirical evidence, albeit limited, supporting the relation between objective measures of medical risk factors and quality of life. Specifically, greater overall life satisfaction demonstrated low, significant correlations with greater illness severity (Kimmel et al., 1996; Kimmel et al., 1998). However, functional abilities in performing routine activities of daily living were not found to influence quality of life ratings in any of the studies reviewed (Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Patel et al., 2002).

Besides illness and treatment factors, there are empirical data linking informal and formal supports with quality of life outcomes. Tell et al. (1995) documented low, significant associations between greater perceived social support and select quality of life indicators (i.e., more positive feelings about life and greater life satisfaction). As well, larger social networks evidenced low, significant correlations with more positive feelings about life and greater life satisfaction. Similarly, Kimmel et al. (1996) found that greater perceived social supports evidenced low, significant correlations with greater life satisfaction in both the incident and prevalent groups. While Patel et al. (2002) found that greater perceived social support depicted moderate correlations with greater overall quality of life, Kimmel et al. found that greater satisfaction with marital or partner relationships evidenced a low, significant association with greater life satisfaction in the incident, but not the prevalent, group.

A couple of studies were identified from the literature that assessed the significance of the link between formal supports and overall quality of life and life satisfaction. Ferrans et al. (1987) found that a significant, moderate correlation existed between greater overall satisfaction with care and greater overall satisfaction with important life domains. As well, greater overall satisfaction with care depicted low to moderate correlations with greater satisfaction with the family, socioeconomic, psychological/spiritual, and health and functioning domains. Finally, greater satisfaction with physicians, nursing care and dialysis treatment, and financial and transportation evidenced significant, low to moderate correlations with greater overall life satisfaction. Similarly, while Patel et al. (2002) found that greater satisfaction with life was moderately correlated with greater overall satisfaction with physicians and the dialysis staff, only greater overall satisfaction with physicians was significantly correlated with greater overall quality of life (i.e., Feinstein QOL score).

A few studies were also identified from the literature that examined the association between adjustment indicators and overall quality of life and life satisfaction. Only the Lok (1996) study examined the relationship between coping resources and quality of life. Less reliance on affective coping and greater reliance on problem-solving coping depicted low to moderate correlations with greater overall quality of life. With regard to specific aspects of quality of life, less reliance on affective coping depicted a low, significant association with higher levels of physical activity, whereas greater reliance on problem-solving coping demonstrated a moderate correlation with greater life satisfaction.

Besides coping resources, a number of studies investigated the effects of depression levels (Killingworth & Van Den Akker, 1996; Kimmel et al., 1996; Patel et al., 2002) and psychosocial adjustment (Killingworth & Van Den Akker; Kimmel et al.) on quality of life indicators. Lower levels of overall and cognitive depression depicted strong correlations with greater overall quality of life (Patel et al.) and moderate correlations with greater life satisfaction (Kimmel et al.). In contrast, Killingworth and Van Den Akker failed to find a significant effect for either anxiety or depression on quality of life. With regard to psychosocial adjustment, Killingworth and van Den Akker found that greater overall psychosocial adjustment depicted moderate to strong correlations with greater overall quality of life. Comparatively, Kimmel et al. found that better social adjustment demonstrated a low to moderate correlation with greater overall quality of life in the prevalent and incident groups, respectively. In contrast, better family and sexual adjustment and vocational adjustment depicted low, significant correlations with greater life satisfaction in the incident, but not the prevalent, group.

Finally, only a few studies were identified from the literature that examined the effects of correlates on quality of life outcomes. The most frequently investigated personal characteristics were age, education, marital status, gender, and employment status. While Kimmel et al. (1998) found that greater life satisfaction was significantly associated with older age, Kimmel et al. (1996) found that the presence of a stable relationship was significantly associated with greater life satisfaction in the prevalent but not the incident group. As well, Tell et al. (1995) found that Black participants reported a higher quality of life (i.e., more positive feelings about life and more satisfied with the meaning and purpose of life) than White participants. In contrast, some researchers found that neither age (Patel et al., 2002; Tell et al.), gender (Patel et al.; Tell et al.), nor education, employment status, and marital status (Tell et al.) influenced quality of life outcomes.

Two studies were identified from the literature that investigated the best predictors of quality of life. Tell et al. (1995) used regression analysis to determine the predictive power of actual and perceived social supports and key personal characteristics (i.e., race, age, gender, education level, employment status, marital status, living arrangement, treatment modality, length of time on dialysis, primary diagnosis, number of secondary diagnosis, number of medications taken, weight change during dialysis, smoking status, and hemoglobin level) on quality of life. Greater perceived social support and Black race emerged as significant predictors of more positive feelings about life and greater life satisfaction, however, the total explained variance was quite low (i.e., 9% and 14%, respectively).

Kimmel et al. (1995) investigated the predictive abilities of perception of illness intrusiveness, social support, psychological adjustment to the illness, and illness severity for satisfaction with life in a sample of individuals on hemodialysis for greater than six months (i.e., prevalent). During regression analysis, less perceived illness intrusiveness, greater perceived support, and greater levels of illness severity combined to predict greater life satisfaction.

Summary

Theorists and researchers are in disagreement over the appropriateness of using health-related versus more global definitions of quality of life with ESRD and dialysis patients. Given the variant conceptual definitions and operational measures, it is extremely difficult to make cross-study comparisons. Interestingly, most study findings suggested that hemodialysis patients are experiencing a moderately high quality of life, especially with respect to levels of satisfaction with important life domains. Significantly, hemodialysis patients satisfaction levels approximate those of healthy normals.

Diverse factors were examined for their effects on overall quality of life and its various components. Despite the limited number of studies examining individual factors, the findings suggest that greater satisfaction with care, greater perceived social support, larger social networks, better psychosocial adjustment, less frequent and severe physical and psychosocial stressors, less perceived illness intrusiveness, and greater reliance on problem-oriented coping strategies enhance hemodialysis patients' quality of life. In contrast to expectations, greater illness severity was found to significantly correlate with greater overall quality of life. Finally, inconsistent findings were reported on the effects of depression and personal characteristics on quality of life. In general, personal characteristics exert minimal to no effects.

Discussion

Individuals living with ESRD and the long-term treatment requirements of in-center hemodialysis portray high resilience when confronted with potentially crippling critical events related to either illness and treatment experiences, social supports, or adjustment to a new normal. Study findings indicated that most individuals perceived slight negative illness effects and reported mild physiological and psychosocial stressors. As well, most study participants wanted to be informed about the illness and treatment and involved in self-care activities. In addition, health care providers ratings of patients physical abilities also indicated mild to moderate functional limitations and low levels of illness severity.

The high ratings given to informal and formal supports was an additional positive finding. Fairly consistent findings were also evident on the most important and helpful members of support networks (i.e., family, friends, dialysis peers, and health care providers). Despite the challenges posed by the chronicity of the illness and treatment, it also seems that these individuals experience mild psychosocial distress and are adjusting well. Given the cross-sectional nature of most studies, prospective, longitudinal designs are needed to document variations in illness and treatment experiences, the availability and usefulness of supports, and adjustment to a new normal in response to a changing health status and concomitant treatment requirements over time.

The literature review highlighted the complex nature of illness and treatment experiences and the moderating effects of social supports. Complicating matters further is the dearth of information on the interactions among stressors, levels of self-care practice, functional limitations, illness severity, and perceived illness intrusiveness. Despite the limited research base, functional limitations have been consistently associated with illness severity. In contrast, neither functional limitations nor illness severity have been found to correlate with perceptions of social support or satisfaction with marital or partner relationships. Although perceived illness intrusiveness is associated with stressor severity, perceived social support, and satisfaction with marital partner relationships, study findings are inconsistent on its association with functional limitations and illness severity. Finally, contradictory findings exist on the effects of personal characteristics (i.e., time on dialysis, age, gender, and education levels) on stressor severity, functional limitations, illness severity, illness intrusiveness, social supports, and satisfaction with marital or partner relationships.

The question of how individuals successfully adjust to a situational context comprised of multiple sources of stressors is an important one. While only a few studies have examined key factors facilitating movement toward adjustment to a new normal, the empirical evidence suggests that positive illness and treatment experiences and supportive networks are important factors. Stressor severity, functional limitations, and perceptions of illness intrusiveness have been found to influence coping abilities, psychosocial distress, and emotional well-being. However, the inconclusive study findings suggest that this process is not completely understood. Nevertheless, there seems to be convincing evidence concerning the influence of social supports on psychosocial distress and emotional well-being. Conceptual and operational ambiguities surrounding important constructs (i.e., 18, 10, 4, 8, and 9 scales used to assess illness and treatment experiences, social supports, coping abilities, and psychosocial adjustment, respectively) may be part of the problem. Methodological limitations (e.g., small sample sizes, validity and reliability of instruments, cross-sectional designs, limited control over extraneous variables, etc.) may also be important contributors. Obviously, more studies are needed to grasp a greater appreciation of the separate and interactive effects of illness and treatment experiences and social supports for facilitating adjustment to a new normal.

When individuals are faced with a chronic illness and long-term treatment requirements, quality of life emerges as an important outcome. Illness and treatment experiences, social supports, and adjustment to a new normal are believed to be important determinants of overall quality of life. The review of literature revealed several indicators or determinants (e.g., stressor severity, illness severity and functional status, emotional well-being, psychosocial distress, etc.) of quality of life. The conceptual and operational ambiguities surrounding the content domains of quality of life are reflected in the 15 different scales used to assess this construct in the studies reviewed. This reality makes cross-study comparisons extremely difficult.

Researchers who used global or dialysis-specific measures focusing on satisfaction with important life domains found that study participants' quality of life was generally high and close to healthy population norms. Study findings on factors influencing quality of life were highly inconclusive due, in part, to the variations in conceptual and operational measures for various factors examined (e.g., stressors, illness severity, illness intrusiveness, psychological states, social supports, coping, psychosocial maladjustment, etc.). Nevertheless, study findings do link positive illness and treatment experiences, supportive informal and formal network members, and increased adjustment to greater overall quality of life.

Given the challenges of ESRD and long-term dependence on technology for survival, it is imperative that health care providers develop a greater understanding of key factors facilitating movement toward higher quality of life. More research is needed to determine the importance of illness and treatment experiences, social supports, and successful adjustment to a new normal. Although the journey to achieving an acceptable quality of life is individual-specific, health care providers, through appropriate and timely interventions, can help individuals manage the uncertainties and daily struggles.

Conceptual Framework

An extensive review of the literature on ESRD and renal replacement therapy revealed limited use of disease-specific conceptual or theoretical frameworks to guide research projects. The conceptual framework used in this study, the LESRD-H model, is presented in Figure 1. The LESRD-H model is based on the findings from a grounded theory study of individuals' experiences with ESRD and hemodialysis (Gregory, 1998).

There are four major constructs in the LESRD-H model: illness and treatment experiences, social supports, adjustment to a new normal, and quality outcome. Illness and treatment experiences refer to the stress resulting from the separate and interactive effects of common symptoms of ESRD, comorbid conditions, and hemodialysis treatment. Another important component of illness and treatment experiences is the ambiguity reflected by the tension created by the individual's knowledge of what should be done to maximize treatment effectiveness and health versus what is actually being done. The social supports construct reflects individuals' perceptions of the availability and usefulness of support from informal and formal network members. Adjustment to a new normal refers to the individual's attempts to maintain a semblance of normalcy while contending with the ongoing emotional, psychological, social, and spiritual struggles due to long-term dependence on technological support for survival. The final construct is quality outcome which reflects evolving end points that are in a constant state of change in response to illness and treatment events, social supports, and adjustment. It is comprised of both subjective (i.e., satisfaction with life) and objective (i.e., morbidity and mortality) components.

The LESRD-H model proposes that illness and treatment experiences and social supports (i.e., formal and informal supports) exert a direct impact on adjustment to a new normal. It is also proposed that critical turning points (i.e., meanings attributed to positive and negative critical events that surface periodically to exert a singular and cumulative effect) link these major constructs. Furthermore, illness and treatment experiences, social supports, and adjustment to a new normal exert a direct impact on quality outcome. Finally, adjustment to a new normal mediates the impact of illness and treatment experiences and social supports on quality outcome.

For the current study, quality outcome was viewed as a subjective state reflective of individuals satisfaction with their overall lives. One of the most comprehensive and detailed conceptualizations of quality of life, with specific relevancy for ESRD patients, was presented by Ferrans (1996). The Ferrans' Conceptual Model for Quality of Life defines quality of life as a sense of well-being that stems from a person's level of satisfaction with important aspects of his/her life. This model proposes that four life domains (i.e., health and functioning, psychological/spiritual, social and economic, and family) interact to determine overall quality of life.

Definitions

This section presents an overview of the definitions used for the key constructs included in the LESRD-H model.

Illness and treatment experiences. The illness and treatment experiences examined in the current study were restricted to individuals' perceptions of physiological stressors, confidence with illness and treatment knowledge, performance of ADL, and self-health management. Exploratory factor analysis confirmed that these four interrelated domains reflected individuals' experiences (Way, Parfrey, & Barrett, 1998).

Social supports. The social supports examined in this study consisted of perceptions of interactions with formal (i.e., nurses, physicians, and allied health providers) and informal (i.e., family) networks. Special emphasis was placed on the level of satisfaction with reciprocity in family relations and the technical, interpersonal, and informational support of health care providers. Exploratory factor analysis confirmed the presence of four separate, but interrelated, domains in the social support category (Way et al., 1998).

Adjustment to a new normal. The multiple losses experienced in most life domains and variable health status leads to major transformations of the self. Gregory's (1998) definition of adjustment to a new normal was used in the current study. Adjustment to a new normal involves accepting and adapting to the changes in emotional, psychological, social, and spiritual functioning.

Exploratory factor analysis confirmed the presence of two separate, but interrelated, domains (i.e., psychosocial distress and emotional well-being) in the adjustment category (Way et al., 1998).

Quality outcome. The outcome variable investigated in this study is quality of life. For the purpose of this study quality of life is defined as "a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her" (Ferrans, 1996, p.296). The four content domains (i.e., health and functioning, psychological/spiritual, social and economic, and family) derived from interviews with hemodialysis patients (N = 40) and an extensive review of the literature provided the basis for the construction of the Quality of Life Index (QLI).

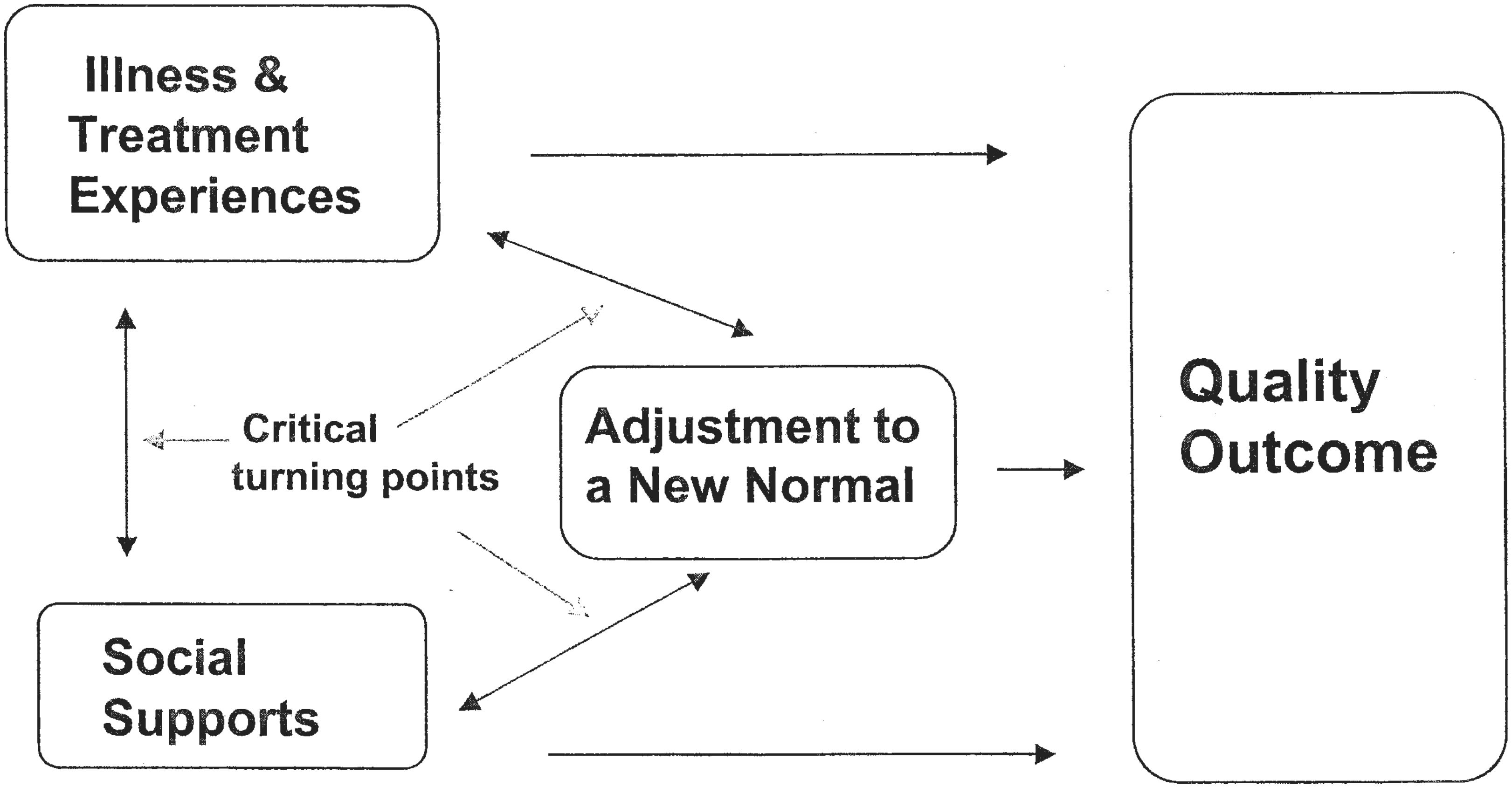

Figure 1. Living with End-Stage Renal Disease (ESRD) & Hemodialysis

Note: The model is based on the Proposed Model of Patients' Perceptions of their Experience with Hemodialysis as presented in "Patients' Perceptions of their Experience with End-stage Renal Disease and Hemodialysis Treatment" by Gregory (1998), Unpublished master's thesis, Memorial University of Newfoundland, St. John's, Canada.

CHAPTER 3

Methodology

A descriptive correlational design was used to investigate individuals' perception of meanings of the illness and treatment experiences, social supports, and adjustment to a new normal while receiving hemodialysis treatment in the province of Newfoundland and Labrador. The intercorrelations among the key study variables (i.e., illness and treatment experiences, supports, adjustment, and quality of life) were also examined. Finally, the effects of select extraneous variables (i.e., demographics and medical risk factors) on each key study variable were examined. This chapter provides an overview of the population and sample, setting, procedure, instruments, ethical considerations, data analysis, and study limitations.

Population and Sample

The target population was all individuals with ESRD who were receiving in-center hemodialysis at one of the four provincial sites (i.e., Health Sciences Centre and Salvation Army Grace General Hospital of the Health Care Corporation of St. John's; Western Memorial Regional Hospital, Western Health Care Corporation; and Central Newfoundland Regional Health Centre, Central West Health Corporation). The accessible population was restricted to individuals who met the following inclusion criteria: (a) on in-center hemodialysis for a minimum of 12 weeks; (b) mentally competent, able to give informed consent, and capable of understanding the interview process; (c) not experiencing an acute illness episode (e.g., acute renal failure, etc.) or a significant decline in health (i.e., terminal phase of dialysis or psychological maladjustment) which in the opinion of the dialysis staff would make it too stressful for study participation; (d) over the age of nineteen; and (e) able to understand and speak English.

The total size of the accessible population was 128. A total of 112 individuals agreed to participate, resulting in a 87.5% response rate. The final sample size was adequate based on power analysis. Specifically, with a power level of .80 and an alpha level of .05, a sample size of 88 was needed to achieve an estimated medium effect of .30 for bivariate correlation tests (Polit & Hungler, 2000). Using the same power and alpha levels, a sample size between 126 and 88 (i.e., medium effect size between .50 and .60) was needed for two-group tests of difference (Polit & Hungler). Finally, using the same power and alpha levels, a sample size of 62 to 129 (i.e., large to medium effect sizes of .26 to .13, respectively) was needed for multiple regression analysis with 10 independent or predictor variables, respectively (Cohen, 1988).

Procedure

Data collection commenced following ethical approval from the Human

Investigation Committee, Faculty of Medicine, Memorial University of Newfoundland (see Appendix A) and the Research Proposal Approval Committee of the Health Care Corporation of St. John's (see Appendix B). Data were collected between July 1998 and February 1999. Potential participants were approached by an intermediary (i.e., program manager, patient care coordinators, or nurses) during a scheduled hemodialysis appointment to provide a brief description of the study, ascertain their interest in participating, and seek permission for the researcher to contact them.

Individuals expressing an interest in the study were subsequently contacted by the researcher. At that time, the researcher provided a more complete explanation of the study and addressed any questions or queries. When the researcher was confident that participants understood the study and expressed a willingness to participate, informed, written consent was obtained (see Appendix C). Face-to face interviews were conducted with participants during the first two hours of hemodialysis treatment. Although study instruments were designed for self-administration, a face-to-face interview format was used to maintain consistency for all participants (i.e., accommodate illiteracy, diminished vision, or other problems which might interfere with ones ability to complete a questionnaire). Each instrument was administered in the same order, following a brief description of standardized instructions. Interview time ranged from 60 to 90 minutes.

Instruments

Data were collected with three instruments: a Personal Data Extraction Form, Patient Perceptions of Hemodialysis Scale (PPHS), and the dialysis version of the Ferrans and Power's Quality of Life Index (QLI). A brief overview is presented of each study instrument.

Personal Data Extraction Form

The personal data extraction form was developed to collect data on extraneous variables which could possibly influence any observed variation in individuals' perceptions of hemodialysis and quality of life (see Appendix D). Information was collected on select demographic (i.e., hemodialysis site, age, gender, and living arrangement) and medical risk factors (i.e., cause of ESRD, type and severity of comorbid illnesses, and time on hemodialysis) variables.

Patient Perceptions of Hemodialysis Scale

The PPHS was developed by a research team from the indicators and descriptors generated from a grounded theory study by Gregory (1998). This 64-item scale was designed to measure individuals' perceptions of hemodialysis in three major content domains (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) (see Appendix E). Drafts of the original PPHS were pilot tested, reviewed, and subsequently modified by the research team to increase item clarity and relevance, and to identify the most meaningful rating scales. An adult literacy expert was also consulted to ensure that the scale was at an appropriate reading level for the target population.

The final version of the PPHS is comprised of 64 items, with 42 of the items positively worded and 22 negatively worded. The rating scales for the items focus on either the frequency of occurrence of certain events or the degree of concern, satisfaction, or confidence felt by participants about select events or situations. Each item is rated on a 5-point Likert-type rating scale, ranging from 0 (*never or not at all*) to 4 (*almost always or extremely*). Negatively worded items were reverse scored prior to data entry. The possible score range was 88 to 168, with higher scores indicative of more positive attitudes.

Way et al. (1998) reported on the strong reliability and validity of the PPHS during the early stages of instrument testing. Construct validity was supported by the strong positive correlations observed between the major subscales and the total scale (range: $r = .80$ to .94), and the moderate to strong positive intercorrelations among the major subscales (range: $r = .43$ to .67). Exploratory factor analysis also tentatively supported the construct validity of the PPHS (i.e., generated three major item clusters - illness and treatment experiences, social supports, and adjustment to a new normal - that aligned with the theoretical constructs comprising the model induced from the qualitative data base). The strong alpha coefficients for the total scale (.92) and the major subscales (i.e., .67 to .89) indicated that the PPHS had strong internal consistency.

Quality of Life Index

The dialysis version of the QLI was developed by Ferrans and Powers (1985). The QLI is designed to assess four domains of quality of life (i.e., family, health and functioning, psychological/spiritual, and social and economic) (see Appendix F). This 64-item scale is comprised of two parts, one measuring satisfaction and the other importance. The 32 items in the satisfaction section are rated on a 6-point Likert scale, ranging from 1 (very dissatisfied) to 6 (very satisfied). The importance section consists of the same items which are rated on a 6-point Likert scale, ranging from 1 (very unimportant) to 6 (very important). Scores are calculated by weighting each satisfaction response with its paired importance response. The overall score and all subscale scores have a possible range of 0 to 30, with higher scores indicating a better quality of life.

The QLI has demonstrated high internal consistency, with Cronbach's alphas ranging from .90 to .93 for the overall scale, and .77, .87, .90, and .82 for the family, health and functioning, psychological/spiritual, and social and economic subscales, respectively (Ferrans & Powers, 1985, 1992). The test-retest reliability score of .81 for a 1-month period was also high (Ferrans & Powers, 1985). The overall scale and subscales also demonstrated good convergent validity with a single-item measure of life satisfaction (Ferrans & Powers, 1992). Finally, factor analysis based on a sample of 349 in-unit hemodialysis patients confirmed a four factor solution representative of the theoretical domains proposed by the conceptual model of quality of life.

Ethical Considerations

Several steps were taken to protect participant rights in the current study. Approval to conduct the study was received from the Human Investigation Committee, Faculty of Medicine, Memorial University of Newfoundland (see Appendix A) and the Research Proposal Approval Committee of the Health Care Corporation of St. John's (see Appendix B).

An intermediary (i.e., program manager, patient care coordinator, or hemodialysis nurse) informed potential participants about the study and ascertained their willingness to be approached by the researcher. The researcher provided a complete explanation of the study and addressed questions prior to obtaining informed, written consent. Participation in the study was voluntary, and participants were assured they could withdraw at anytime.

Confidentiality of all data was maintained by coding all forms and questionnaires. A master list of participants' names and corresponding codes was kept in a locked filing cabinet accessible only to the researcher.

Data Analysis

Data were coded and entered into the Statistical Package for the Social Sciences (SPSS) for analysis. Descriptive statistics were used to examine demographic and medical risk factors, as well as the distribution of individual item, subscale, and total scale scores. Close scrutiny of the data base for missing item values revealed a fairly random pattern. The decision was made to replace missing values with the item mean to ensure that enough cases were available for regression analysis.

One-Way Analysis of Variance (ANOVA) and the t-test for independent groups were used to assess group differences for the subscales and total scores of major study variables. The Bonferroni and Tamhane multiple comparison procedures were used to determine specific differences in group means for ANOVA. Bivariate correlation coefficients were used to determine the relationships between variables. When the assumptions for Pearson's r were not met, the appropriate non-parametric tests were used to assess variable relationships. An alpha level of .05 was selected as the significance level for all statistical tests.

Stepwise multiple regression, using a sequential or hierarchical approach based on the logic of the LESRD-H model was used to determine the best predictors of intermediate outcomes (i.e., psychosocial distress and emotional well-being) and quality outcome (i.e., overall quality of life). Cronbach's alpha was used to assess the internal consistency of all subscales and total scales.

Limitations

The use of a non-probability sample limits the generalizability of study findings to other hemodialysis patients. Additional study limitations include the decreased sample representativeness due to the restrictiveness of the inclusion criteria. The use of self-report measures, without collaborating objective data, and data collection during hemodialysis treatment may also threaten the reliability and validity of study findings.

CHAPTER 4

Results

Study findings are presented in three sections. The first section presents a descriptive profile of the sample and key variables. The second section summarizes the relationships among study variables, including the results of multiple regression analysis on adjustment to a new normal and quality of life. The final section discusses the reliability and validity of the instruments based on study findings.

Descriptive Profile

This section presents an overview of study findings on demographics and medical risk factors. Descriptive findings are also presented on key study variables: illness and treatment experiences, social supports, adjustment to a new normal, and quality of life.

Demographics

Table 5 summarizes select characteristics of the sample (*N* = 112). Most of the participants were male (55.4%), living with a spouse (66.1%), receiving hemodialysis treatment at two sites of the Health Care Corporation of St. John's (76.8%), and over 50 years of age (65.2%). The mean age of the sample was 57.9 (*SD* ± 16.7), with a range from 21 to 86 years.

Table 5

Demographic Characteristics (N = 112)

Characteristic	*n*	%
Gender		
Male	62	55.4
Female	50	44.6
Living Arrangement		
Alone	11	9.8
Spouse	74	66.1
Parents/Children	8	7.1
Another Adult	16	14.3
Institution	3	2.7
Hemodialysis Site		
Site 1[1]	47	42.0
Site 2[2]	39	34.8
Site 3[3]	16	14.3
Site 4[4]	10	8.9
Age in years		
<35	11	9.8
35 - 49	28	25.0
50 - 65	31	27.7
>65	42	37.5

[1] Health Care Corporation of St. John's, Health Sciences Centre. [2] Health Care Corporation of St. John's, Salvation Army Grace General Hospital. [3] Western Health Care Corporation, Western Memorial Regional Hospital. [4] Central West Health Corporation, Central Newfoundland Regional Health Centre.

Medical Risk Factors

Information was also collected on select medical risk factors. Table 6 presents a summary of study findings. The causal factors implicated in the onset of ESRD varied across participants, with glomerulonephritis or autoimmune disease (18.8%), diabetes (17.9%), and renal vascular disease (14.3%) the most common. These findings are comparable to the leading causes of renal failure across Canada (CIHI, 2001).

Most study participants had been on hemodialysis for less than 3 years (79.5%). The average time on hemodialysis was 21.95 months (*SD* ± 18.9). Most participants had one or more comorbid illnesses (85.7%), with a mean of 1.95 (*SD* ± 1.46) and 0 to 7 range. The illness severity scores based on the Charleston Comorbidity Index (see Table 6), ranged from 2 to 11 (M = 5.07, *SD* ± 2.42), and reflected low to moderate severity for most participants (58%).

Table 7 summarizes the type and frequency of dominant comorbidities in the study sample. The most common types were ischemic heart disease, congestive heart failure, stroke, diabetes, major lung problems, cancer, severe arthritis, and amputations. For the most part, the incidence of these diseases was low in the sample. The most frequent comorbid illnesses were ischemic heart disease (33.9%), diabetes (29.5%), and cancer (19.6%).

Table 6

Medical Risk Factors (N = 112)

Characteristic	*n*	%
Cause Of ESRD		
Diabetes	20	17.9
Glomerulonephritis/Autoimmune	21	18.8
Renal Vascular Disease	16	14.3
Polycystic Kidney Disease	9	8.0
Other	46	41.0
Time on Hemodialysis		
< 1 year	49	43.8
1 to 3 years	40	35.7
>3 years	23	20.5
Comorbid Illness		
0	16	14.3
1 to 2	45	40.2
>2	51	45.5
Illness Severity Index[1]		
Low (≤3)	35	31.3
Moderate (4 to 5)	30	26.8
High (6 to 7)	29	25.9
Very High (≥ 8)	18	16.0

[1] The illness severity index is based on the modified version of the Charlson Comorbidity Index for the dialysis population as presented by Beddhu et al. (2000).

Table 7

Type and Frequency of Comorbidity **(*N* = 112)**

Variable	*N*	%
Ischemic Heart Disease		
Present	38	33.9
Absent	74	66.1
Congestive Heart Failure		
Present	11	9.8
Absent	101	90.2
Stroke		
Present	13	11.6
Absent	99	88.4
Diabetes		
Present	33	29.5
Absent	79	70.5
Major Lung Problems		
Present	10	8.9
Absent	102	91.1
Cancer		
Present	22	19.6
Absent	90	80.4
Severe Arthritis		
Present	13	11.6
Absent	99	88.4
Amputation		
Present	8	7.1
Absent	104	92.9

Perception of ESRD and Hemodialysis

The areas under perception of ESRD and hemodialysis included illness and treatment experiences, social supports, and adjustment to a new normal. Table 8 presents the means, standard deviations, and weighted means for the sub-scales and total scores of the PPHS. For the most part, higher scores are indicative of more positive attitudes. The exceptions are the physiological stressors and psychosocial distress sub-scales (i.e., lower scores, more positive perceptions).

The findings indicated that most participants had positive attitudes toward the illness and treatment, were satisfied with social supports, and were adjusting well to a new normal. Participants were most positive about social supports, followed by adjustment to a new normal, and illness and treatment experiences, respectively. The presentation of findings is organized according to the major subscales of the PPHS. The percentage of positive and negative responses reflect a collapsing of scale steps into low (*never or not at all and rarely or a little bit*) and moderate to high (*sometimes or moderately, often or quite a bit, and almost always or extremely*).

Illness and treatment experiences. Overall, participants had positive attitudes towards their illness and treatment (M = 2.55). The individual subscales making up this scale provide greater insight into participants' perceptions. The discussion is organized according to the findings for each subscale.

Table 8

Mean and Standard Deviation Scores for the PPHS (N = 112)

Subscales	***M***	***SD***	**Weighted[1,2] *M***
Illness and Treatment Experiences	48.49	9.62	2.55
Physiological Stressors	17.99	5.94	2.25
Knowledge	10.31	3.56	2.58
Performance of ADL	7.26	2.72	2.42
Self-Health Management	12.93	2.73	3.23
Social Supports	57.31	9.11	3.18
Family	9.06	2.71	3.02
Nurses	26.83	4.54	3.35
Physicians	15.71	3.80	3.14
Allied Health	5.66	1.79	2.83
Adjustment to a New Normal	66.13	16.06	2.65
Psychosocial Distress	30.73	10.98	2.36
Emotional Well-being	35.43	7.86	2.95
PPHS	172.09	28.68	2.78

Note. PPHS = Patient Perceptions of Hemodialysis Scale.

[1] Scores were summed and divided by scale item totals. [2] Rating scales ranged from 0 (*never/not at all*) to 4 (*almost always/extremely*), with a mean of 2.

The weighted mean score for physiological stressors (*M* = 2.25) indicated that most participants experienced a moderate level of stressors. On the positive side, most participants usually felt comfortable after dialysis (77.7%), rarely experienced breathing difficulties (68.8%), rarely experienced itching (51.8%), and were rarely bothered by walking short distances (51.8%). In contrast, a significant number of participants sometimes to often felt tired and low on energy (76.8%), felt exhausted after dialysis (76.8%), and experienced hypotension during or after dialysis (69.6%), and muscle cramps (53.6%).

The weighted mean knowledge score (*M* = 2.58) indicated that participants were moderately to quite confident with information about their illness and treatment. Specifically, the majority of participants were quite confident that they understood why diet and fluid restrictions were needed (87.5%) and quite satisfied with their information on the benefits and side-effects of dialysis (87.5%). As well, most participants were confident that they understood the causal factors responsible for the loss of kidney function (61.6%) and the requirements for a kidney transplant (64.5%).

The performance of activities of daily living (ADL) weighted mean score (*M* = 2.42) indicated that participants were moderately satisfied with daily activity levels. Specifically, the majority of participants were satisfied with the amount of self-care responsibilities that they could assume on a given day (84.8%) and their ability to do housework or other work activities (68.8%). As well, most participants frequently participated in social activities (63.4%).

The weighted mean score for self-health management (*M* = 3.23) indicated that participants were actively involved in helping to manage their health. Specifically, the majority of participants monitored nurses' activities during dialysis (94.6%), informed the nurse about problems that occurred during dialysis (97.3%), followed recommended diet and fluid restrictions (83.9%), and watched for potential problems that could occur during dialysis (80.4%).

Social supports. Overall, most participants were satisfied with their support systems (*M* = 3.18). The individual subscales comprising this scale present a greater understanding of participants' perceptions of informal and formal supports. The discussion is organized according to each major content domain.

The weighted mean score for family supports (*M* = 3.02) indicated that most participants were quite satisfied with this form of support. The majority of participants indicated that family members helped them accept their illness and dialysis treatment requirements (92%) and often reminded them about diet, fluid, and activity restrictions (73.2%). Most participants also indicated that they often tried to lessen the impact of their illness and treatment on family members (88.4%).

The weighted mean score for nursing support (*M* = 3.35) indicated that most participants were quite satisfied with this form of support. Specifically, all study participants were quite satisfied with the overall quality of nursing care (100%). The majority of participants were confident that nurses had the knowledge and ability to know what to do if they became ill on dialysis (100%), were not concerned that nurses were too busy to monitor what was happening to them while on dialysis (74.1%), and rarely experienced delays in receiving scheduled treatments (64.3%). As well, most participants were satisfied with nurses' willingness to listen to what they had to say about their illness and treatment (97.3%) and the time spent helping them understand illness and treatment requirements (96.4%). Finally, most participants were satisfied with nurses' comfort measures (98.2%) and attempts to promote a relaxed, family-like atmosphere on the dialysis unit (94.6%).

The weighted mean score for physician support (*M* = 3.14) indicated that most participants were quite satisfied with this form of support. Specifically, all participants were very satisfied with the overall quality of medical care (97.3%). The majority of participants were quite confident that physicians had the necessary knowledge and ability to monitor their overall physical needs (93.8%) and were very satisfied with the quickness of physicians' response to their needs while on dialysis (82.1%). As well, most participants were satisfied with physicians' willingness to listen to what they had to say about their illness and treatment (92%) and the time spent helping them understand illness and treatment requirements (89.3%).

The weighted mean score for allied health providers ($M = 2.83$) indicated that most participants were quite satisfied with the support received from social workers and dieticians. Specifically, the majority of participants were satisfied with the support provided by social workers to help them deal with illness-and treatment-related problems (85.3%) and the diet information provided by dieticians (89.3%).

Adjustment to a new normal. Overall, most participants were adjusting to a new sense of normal ($M = 2.65$). The individual subscales comprising this scale present a greater understanding of participants overall adjustment. Despite the overall tendency to believe that one was experiencing a fairly high level of emotional well-being, there was also evidence of psychosocial distress. The discussion is organized according to each major content domain defining overall adjustment.

The weighted mean score for psychosocial distress ($M = 2.36$) indicated that most participants were experiencing low to moderate distress. On the negative side, the majority of participants were concerned about the impact of the illness and treatment on family members (77.7%), with what could happen if they failed to follow recommended diet and fluid restrictions (64.3%), and about becoming too dependent on their families (61.6%). As well, most participants reported feeling distressed by the severity of the illness and long-term treatment requirements (57.1%), depressed about their illness and long term treatment requirements (55.4%), so frustrated with things that they wanted to come off the machine and go home (53.6%), useless due to their dependance on others (52.7%), and upset by seeing others become suddenly ill (50.9%). In contrast, most participants were not concerned for their personal safety while on dialysis (65.2%), or about voicing their needs to nurses or physicians due to the physical closeness of others during dialysis (75.9%). As well, most participants rarely dwelled on their own health problems following the death of another patient (64.9%), were only a little concerned that their health would get worse regardless of what they or the doctors did (56.3%), and rarely experienced fears or worries about unexpected illness and treatment events (51.8%).

The weighted mean score for emotional well-being (*M* = 2.95) indicated that overall participants had accepted and were adjusting to illness and treatment experiences. Specifically, the majority of participants indicated that they had accepted dialysis as a normal part of life (100%), were satisfied with how well they had adjusted to dialysis (94.6%), tried to maintain a positive attitude toward dialysis (93.8%), were coping well with dialysis restrictions (92. 9%), were confident about coming to terms with the illness (78.6%), and felt stronger as a person due to the illness (69.4%). As well, most participants reported feeling a special closeness with fellow dialysis patients (96.4%), relaxed during dialysis (93.8%), and in control of the ups and downs of dialysis and its effects on health and well-being (80.4%). Finally, most participants were satisfied with the amount of quality time spent with family and friends (86.6%), believed that it was possible to manage the financial costs resulting from dialysis (67.9%), and perceived that dialysis had improved their quality of life (83%).

Quality of Life

The dialysis version of Ferrans and Powers' QLI was used to measure perceived quality of life. The major domains addressed under quality of life included family, health and functioning, psychological and spiritual, and social and economic. Table 9 presents the means and standard deviations for the subscales and total score of the QLI. Higher scores are indicative of a better quality of life.

The findings indicated that most participants were quite satisfied with the areas of life most important to them (M = 24.01). The weighted mean score was higher than the normative value for overall quality of life (M = 20.70) reported by Ferrans and Powers (1993). As well, participants were most satisfied with the family aspects of their lives, and were least satisfied with their personal health and functioning. The presentation of findings is organized according to the major subscales of the QLI. The percentage of positive and negative responses reflect a collapsing of scale steps into low (*very or moderately or slightly dissatisfied/ important*) to high (*very or moderately or slightly satisfied/important*).

Table 9

***Mean and Standard Deviation Scores for the QLI* (*N* = 112)** [1]

Subscales	***M*** [2]	***SD***	**Range** [3]
Family	27.03	4.50	9.0 - 30
Health and Functioning	22.17	5.42	4.9 - 30
Psychological/Spiritual	25.52	6.13	5.0 - 30
Social and Economic	24.60	5.19	7.3 - 30
Total Score	24.01	4.78	7.3 - 30

Note. QLI = Quality of Life Index.

[1] Sample size is a function of missing data. [2] The mean score was calculated by weighting satisfaction responses with importance responses. [3] The possible range for overall and subscale scores is 0 to 30.

Family. The weighted mean score for the family domain (*M* = 27.03) indicated that most participants were very satisfied with those aspects of family life that were most important to them. Specifically, the majority of participants placed high value on their family's health and happiness (99.1%), children (99.1%), and relationship with spouses or significant others (98.2%). With regard to the degree of satisfaction with those areas, most participants were quite satisfied with their family's health (93.8%), family's happiness (89.3%), children (95.5%), and relationship with spouses or significant others (97.3%).

Health and functioning. The weighted mean score for the health and functioning domain (*M* = 22.17) indicated that most participants were satisfied with their physical health and level of participation in family and social activities. With regard to the physical aspects of health, the majority of participants rated their personal health (100%), physical independence (100%), potential to live a long life (95.5%), potential for getting off dialysis (95.5%), amount of stress or worries (95.5%), and potential for a happy old age/retirement (93.8%) as very important. Although most participants were satisfied with these components, satisfaction levels did not parallel the importance attached to them. Specifically, the majority of participants were satisfied with their personal health (76.8%), physical independence (89.2%), potential to live a long life (88.4%), potential for getting off dialysis (79.1%), amount of stress or worries (73.2%), and potential for a happy old age/retirement (73.2%).

With regard to family and social activities, the majority of participants placed high value on their ability to meet family responsibilities (98.2%), usefulness to others (98.2%), ability to participate in leisure activities (97.3%), and freedom to travel (87.4%), as well as their sex life (76.6%). Overall, most participants were satisfied with their level of participation in valued activities. The greatest discrepancy in importance and satisfaction ratings was with their ability to travel on vacations. Specifically, the majority of participants were satisfied with their ability to meet family responsibilities (88.4%), usefulness to others (82.1%), ability to participate in leisure activities (85.7%), sex life (74.3%), and freedom to travel (51.2%).

The final aspect of the health and functioning domain focussed on health care and dialysis treatment. The majority of participants viewed dialysis treatment (99.1%), current health care (99.1%), and efforts to increase their potential for a successful kidney transplant (89.9%) as being important. Significantly, most participants were quite satisfied with dialysis treatment (99.1%), current health care (99.1%), and efforts to increase their potential for a successful kidney transplant (74.2%).

Psychological/spiritual. The weighted mean score for the psychological/ spiritual domain (*M* = 25.52) indicated that most participants were very satisfied with what was important for psychological well-being. The psychological/spiritual domain evidenced strong concurrence between importance and satisfaction ratings. The majority of participants placed high value on having peace of mind (99.1%), happiness in general (99.1%), the self in general (99.1%), achievement of personal goals (98.2%), life in general (98.2%), personal appearance (96.4%), and personal faith in God (95.4%). As well, most participants were satisfied with their peace of mind (88.3%), overall happiness (91.1%), overall self (88.4%), achievement of personal goals (86.6%), life in general (86.6%), personal appearance (90.2%), and faith in God (94.4%).

Social and economic. The weighted mean score for the social and economic domain ($M = 24.60$) suggested that most participants were quite satisfied with friends and emotional support, as well as their economic situation. The majority of participants valued and were satisfied with friends (100% and 96.4%, respectively) and the emotional support received from others (97.3% and 95.5%, respectively). As well, most participants placed high value on their living quarters and furnishings (100%), standard of living (99.1%), neighborhood (96.4%), financial independence (96.4%), education (91.1%), and job status (90.3%). Comparatively, most participants were satisfied with their current homes (92%), standards of living (87.5%), neighborhoods (92.3%), financial independence (82.1%), education level (85.7%), and job status (67.3%).

Interrelationships Among Study Variables

This section examines the effect of demographic (i.e., gender, living arrangement, hemodialysis site, and age) and medical risk factors (i.e., the type and frequency of comorbid illnesses, illness severity, and length of time on hemodialysis) on illness and treatment experiences, social supports, adjustment to a new normal, and quality of life. The relationships among major study variables were also examined.

Perception of ESRD and Hemodialysis and Personal Characteristics

The findings revealed few significant differences for perception of ESRD and hemodialysis variables across most demographic and medical risk factors. The presentation of findings is organized according to major personal characteristics.

Demographic. There were no significant differences observed for any of the perception of hemodialysis variables based on hemodialysis site. Living arrangement, gender, and age were observed to exert variant, but minimal effects, on these variables. Participants who were living with a spouse were significantly more satisfied with family supports than those living alone or with other individuals, $F(2, 109) = 7.61$, $p = .001$. Participants who were living with a spouse were significantly more satisfied with their overall support systems than those living with other individuals, $F(2, 109) = 4.14$, $p = .02$. Male participants were significantly more satisfied with performance of ADL, $t(89.44) = 2.95$, $p = .004$, and family supports, $t(110) = 2.00$, $p = .048$, than were female participants.

As well, older participants were significantly less confident with their knowledge of the illness and treatment than their younger counterparts, *r* = -.48, *p* = .000. In contrast, older participants experienced less psychosocial distress than their younger counterparts, *r* = .26, *p* = .005.

Medical risk factors. The frequency of comorbid illness, illness severity, and length of time on hemodialysis were found to exert variant, but minimal, effects on perception of hemodialysis. Participants with a greater number of comorbid illnesses were significantly more likely to report a greater frequency of physiological stressors, *r* = -.27, *p* = .004, and to be less confident with illness and treatment knowledge, *r* = -.33, *p* = .000, than those with less comorbidity. As well, participants with greater illness severity were significantly more likely to be less confident with illness and treatment knowledge, *r* = -.46, *p* = .000, and to have less psychosocial distress, *r* = .20, *p* = .03, than those with less illness severity. Finally, participants who had been on hemodialysis for a longer period of time were significantly less satisfied with allied health support, *r* = -.19, *p* = .04, than those on hemodialysis for a shorter period of time.

Quality of Life and Personal Characteristics

The findings revealed few significant differences for the quality of life variables across most demographic and medical risk factors. The presentation of findings is organized according to major personal characteristics. Table 10 summarizes select results.

Demographic. No significant differences were observed for any quality of life variables based on hemodialysis site or gender. The strongest effects were exerted by living arrangement and age. Participants who were living with a spouse were significantly more satisfied with valued aspects of family life than those living with other individuals, *F*(2, 109) = 6.98, *p* = .001. As well, participants who were living alone or with a spouse were significantly more satisfied with their psychological and spiritual well-being than those living with other individuals, *F*(2, 109) = 4.20, *p* = .02. In addition, participants who were living with a spouse had a significantly higher quality of life than those living with other individuals, *F*(2, 109) = 3.30, *p* = .04. Finally, older participants were significantly more satisfied with valued aspects of family life, *r* = .38, *p* = .000, physical health and level of participation in family and social life activities, *r* = .23, *p* = .02, psychological and spiritual well-being, *r* =.41, *p* = .000, friends and emotional support and economic situation, *r* = .45, *p* = .000, and overall quality of life, *r* = .39, *p* = .000, than younger ones.

Medical risk factors. No significant differences were observed for the quality of life variables based on number of comorbid illnesses. Illness severity and length of time on hemodialysis exerted variant effects. Participants with greater illness severity were significantly more satisfied with their overall

Table 10

***Quality of Life by Personal Characteristics* (*N* = 112)**

Subscales	**Living Status**	**Age**	**Time on Dialysis**	**Illness Severity**
Family	*F* = 6.98**	*r* = .38***	*r* = -.18	*r* = .19
Health and Functioning	*F* = 1.19	*r* = .23*	*r* = -.23*	*r* = .13
Psychological/Spiritual	*F* = 4.20*	*r* = .41***	*r* = -.22*	*r* = .31**
Social and Economic	*F* = 2.86	*r* = .45***	*r* = -.17	*r* = .32**
Overall Quality of Life	*F* = 3.30*	*r* = .39***	*r* = -.25**	*r* = .26**

* $p < .05$. ** $p < .01$. *** $p < .001$.

quality of life, r = .26, p = .005, social and economic situation, r = .32, p = .001 and spiritual well-being, r = .31, p = .001, than those with less severity. As well, participants on hemodialysis for a longer time were significantly less satisfied with their physical health and level of participation in family and social life activities, *r* = -.23, *p* = .02, psychological and spiritual well-being, *r* = -.22, *p* = .02, and overall quality of life, *r* = -.25, *p* = .009, than their counterparts on hemodialysis for less time.

Illness/Treatment Experiences, Supports and Adjustment

Psychosocial distress evidenced statistically significant, positive relationships with some experience and support variables (see Table 11). The exceptions were illness and treatment knowledge, self-health management, and family and allied health support. The findings suggested that individuals with less distress were more likely to have fewer physiological stressors, and to be more satisfied with performing ADL, and with nursing and physician support. In terms of the coefficient of determination (i.e., r^2), physiological stressors, performance of ADL, nursing support, and physician support accounted for 14.4%, 15.2%, 10.9%, and 7.3% of the variance in psychosocial distress, respectively.

Emotional well-being evidenced statistically significant, positive relationships with all of the experience and support variables (see Table 11).

Table 11

Illness/Treatment Experiences, Social Supports, and Adjustment

Subscales	**Psychosocial Distress** *r*	**Emotional Well-Being** *r*
Illness and Treatment Experiences	.42***	.50***
Physiological Stressors	.38***	.34***
Knowledge	.15	.31**
Performance of ADL	.39***	.36***
Self-health Management	.05	.28**
Social Supports	.30**	.59***
Family	.01	.27**
Nurses	.33***	.46***
Physicians	.27**	.57***
Allied Health	.05	.21*
Adjustment		
Psychosocial Distress	---	.46***

Note. * $p < .05$. ** $p < .01$. *** $p < .001$.

The findings indicated that individuals with greater emotional well-being were more likely to have fewer physiological stressors, to be more confident with their illness and treatment knowledge, to be more satisfied with performing routine ADL, and to be more involved in self-health management. As well, individuals with greater emotional well-being also tended to be more satisfied with family, nursing, physician, and allied health support. Based on the coefficient of determination (i.e., r^2), physiological stressors, performance of ADL, illness and treatment knowledge, and involvement in self-health management accounted for 11.6%, 9.6%, 13%, and 7.8% of the variance in emotional well-being, respectively. Finally, family, nursing, physician, and allied health support accounted for 7.3%, 21.2%, 32.5%, and 4.4% of the variance in emotional well-being.

Perception of ESRD and Hemodialysis and Quality of Life

There were statistically significant, positive relationships among most major components of the PPHS and the QLI (see Table 12). Many of these relationships were in the low to moderate range. The findings suggested that individuals with more positive perceptions of hemodialysis (i.e., attitudes toward illness and treatment, satisfaction with social supports, and adjustment to a new normal) were also more likely to have a higher overall quality of life and to more

Table 12

Perception of ESRD and Hemodialysis and Quality of Life

Subscales	**FA** *r*	**HF** *r*	**PS** *r*	**SE** *r*	**QLI** *r*
Illness/Treatment Experiences	.23*	.51***	.23*	.30**	.41***
Physiological Stressors	.24*	.46***	.25**	.31**	.39***
Knowledge	.00	.11	-.11	-.07	.00
Performance of ADL	.20*	.47***	.26**	.30**	.40***
Self-health Management	.09	.17	.14	.16	.19
Social Supports	.41***	.46***	.41***	.48***	.52***
Family	.27**	.15	.30**	.31**	.28**
Nurses	.22*	.38***	.22*	.29**	.35***
Physicians	.44***	.44***	.39***	.46***	.50***
Allied Health	.11	.18	.17	.22*	.20*
Adjustment to a New Normal	.39***	.62***	.51***	.54***	.62***
Psychosocial Distress	.24*	.48***	.37***	.43***	.47***
Emotional Well-being	.44***	.59***	.53***	.50***	.61***

Note. FA = Family. HF = Health and Functioning. PS = Psychological/Spiritual. SE = Social and Economic. QLI = Quality of Life Index.

* $p < .05$. ** $p < .01$. *** $p < .001$.

satisfied with valued aspects of family life, physical health and level of participation in family and social activities, psychological/spiritual well-being, and social and economic situations.

Based on the coefficient of determination (i.e., r^2), physiological stressors accounted for 5.8%, 21.2%, 6.3%, 9.6%, and 15.2% of the variance in the family, health and functioning, psychological/spiritual, and social and economic domains, and overall quality of life, respectively. Performance of ADL accounted for 4%, 22.1%, 6.8%, 9%, and 16% of the variance in the family, health and functioning, psychological/spiritual, and social and economic domains, and overall quality of life, respectively.

With regard to social support, family support accounted for 7.3%, 9%, 9.6%, and 7.8% of the variance in the family, psychological/spiritual, and social and economic domains, and overall quality of life, respectively. Nursing support accounted for 4.8%, 14.4%, 4.8%, 8.4%, and 12.3% of the variance in the family, health and functioning, psychological/spiritual, and social and economic domains, and the overall perceived quality of life, respectively. Physician support accounted for 19.4%, 19.4%, 15.2%, 21.2%, and 25% of the variance in the family, health and functioning, psychological/ spiritual, and social and economic domains, and the overall quality of life, respectively. Allied health support accounted for 4.8% and 4% of the variance in the social and economic domain and overall quality of life, respectively.

Finally, overall adjustment to a new normal revealed that psychosocial distress accounted for 5.8%, 23%, 13.7%, 18.5%, and 22.1% of the variance in the family, health and functioning, psychological/spiritual, and social and economic domains, and overall quality of life, respectively. As well, emotional well-being accounted for 19.4%, 34.8%, 28.1%, 25%, and 37.2% of the variance in the family, health and functioning, psychological/spiritual, and social and economic domains, and overall quality of life, respectively.

Predictors of Outcome

Stepwise multiple regression analysis was used to identify significant predictors of adjustment to a new normal (i.e., psychosocial distress and emotional well-being) and overall quality of life. Different combinations of predictor variables were used to identify the best regression model for each outcome variable. The illness and treatment experience variables (i.e., physiological stressors, knowledge about illness and treatment, performance of ADL, and self-health management) were entered first as a group for psychosocial distress and emotional well-being, followed by social support variables (i.e., family, nurses, physicians, and allied health), and personal characteristics or correlates. In addition, illness and treatment experience variables were entered first as a group for overall quality of life, followed by social support variables, adjustment variables, and correlates.

Psychosocial Distress

The first level modelling examined the predictive power of illness and treatment and social support variables for psychosocial distress. Correlational analysis demonstrated significant, positive relationships between less distress and fewer physiological stressors, greater satisfaction with performing ADL, and greater satisfaction with nursing and physician support. Only two correlates (i.e., age and illness severity) influenced distress.

During the first step of regression analysis, physiological stressors and performance of ADL combined to explain 21.7% of the variance in distress. Performance of ADL entered the regression equation first, accounting for 14.8% of the variance. Knowledge and self-health management failed to enter.

With the addition of the support variables at the second step, stressors became the dominant predictor variable. As well, nursing support was added and surpassed performance of ADL in predictive power. Family, physician, and allied health support failed to enter the regression equation. Stressors, nursing support, and performance of ADL combined to explain 30.7% of the variance in distress, contributing 17.2%, 9.1%, and 4.4%, respectively.

The correlates were entered at the final step. In the final model, physiological stressors, performance of ADL, nursing support, and illness severity combined to explain 36.4% of the variance in psychosocial distress (see

Table 13). Stressors was entered first, accounting for 17.2% of the explained variance. Stressors was followed by nursing support, illness severity, and performance of ADL, contributing 9%, 4.8%, and 5.4%, respectively.

Emotional Well-Being

The second level modeling examined the predictive power of illness and treatment and social support variables for emotional well-being. Correlation analysis demonstrated significant, positive relationships between emotional well-being and all of the illness and treatment experience and support variables. None of the correlates were found to influence well-being.

During the first step, all of the illness and treatment variables combined to explain 26.2% of the variance in emotional well-being. Performance of ADL entered the regression equation first, accounting for 12.7% of the variance. This variable was followed by physiological stressors, self-health management and knowledge about the illness and treatment which accounted for an additional 5.1%, 5%, and 3.4%, respectively.

When the support variables were added at the final step, physician and nursing support were added, and performance of ADL and knowledge removed. The final model revealed that four variables combined to explain 46.5% of the variance in emotional well-being (see Table 13). Physician support became the dominant predictor variable, accounting for 31.9% of the explained variance.

Table 13

Stepwise Multiple Regression on Psychosocial Distress, Emotional Well-Being, and Overall Quality of Life (Final Models)

	Multiple R	Adj. R^2	R^2 change	F Value	p
		Psychosocial Distress			
Physiological Stressors	.415	.164	.172	21.66	.000
Nursing Support	.513	.248	.090	18.36	.000
Illness Severity	.558	.291	.048	15.34	.000
Performance of ADL	.604	.339	.054	14.48	.000
		Emotional Well-being			
Physician Support	.565	.312	.319	48.73	.000
Physiological Stressors	.633	.389	.081	34.40	.000
Nursing Support	.660	.419	.035	26.28	.000
Self-health	.682	.444	.030	22.00	.000
		Overall Quality of Life			
Emotional Well-being	.610	.366	.372	60.94	.000
Age	.713	.498	.136	52.66	.000
Physiological Stressors	.745	.542	.047	42.08	.000
Performance ADL	.763	.566	.027	34.90	.000
Physician Support	.775	.580	.018	29.72	.000
Time on Dialysis	.787	.596	.019	26.62	.000

This variable was followed by stressors, nursing support, and self-health management which contributed an additional 8.1%, 3.5%, and 3%, respectively.

Overall Quality of Life

The third level modelling considered the predictive power of illness and treatment experience, social support, and adjustment variables, as well as correlates on overall quality of life. Quality of life depicted low to moderate positive correlations with physiological stressors, performance of ADL, and all of the support variables. As well, quality of life demonstrated moderate to strong positive correlations with psychosocial distress and emotional well-being, respectively. Four correlates (i.e., age, living arrangement, time on dialysis, and illness severity) were found to influence quality of life.

During the first step of regression analysis, performance of ADL and physiological stressors combined to explain 23.4% of the variance in quality of life, contributing 15.9% and 7.5%, respectively. Knowledge and self-health management failed to entered the regression equation.

At the second step, the only support variable to enter the regression equation was physician support. As well, knowledge about the illness and treatment was added. Physician support, stressors, performance of ADL, and knowledge combined to explain 46% of the variance in quality of life, contributing 24.9%, 13.6%, 3.5%, and 4.0%, respectively.

When the adjustment variables were added at the third step, emotional well-being became the dominant predictor, followed by psychosocial distress. Emotional well-being, psychosocial distress, knowledge, performance of ADL, physician support, and stressors combined to explain 56.4% of the variance in quality of life, contributing 37.2%, 5.5%, 3.6%, 4.2%, 3.5%, and 2.4%, respectively.

Two correlates, age and time on dialysis, entered the regression model at the final step. Distress and knowledge were removed. The final model revealed that emotional well-being, age, stressors, performance of ADL, physician support, and time on dialysis combined to explain 61.9% of the variance in quality of life (see Table 13). Emotional well-being entered first, accounting for 37.2% of the explained variance. This variable was followed by age, stressors, performance of ADL, physician support, and time on dialysis which contributed an additional 13.6%, 4.7%, 2.7%, 1.8%, and 1.9%, respectively.

Reliability and Validity of Study Instruments

The reliability and validity of the PPHS and QLI were also examined for the study sample. Cronbach's alpha was used to assess internal consistency. The intercorrelations among subscales and total scores were used to determine construct validity of study instruments.

PPHS

The total instrument had an alpha coefficient of .91, indicating a high level of internal consistency. Alpha coefficients for the three major subscales ranged from .71 to .88: adjustment to a new normal (.88), social supports (.84), and illness and treatment experiences (.71). These findings indicate that the total scale and major subscales have good internal consistency.

All of the major subscale scores depicted strong, positive correlations with the total PPHS score. Social supports had the lowest and overall adjustment the strongest correlation with the total scale (see Table 14). Furthermore, all of the intercorrelations among the major subscales were statistically significant and within the moderate to strong range, indicating very good construct validity.

With regard to the individual subscales comprising illness and treatment experiences, alpha coefficients ranged from .43 to .70: self-health management (.43), performance of ADL (.49), knowledge about illness and treatment (.61), and physiological stressors (.70). The alpha coefficients for the individual subscales comprising social supports ranged from .51 to .89: allied health (.51), family (.53), nurses (.82), and physicians (.89). Finally, the alpha coefficients for the emotional well-being and psychosocial distress subscales of overall adjustment were .84 and .86, respectively. The findings indicated that the individual subscales comprising the experience, supports, and adjustment scales

Table 14

Correlations Among PPHS and Major Subscales

Variable	Experiences	Supports	Adjustment
Experiences			
Supports	.34***		
Adjustment	.54***	.49***	
PPHS	.77***	.71***	.91***

Note. Experiences = Illness and Treatment Experiences Scale. Supports = Social Supports Scale. Adjustment = Adjustment to a New Normal Scale. PPHS = Patient Perceptions of Hemodialysis Scale.

*** $p < .001$.

have a fair to very good internal consistency. The low reliability scores for some of the subscales (i.e., self-health management, allied health, and family) could be attributed to the small number of items comprising these subscales.

In addition, the individual subscales of the illness and treatment experience scale were significantly correlated with the overall experience score. Specifically, self-health management, *r* = .41, *p* = .000, knowledge, *r* =. 58, *p* = .000, performance of ADL, *r* = .65, *p* = .000, and physiological stressors, *r* = .78, *p* = .000, depicted moderate to strong positive correlations with the illness and treatment experience scale. As well, the individual subscales of the social supports scale significantly correlated with overall supports. Specifically, allied health, *r* = .43, *p* = .000, family, *r* = .53, *p* = .000, physicians, *r* = .81, *p* = .000, and nurses, *r* = .82, *p* = .000, depicted moderate to strong, positive correlations with the social supports scale. Finally, psychosocial distress and emotional well-being were significantly correlated with the overall adjustment score. Specifically, psychosocial distress, *r* = .90, *p* = .000 and emotional well-being, *r* = .80, *p* = .000, depicted strong, positive correlations with overall adjustment.

In summary, the findings suggest that all of the major subscales are measuring some aspect of individuals' perceptions of hemodialysis. As well, the findings suggest that the major subscales are related and represent distinct dimensions of individuals' perceptions. Finally, study findings suggest that the PPHS has good construct validity.

QLI

Alpha coefficients were also generated for the QLI and its subscales. The alpha coefficient for the total score was .94. The subscale alphas ranged from .56 to .92: family (.56), health and functioning (.89), psychological/spiritual (.92), and social and economic (.82). These findings indicate that the subscales have moderate to high internal consistency.

The QLI subscale scores demonstrated moderate to strong, positive associations with the total score (see Table 15). The family subscale had the lowest correlation with the total scale, $r = .73$, $p = .000$, and health and functioning the strongest, $r = .91$, $p = .000$. The findings suggest that all of the subscales are measuring some aspect of quality of life.

All of the intercorrelations among the subscales were statistically significant and within the moderate to strong range. These findings suggest that the subscales are related and represent distinct dimensions of quality of life. In summary, the intercorrelations among the subscales and the subscales to total scale suggest that the QLI has good construct validity.

Table 15

Correlations Among QLI and its Subscales

Variable	FA	HF	PS	SE
Family (FA)				
Health and Functioning (HF)	.58***			
Psychological/Spiritual (PS)	.66***	.69***		
Social and Economic (SE)	.60***	.65***	.78***	
Quality of Life Index (QLI)	.73***	.91***	.89***	.86***

*** $p < .001$.

Summary

Study participants were generally positive about illness and treatment experiences, social supports, and adjustment to a new normal. Participants were most positive about supports. Demographic (i.e., living arrangement, gender, and age) and medical risk factors (i.e., frequency and type of comorbid illness and time on dialysis) variables were found to exert significant, but minimal, effects on participants' perceptions of ESRD and hemodialysis. While the demographic variables were more likely to influence perceptions of support systems, medical risk factors were more likely to influence perceptions of illness and treatment experiences.

The findings also demonstrated that most participants were quite satisfied with their overall quality of life. With regard to the specific domains of quality of life, participants indicated that they were satisfied with valued aspects of their family life, their physical health and ability to participate in family and social activities, their psychological and spiritual well-being, and their social and economic situation. As well, participants were most satisfied with the family aspects of their lives, and least satisfied with their personal health and functioning. Two demographic variables (i.e., living arrangement and age) and two medical risk factors (i.e., illness severity and time on dialysis) were found to exert a significant, but minimal, influence on perceived overall quality of life and specific quality of life domains.

Most of the illness and treatment experience and support variables depicted significant, positive relationships with the adjustment variables. That is, less physiological stressors and greater performance of ADL were associated with less psychosocial distress. Whereas, less stressors, greater knowledge about illness and treatment, greater performance of ADL, and greater participation in self-health management were associated with greater emotional well-being. As well, greater satisfaction with nursing and physician support were associated with less distress. Finally, greater satisfaction with family, nursing, physician, and allied health support were associated with a greater emotional well-being.

Most of the perception of ESRD and hemodialysis variables were also significantly and positively related to overall quality of life and its major components. Specifically, more positive illness and treatment experiences, greater satisfaction with social supports, and more positive adjustment to a new normal were associated with a greater perceived overall quality of life, as well as greater satisfaction with family life, health and functioning, psychological and spiritual well-being, and social and economic aspects of life.

Different combinations of illness and treatment experiences and support variables emerged as significant predictors of adjustment to a new normal. One support variable (i.e., nurses), two experience variables (i.e., physiological stressors and performance of ADL), and one correlate (illness severity) emerged as significant predictors of psychosocial distress, accounting for 36.4% of the explained variance. Two support variables (i.e., physicians and nurses) and two experience variables (physiological stressors and self-health management) emerged as significant predictors of emotional well-being, accounting for 46.5% of the explained variance. Emotional well-being, two experience variables (i.e., physiological stressors and performance of ADL), one support variable (i.e., physicians), and two correlates (i.e., age and time on dialysis) emerged as significant predictors of overall quality of life, accounting for 61.9% of the explained variance.

CHAPTER 5

Discussion

The current study examined the separate and interactive effects of illness and treatment experiences, social supports, adjustment to a new normal, and quality of life for individuals living with ESRD and hemodialysis. The LESRD-H model was used as the conceptual framework.

The LESRD-H model proposes that illness and treatment experiences, social supports, and adjustment to a new normal exert separate and interactive effects on quality of outcome. As well, adjustment is viewed as an intermediate state which moderates the impact of experiences and supports. This conjecture does not ignore the direct influence of experiences and supports on outcome. A major model implication is that adjustment is a psychosocial state amenable to intervention from health care providers. The discussion of findings is organized according to major components of the LESRD-H model and the proposed relationships among them.

Perception of ESRD and Hemodialysis

A focus of the current study was to investigate how individuals living with ESRD and hemodialysis perceive illness and treatment experiences, social supports, and adjustment to a new normal. The discussion is organized according to these constructs.

Illness and Treatment Experiences

Illness and treatment experiences have been identified as important determinants of outcome in the hemodialysis population. Frequency of physiological stressors (i.e., disease- and treatment-related), confidence with illness and treatment knowledge, satisfaction with performance of ADL, and active participation in self-health management were key aspects of illness and treatment experiences selected for investigation in the current study. The separate and interactive effects among these factors are believed to exert a powerful influence on acceptance of the illness and long-term treatment requirements.

The frequency of physical symptoms associated with ESRD and hemodialysis treatment is a significant force shaping attitudes toward illness and treatment experiences. The moderate level of physiological stressors documented in the current study is comparable to the findings of Baldree et al. (1982), Gurklis and Menke (1995), Killingworth and Van Den Akker (1996), and Parfrey et al. (1988). In contrast, other researchers have documented infrequent or slight severity of illness- and treatment-related stressors in the hemodialysis population (Bihl et al., 1988; Fuchs & Schreiber, 1988; Gurklis & Menke, 1988; Klang & Clyne, 1997; Lev & Owen, 1998; Parfrey et al., 1989). The most problematic areas in the current study were feelings of exhaustion following dialysis, generally feeling tired and low on energy, hypotensive episodes, and muscle cramps. Similar findings were reported by Gregory et al. (1998) and Gurklis and Menke (1995). Other researchers have also found that fatigue and general tiredness create difficulties for individuals on hemodialysis (Bihl et al.; Cormier-Daigle & Stewart, 1997; Faber, 2000; Fuchs & Schreiber; Gurklis & Menke, 1988; Killingworth & Van Den Akker; Klang & Clyne; Lev & Owen; Lok, 1996; Parfrey et al., 1988; Welch & Austin, 1999; White & Grenyer, 1999).

In the current study, participants were moderately confident with their understanding of the benefits and side-effects of dialysis, the need for diet and fluid restrictions, causal factors responsible for the illness, and requirements for a kidney transplant. Only qualitative studies were identified from the literature reviewed for the current study that examined confidence with understanding the illness and treatment in the hemodialysis population. Gregory et al. (1998), Gurklis and Menke (1995), Kutner (1987), and Nagle (1998) found support for the importance attached to learning about the disease and treatment regimes for successful adaptation to a new normal.

Participation in self-care is viewed as an important force facilitating acceptance of and adjustment to a chronic illness with long-term treatment requirements. In the current study, most participants were moderately satisfied with their ability to perform ADL (i.e., recreation, household, and self-care). In a somewhat similar vein, Christensen et al. (1992), Kimmel et al. (1996), Killingworth and Van Den Akker (1996), Klang and Clyne (1997), Kimmel et al.

(1998), Kovac et al. (2002), and Patel et al. (2002) found that individuals on hemodialysis experience minor impairments in activities of daily living. In addition, participants in the current study reported being involved in self-health management (i.e., following recommended diet and fluid restrictions, monitoring nurses activities and physical well-being during dialysis, and informing the nurse about problems during dialysis). Similarly, Lev and Owen (1998) found that individuals on hemodialysis were moderately confident with using self-care measures to modify physical and psychosocial stressors. As well, several authors (Gregory et al., 1998; Gurklis & Menke, 1995; Jones & Preuett, 1986; Kutner, 1987; Nagle, 1998) have found that individuals tend to recommend treatment plans and assume a great deal of responsibility for monitoring health states and providers' activities.

Social Supports

There is considerable evidence for the strong influence of social supports on adjustment to chronic illness and long-term treatment. The empirical evidence is also fairly convincing on how supportive networks help buffer the impact of negative illness and treatment events.

In the current study, participants were very satisfied with overall supports. Several authors (e.g., Gregory et al., 1998; Gurklis & Menke, 1995; Kimmel et al., 1996; Kimmel et al., 1998; Kimmel et al., 2000; Kovac et al., 2002; Kutner, 1987; Patel et al., 2002; Siegal et al., 1987; Weil, 2000) have found that individuals on hemodialysis tend to give moderate to strong ratings to social supports. In the current study, participants were most satisfied with support from nurses, physicians, families, and allied health professionals, respectively. In contrast, Gregory et al., Gurklis and Menke, Kutner, Siegal et al., and Weil reported greater satisfaction with family than with health care providers support. One possible explanation for these conflicting findings could be the emphasis placed on assessing satisfaction with nursing and medical care in the current study. Surveys of individuals' views of health care have documented generally high levels of satisfaction with health care providers. A second explanation for the different findings is the small number of items forming the family and allied health professionals subscales and the resulting low internal consistencies (i.e., .51 to .53).

In this study, participants were quite satisfied with family members' efforts to facilitate acceptance of illness and treatment regimes. As well, participants tried to reduce the impact of the illness and treatment on family members. Comparable study findings exist on the reciprocity within families (Gregory et al., 1998; Gurklis & Menke, 1995; Kutner, 1987; Weil, 2000; White & Grenyer, 1999).

Health care providers play an important role in facilitating adjustment to ESRD and hemodialysis. In the current study, nurses and physicians were seen as providing useful information and being quite knowledgeable, competent, and caring. Ferrans et al. (1987) and Gregory et al. (1998) reported comparable findings. As well, Gurklis and Menke (1995), Kutner (1987), Siegal et al. (1987) and Kovac et al. (2002) found that participants rated nurses and physicians as being quite helpful. In the current study, most participants gave comparable ratings to the informational and emotional supportiveness of nurses and physicians. In contrast, Kovac et al. noted that participants tend to rate the caring behaviors of physicians and dialysis staff higher than informational support. Finally, participants in the current study were very satisfied with allied health support. Only Gurklis and Menke commented on the perceived helpfulness of social workers and dieticians.

Adjusting to a New Normal

While some individuals enjoy a fairly high level of emotional well-being, others are greatly distressed and overwhelmed by the scope and magnitude of the impact of the illness and treatment requirements. Although distress and well-being are normally viewed as occupying opposite ends of a continuum, they are not perfect opposites, especially when different feeling states are being assessed as in the current study. Nevertheless, successful adjustment to the many losses associated with ESRD and hemodialysis treatment requires that individuals create a meaningful balance between distress and well-being.

In the current study, participants were experiencing low to moderate psychosocial distress. Kimmel et al. (1996), Kimmel et al. (1998), Kimmel et al. (2000), Klang and Clyne (1997), Kovac et al. (2002), Lev and Owen (1998), Patel et al. (2002), and Sacks et al. (1990) found that individuals were experiencing low levels of depression and/or minor difficulties with adjustment. In contrast, some authors found indications of clinical levels of anxiety and depression (Killingworth & Van Den Akker, 1996, Siegal et al., 1987; Walters et al., 2002) and significant psychosocial maladjustment (Killingworth & Van Den Akker) in samples of individuals on hemodialysis. In the current study, the greatest difficulties were posed by dependency concerns, worries about the impact of illness and treatment on family members, dwelling on diet and fluid restrictions, and feeling depressed or worried about illness severity and long term treatment requirements. In contrast, the hemodialysis environment (e.g., seeing others becoming ill, sense of belonging, etc.) was seen as mildly distressful. Several qualitative studies (e.g., Faber, 2000; Gregory et al., 1998; Kutner, 1987; Nagle, 1998; O'Brien, 1983) have provided insight into how individuals struggle with dependency issues, consequences of not complying with treatment plans, severity of the illness, and chronicity of treatment. As well, several authors (e.g., Faber; Gregory et al.; Nagle; Rittman et al., 1993) have noted that adjustment to the hemodialysis environment involves striking a balance between positive and negative events.

In the current study, participants reported high levels of emotional well-being (i.e., accepting of and adjusting to the limitations imposed by the illness/treatment). Specifically, participants were quite accepting of hemodialysis (i.e., daily norm, relaxed during treatment, special closeness with dialysis peers, and adjusting to negative treatment effects) and were coping well with the challenges posed by the illness and treatment (i.e., positive attitude, satisfied with time spent with family/friends, confident about coming to terms with the illness, and perceptions of improved quality of life). As well, participants were adjusting to financial costs, felt somewhat stronger as a person, and felt in control of illness and treatment effects. Similar findings on the moderate to strong acceptance of and adjustment to the illness and treatment by individuals with ESRD and receiving hemodialysis are reported in the literature (Gregory et al., 1998; Keogh & Feehally, 1999; Nagle, 1998; O'Brien, 1983; Rittman et al., 1993). As well, several authors have found that study participants relied more on positive than negative coping strategies (Baldree et al., 1982; Cormier-Daigle & Stewart, 1997; Faber, 2000; Gregory et al.; Gurklis & Menke, 1988, 1995; Lok, 1996; Nagle; Rittman et al.).

Quality of Outcome

The outcome variable selected for investigation in the current study was quality of life. The focus was on satisfaction with overall quality of life and important life domains (i.e., family, health and functioning, psychological/spiritual, and social and economic).

Study participants were quite satisfied with their overall quality of life. The overall score was considerably higher than the normative value (i.e., 20.70) obtained from a random sample of in-center hemodialysis patients by Ferrans and Powers (1993). These authors also noted that the baseline score was only slightly below healthy population levels. Similar findings on the close proximity of life satisfaction and overall quality of life scores for hemodialysis and healthy populations were reported by Bihl et al. (1988), Killingworth and Van Den Akker (1996), Kimmel et al. (1996), Lok (1996), Kimmel et al. (1998), and Patel et al. (2002).

The rankings of life domains in the current study (i.e., most satisfied with the family, psychological/spiritual, socioeconomic, and health and functioning domains, respectively) are consistent with those of Ferrans and Powers (1993). In contrast, participants in Bihl et al.'s (1988) study were least satisfied with social and economic conditions.

Factors Influencing Adjustment and Quality of Life

The LESRD-H model proposes that illness and treatment experiences, social supports, and adjustment to a new normal exert separate and interactive effects on quality outcome. The model also proposes that adjustment acts as an intermediate outcome (i.e., buffers the impact of experiences and supports). The following discussion is organized according to the various relationships described in the LESRD-H model.

Adjustment to a New Normal

A focus of the current study was to examine whether illness and treatment experiences, social supports, and personal characteristics were significantly related to adjustment to a new normal. The discussion is organized according to the major dimensions of adjustment - psychosocial distress and emotional well-being.

Psychosocial distress. In the current study, psychosocial distress correlated with select aspects of illness and treatment experiences. Participants who were more satisfied with their ability to perform ADL and experienced fewer physiological stressors were less distressed. Confidence with illness and treatment knowledge and self-health management failed to correlate with distress.

The theoretical and research literature revealed numerous indicators for psychosocial distress (e.g. anxiety, depression, psychosocial maladjustment, social disruptions, etc.). Similar to the current study's findings, Killingworth and Van Den Akker (1996), Kimmel et al. (1996), and Patel et al. (2002) found that participants experiencing less difficulties with activities of daily living also evidenced less anxiety and depression. In a somewhat similar vein, Kimmel et al. (1996), Kimmel et al. (1998), and Sacks et al. (1990) found support for the impact of perceived illness intrusiveness in various life domains on depression levels (i.e., greater illness intrusiveness, greater depression). In addition, Killingworth and Van Den Akker found that greater severity of physical symptoms was associated with greater anxiety and depression. In contrast to the current study's findings, Lev and Owen (1998) found that greater confidence in using self-care strategies to promote health significantly correlated with less mood distress.

There are also comparable research findings to the current study on other forms of distress. Killingworth and Van Den Akker (1996) and Kimmel et al. (1996) found that increased difficulties with activities of daily living was associated with greater overall psychosocial maladjustment and social maladjustment, respectively. Similarly, Kimmel et al. (1996) and Sacks et al. (1990) found that greater perceived illness intrusiveness correlated with greater psychosocial maladjustment (i.e., social, vocational, and extended family and sexual relationships) and greater role disruptions, respectively. As well, Devins et al. (1997) and Killingworth and Van Den Akker found that greater severity of physical symptoms was significantly associated with greater emotional distress and greater overall psychosocial maladjustment, respectively.

In the current study, greater satisfaction with overall supports and the supportiveness of nurses and physicians were significantly correlated with less psychosocial distress. Satisfaction with the supportiveness of family and allied health professionals were not significant correlates of this construct. In contrast to the current study's findings, Kovac et al. (2002) failed to find an association between depression and satisfaction with physicians and dialysis staff. As well, Kimmel et al. (1996) and Kimmel et al. (2000) found that greater overall social support and greater satisfaction with marital or partner relationships correlated with less overall and cognitive depression. Finally, Kimmel et al. (2000) found that increased dyadic conflict was significantly correlated with increased depression.

Kimmel et al. (1996) found that lower perceived overall support was associated with increased social and vocational maladjustment. Despite the significant link between less satisfaction with marital or partner relationships and greater family and sexual maladjustment in both incident and prevalent groups, this variable only significantly correlated with greater social maladjustment in the prevalent group. Siegal et al. (1987) also found that less perceived supportive family and friends correlated with increased psychological symptoms.

An important focus of the current study was to examine the effects of demographic and medical risk factors on psychosocial distress. Gender, living arrangements, length of time on dialysis, and number or type of comorbid illness did not influence distress levels. Only illness severity and age exerted significant, but low, effects (i.e., greater illness severity and older age with less distress). These findings are counter to expectations. One possible explanation is that older people are already dealing with declining health and increasing dependency on others and may, therefore, less distressed by ESRD and its treatment requirements. Given the fact that age is a key factor used to calculate illness severity scores, one would expect both of these variables to correlate with other variables in a similar fashion.

Other researchers have not consistently found support for the effects of personal characteristics on anxiety and depression levels in the hemodialysis population. Some researchers failed to document a significant effect for age (Killingworth & Van Den Akker, 1996; Kimmel et al., 1998; Klang & Clyne, 1997; Patel et al. 2002), gender (Killingworth & Van Den Akker; Kimmel et al., 2000; Kovac et al. 2002), presence of a stable relationship (Kimmel et al., 2000), or time on dialysis (Killingworth & Van Den Akker; Kimmel et al., 1998; Sacks et al., 1990). In contrast to the current study's findings, Sacks et al. found that increased age was associated with greater depression. While Sacks et al. found that greater illness severity was associated with increased depression, Kimmel et al. (1996) failed to document such an effect. Finally, while Sacks et al. found higher cognitive depression levels for women, Patel et al. found that men had higher cognitive and overall depression levels than women.

Inconsistent findings were also evident in studies focusing on psychosocial adjustment. Kimmel et al. (1996) and Sacks et al. (1990) found that older age and greater illness severity significantly correlated with greater extended family and sexual maladjustment and increased role disruptions, respectively. Conversely, Devins et al. (1997) failed to document a direct effect for age on emotional distress. Gender was not found to exert a significant effect on role disruptions (Sacks et al.) or emotional distress (Devins et al.). Finally, while Kimmel et al. found that individuals on dialysis for greater than six months had lower family and sexual adjustment scores, Segal et al. (1987) documented greater psychological adjustment for those on dialysis for longer periods of time.

Emotional well-being. In the current study, emotional well-being correlated with all aspects of the illness and treatment experience. Participants who had infrequent physiological stressors, were more satisfied with performance of ADL, were more confident with illness and treatment knowledge, and were actively involved in self-health management were significantly more likely to evidence greater emotional well-being.

The literature also revealed different indicators for emotional well-being (e.g. coping, psychosocial well-being, illness acceptance, etc.). Similar to the current study, there is some support from both qualitative and quantitative studies for the association between less frequent and severe physical stressors and greater emotional well-being (Devins et al., 1997; Gurklis & Menke, 1988;

Lok, 1996; Gregory et al., 1998). Consistent with the current study's findings, the importance of coming to know and understand the illness and treatment emerged as an integral force facilitating adjustment to a new normal in several qualitative studies (Faber, 2000; Gregory et al.; Gurklis & Menke, 1995; Kutner, 1987; Nagle, 1998; Rittman et al., 1993). Qualitative study findings also provide support for the important link between greater participation in activities of daily living and increased psychosocial well-being and greater illness acceptance (Gregory et al.; Gurklis & Menke, 1995; Nagle; Weil, 2000). Finally, several studies (Faber; Gregory et al.; Jones & Preuett, 1986; Nagle; Rittman et al.) highlight the importance of self-health management for achieving a greater sense of normalcy and overall well-being.

In the current study, greater emotional well-being significantly correlated with greater satisfaction with overall supports, and greater satisfaction with the supportiveness of family members, nurses, physicians, and allied health professionals. Although there is no single factor that facilitates adjustment to a changing self, research findings highlight the key role played by supports. Within the hemodialysis literature, there is some evidence suggesting that positive appraisal of overall supports is associated with greater illness acceptance and more effective coping (Cormier-Daigle & Stewart, 1997; Gurklis & Menke, 1995; Patel et al., 2002). As well, supportive family environments have been identified as a crucial factor in promoting illness acceptance, positive coping, and overall well-being (Faber, 2000; Gregory et al., 1998; Gurklis & Menke; Kutner, 1987; Weil, 2000; White & Grenyer, 1999). Comparable findings have been reported on the positive influence of emotional, instrumental, and informational support from health care providers, especially nurses and physicians, on illness and treatment acceptance and adjustment to a new normal (Gregory et al.; Gurklis & Menke; Kutner; Nagle, 1998).

None of the personal characteristics examined in the current study were found to exert a significant effect on emotional well-being. Similar to the current study, most of the studies reviewed failed to document a significant effect for age (Baldree et al., 1982; Cormier-Daigle & Stewart, 1997; Devins et al., 1997), gender (Baldree et al.; Devins et al.; Keogh & Feehally, 1999), or length of time on dialysis (Baldree et al.; Lok, 1996). The exceptions were the significant relationship between younger age and increased illness acceptance (Keogh & Feehally), and increased time on dialysis and increased coping (Gurklis & Menke, 1988). Counter to the current study's findings, Devins et al. found that individuals with less comorbidity evidenced greater well-being.

Quality of Life

Illness and treatment experiences, social supports, adjustment to a new normal, and personal characteristics were examined for their effects on overall quality of life, and the individual life domains defining this construct (i.e., health and functioning, social and economic, psychological/spiritual, and family). Fewer physiological stressors and greater satisfaction with performance of ADL were significantly correlated with greater overall life satisfaction, health and functioning (i.e., physical health and participation in family/social activities), psychological and spiritual well-being, social and economic conditions, and family life. Confidence with illness and treatment knowledge and involvement in self-health management were not found to correlate with overall quality of life or any of its components.

There were few comparable studies found in the literature that specifically examined the effects of illness and treatment experiences on quality of life. Similar to the current study's findings, Barrett et al (1990), Killingworth and Van Den Akker (1996), and Lok (1996) reported that more frequent physiological stressors were associated with a diminished overall quality of life. Lok also found that a greater frequency of psychosocial stressors was associated with a lower quality of life. Counter to the current study's findings, Killingworth and Van Den Akker, Kimmel et al. (1996), and Patel et al. (2002) failed to document a significant relationship between the level of assistance required in performing activities of daily living and quality of life. However, Kimmel et al. and Patel et al. did find that greater perceived illness intrusiveness in important life domains (i.e., subjective level of function) significantly correlated with lower overall life satisfaction and quality of life, respectively.

In the current study, greater satisfaction with overall supports and the supportiveness of family members, nurses, and physicians depicted significant correlations with greater satisfaction with overall quality of life, psychological and spiritual well-being, social and economic conditions, and family life. As well, greater satisfaction with allied health support was linked with greater satisfaction with overall quality of life and social and economic situations. Finally, greater satisfaction with overall supports and nursing and physician support significantly correlated with greater satisfaction with health and functioning.

The positive effect of overall social supports on satisfaction with important life domains found in the current study is consistent with other findings on the hemodialysis population (Kimmel et al., 1996; Patel et al., 2002; Tell et al., 1995). Kimmel et al. found that greater satisfaction with marital or partner relationships significantly correlated with greater life satisfaction. Inconsistent findings exist on the influence of health care provider support on quality of life. Ferrans et al. (1987) found that greater satisfaction with overall care and its components (i.e., physicians, nurses/dialysis environment, and financial/ transportation) were associated with greater satisfaction with overall quality of life, health and functioning, psychological and spiritual well-being, social and economic situations, and family life. Patel et al. also found a positive effect for satisfaction with physician care, but not the dialysis staff (i.e., nursing and technical).

In the current study, less psychosocial distress and greater emotional well-being were significantly correlated with greater satisfaction with overall quality of life, health and functioning, psychological and spiritual well-being, social and economic situations, and family life. A few studies were identified from the literature that investigated the relationship of distress and well-being with quality of life.

Similar to the current study's findings, Killingworth and Van Den Akker (1996) found that greater overall psychosocial maladjustment significantly correlated with a lower overall quality of life. Kimmel et al. (1996) found that greater social, vocational, and family and sexual maladjustment significantly correlated with less life satisfaction in the incident group, whereas only greater social maladjustment correlated with less life satisfaction in the prevalent group. Conflicting findings also exist on the effects of anxiety and depression on quality of life. While Kimmel et al. and Patel et al. (2002) have documented significant associations between less life satisfaction and greater cognitive and overall depression, Killingworth and Van Den Akker failed to find a significant effect. Finally, the positive correlation between emotional well-being and quality of life in the current study is similar to that found between greater coping effectiveness and increased quality of life (Lok, 1996; Patel et al.)

Personal characteristics had a minimal effect on quality of life. Specifically, participants living with a spouse were more satisfied with their overall quality of life and family life than their counterparts living with other individuals. Individuals living alone or with a spouse were more satisfied with their psychological and spiritual well-being than those living with other individuals. Older participants were more satisfied with their overall quality of life and all of its components than younger participants. Participants on dialysis for longer periods of time were less satisfied with their overall quality of life, health and functioning, and psychological and spiritual well-being than those on dialysis for shorter periods. Finally, individuals with greater illness severity were more satisfied with their overall quality of life, social and economic situations, and psychological and spiritual well-being. As Kimmel et al. (1995) note, it is not evident why increased illness severity and greater age are associated with greater life satisfaction. With age a major factor in constructing illness severity scores, these authors conjecture that "perhaps older patients have achieved more of an accommodation to the constraints of chronic illness and appreciation for life than younger patients" (p 1424).

The research literature revealed inconsistent findings on the impact of personal characteristics on quality of life. The positive effect of age on quality of life observed in the current study concurs with the findings of Ferrans and Powers (1993), Kimmel et al. (1996), Kimmel et al. (1998), and Patel et al. (2002). In contrast, Tell et al. (1995) failed to find a significant effect for age. The non-significant effects of gender on quality of life is comparable to other study findings (Ferrans & Powers; Lok, 1996; Patel et al.; Tell et al.). The paradoxical relationship noted between greater illness severity and greater quality of life in the current study was also reported by Kimmel et al. (1995), Kimmel et al. (1996), and Kimmel et al. (1998).

Predictors of Adjustment and Quality of Life

An important focus of the current study was to identify the best predictors of adjustment to a new normal and overall quality of life. Stepwise multiple linear regression was used for this purpose. The following discussion is organized according to major outcomes.

Adjustment to a New Normal

The LESRD-H model proposes that illness and treatment experiences and social supports have a direct impact upon the psychosocial distress and emotional well-being components of adjustment to a new normal. The model also postulates that personal characteristics (i.e., demographic variables and medical risk factors) will have a significant, but minimal, impact on adjustment.

Psychosocial distress. In the current study, two illness and treatment experience variables (i.e., physiological stressors and performance of ADL), one support variable (i.e., nursing support), and personal characteristic (i.e., illness severity) emerged as significant predictors of psychosocial distress. The illness and treatment experience variables accounted for 22.6% of the explained variance, with frequency of physiological stressors surfacing as the best predictor (i.e., 17.2%). These findings provide partial support for the direct effect of illness and treatment experiences on distress levels.

Only one study was identified from the ESRD literature that examined the predictive power of stressors for distress levels. In a study of individuals receiving variant forms of renal replacement therapy, Devins et al. (1997) found that more frequent uremic symptoms were predictive of greater emotional distress (i.e., 7.8% of the explained variance). Although no studies specifically examined the effects of satisfaction with performance of ADL, a couple of studies did investigate the predictive power of a similar variable (i.e., perceived illness intrusiveness in select life domains). Sacks et al. (1990) found that greater perceived illness intrusiveness accounted for 43% of the explained variation in greater overall depression. Kimmel et al. (1995) also reported that greater perceived illness intrusiveness was a significant predictor of greater social maladjustment, but only contributed 5% to the explained variance. Finally, Devins et al. found that greater perceived illness intrusiveness emerged as a significant predictor of greater distress.

The current study's findings also support the direct effect of satisfaction with nursing support and illness severity (i.e., 9% and 4.8% of the explained variance, respectively) on distress levels. No studies were identified from the literature reviewed for the current study that examined the predictive power of nursing support for distress. Similar to the current study, Kimmel et al. (1995) found that illness severity (5%) made minimal contributions to the explained variance in greater social maladjustment. Sacks et al. (1990) also reported that greater illness severity was a significant predictor of greater overall depression (i.e., 8.5% of the explained variance).

Counter to the current study's findings, Siegal et al. (1987) found that active employment and a shorter length of time on dialysis were significant predictors of greater adjustment (i.e., explained 19.4% of the variance). As well, Sacks et al. reported that gender accounted for 6.9% of the explained variance in depression. Finally, Devins et al. (1997) found that age exerted a significant main effect on distress levels.

Emotional well-being. In the current study, two illness and treatment experience variables (i.e., physiological stressors and self-health management) and two support variables (i.e., nursing and physician) emerged as significant predictors of emotional well-being. Greater satisfaction with physician support was the dominant predictor variable (i.e., 31.9% of the explained variance), followed by fewer physiological stressors (8.1%), more positive perceptions of nursing support (3.5%), and greater self-health management (3%). These findings provide partial support for the direct effect of experience and social support variables on emotional well-being.

No comparable studies were identified in the literature reviewed that used regression analysis to examine the effect of social supports on emotional well-being. However, Devins et al. (1997) investigated the effects of illness and treatment experiences (i.e., uremic symptoms and illness intrusiveness), self concept and age on well-being. Similar to the current study, fewer uremic symptoms was predictive of greater overall well-being. Counter to the current study's findings, greater perceived illness intrusiveness emerged as a significant predictor of reduced overall well-being, and age was found to exert a main effect.

Quality of Life

The LESRD-H model proposes that illness and treatment experiences, social supports, adjustment to a new normal, and personal characteristics exert direct effects on overall quality of life. It is also postulated that experience and support variables, as well as personal characteristics, exert an indirect effect on quality of life through the intervening adjustment variables. Study findings provide partial support for the LESRD-H model.

As predicted, the contributions of experience and support variables were significantly reduced when emotional well-being entered the model and became the dominant predictor variable (i.e., 37.2% of the variance). Counter to expectations age became the second best predictor (i.e., 13.6% of the variance) and psychosocial distress failed to enter the model. The final model revealed that greater emotional well-being, fewer physiological stressors, greater satisfaction with performance of ADL, greater satisfaction with physician support, older age, and less time on dialysis combined to explain 62% of the variance in overall quality of life. It is important to note that even when emotional well-being was not included in the predictor variable list, psychosocial distress still failed to enter the final model. Thus, the predictive power of this variable for overall quality of life certainly requires further investigation.

Few studies have assessed the predictive power of experience, support, and adjustment variables, as well as correlates, for quality of life in the hemodialysis population. Similar to the current study, Kimmel et al. (1995) found that less perceived illness intrusiveness was a significant predictor of greater life satisfaction. As well, while social maladjustment was not a significant predictor, greater perceived overall supports (i.e., included physician supports) was a significant predictor of life satisfaction. Counter to the current study's findings, Kimmel et al. found that greater illness severity had a significant effect on greater life satisfaction. Tell et al. (1995) also reported that greater perceived social support was a significant predictor of greater life satisfaction and more positive feelings about life. Inconsistent findings have been reported on the effects of age on quality of life. While Ferrans and Powers (1993) found that older age made a significant, but minimal, contribution to greater overall quality of life, Tell et al. failed to document a significant effect for age on life satisfaction and feelings about life. Counter to the current study's findings, Ferrans and Powers and Tell et al. failed to find a significant effect for time on dialysis.

Implications of Findings for the LESRD-H Model

The current study's findings provided partial support for the major assumptions of the LESRD-H model. Overall, the findings support the premise that different combinations of experience and support variables exert a direct effect on adjustment (i.e., psychosocial distress and emotional well-being) and overall quality of life.

In partial support of model predictions, experience and support were significant predictors of psychosocial distress and emotional well-being. Knowledge about the illness and treatment, family support, and allied health support failed to exert a significant effect on the adjustment variables. As well, study findings provide partial support for the predictive power of experience, support, psychosocial distress, and emotional well-being for quality of life. Knowledge, self-health management, family support, nursing support, allied health support, and psychosocial distress failed to exert a significant independent effect on overall quality of life. More research is needed to investigate the predictive power of illness and treatment experiences and social supports for adjustment to a new normal, as well as the predictive power of experience, support, and adjustment variables for quality of life. Given the low internal consistency of certain subscales of the PPHS, it seems that not all of the illness and treatment experiences and social support factors are being assessed in a comprehensive fashion. Further psychometric testing of the PPHS is needed with a larger and more diverse hemodialysis population to improve its reliability and validity.

The current study's findings also provide partial support for the causal, linear process depicted by the LESRD-H model. It was postulated that the adjustment variables would have a stronger effect on quality of outcome. This assumption was partially supported. With emotional well-being emerging as the dominant predictor of quality of life, it buffers the impact of experience and support variables. Counter to expectations, age emerged as the second most important predictor variable for quality of life as opposed to psychosocial distress. The reliance on cross-sectional data and multiple regression analysis in the current study probably compromised the conclusiveness of the findings. It is conjectured that longitudinal data and structural equation modeling or path analysis would provide more meaningful insights into the appropriateness of the causal linear process depicted by the LESRD-H.

Finally, study findings partially supported the assumption that personal characteristics or correlates exert significant effects on adjustment and quality of life. Only one correlate, illness severity, emerged as a significant predictor of psychosocial distress. In contrast, age was a key predictor of quality of life. Only time on dialysis, was predictive of overall quality of life.

Summary

The current study investigated how individuals with ESRD and receiving hemodialysis perceived their illness and treatment experiences, social supports, adjustment to a new normal, and overall quality of life. A second focus of this study was to identify key predictors of adjustment to a new normal and quality of life. The LESRD-H model provided the conceptual framework for this study.

The current study's findings on individuals' perceptions of illness and treatment experiences, social supports, adjustment, and overall quality of life were, in general, supported by the literature. Study findings also provide partial support for the major premises of the LESRD-H model. The findings confirm that quality of life is shaped by the separate and interactive effects of experience, supports, adjustment, and personal characteristics. While there was partial support for the moderating role of adjustment to a new normal (i.e., emotional well-being) between experience and support variables and quality of life, psychosocial distress failed to perform such a role. Counter to expectations, the predictive power of age was only partially moderated by adjustment. These findings stress the importance of further investigation of the LESRD-H model with other individuals living with ESRD and hemodialysis.

CHAPTER 6

Limitations and Implications

This chapter presents a discussion of the limitations and implications of the study findings. The first section summarizes the limitations of the study. The second section presents an overview of the implications for nursing practice, education, and research.

Limitations

The small, non-probability sample used in this study limits the generalizability of the findings, and results should be interpreted with caution. Despite the high response rate (87.5%) across hemodialysis sites, the exclusion criteria (i.e., acute illness episode, significant decline in health, or on dialysis for less than three months) decreases the sample representativeness. As well, the use of cross-sectional data limits the ability to draw causal inferences of the findings and testing of the PPHS. Finally, using self-report measures, without collaborating (e.g., information from family members and health care providers on select indicators), and data collection during hemodialysis may have threatened the reliability and validity of study findings.

Implications

Study findings have important implications for nursing practice, education, and research. The implications for each of these components are presented separately in the following discussion.

Practice

Study findings suggest that individuals receiving hemodialysis were generally positive about illness and treatment experiences, despite experiencing moderate levels of physiological stressors. Additionally, physiological stressors emerged as the best predictor of psychosocial distress. The frequency of physical stressors associated with ESRD and hemodialysis treatment is a significant force shaping perceptions toward illness and treatment experiences. As patient advocates, nephrology nurses must have a thorough understanding of physiological and psychosocial needs of hemodialysis patients. Greater efforts should be placed on developing nursing assessments and innovative interventions that will identify and modify stressors, thus help decrease or alleviate the distress associated with the illness and treatment.

The findings also indicate that participants were very satisfied with their formal and informal support systems. The literature review reinforced the importance of a supportive environment for individuals receiving hemodialysis. Interestingly, in the current study, physician support emerged as the best predictor of emotional well-being. Nurses must focus efforts on improving their influence on the emotional well-being of hemodialysis patients. Comprehensive nursing assessments must identify, monitor, and evaluate all support networks (i.e., family, nursing, physician, allied health). These assessments can help nurses develop more effective interventions that enhance social supports and emotional well-being. It is imperative that nurses collaborate with all support networks to enhance resources for patients and their family members, thus helping to promote a positive adjustment to a new normal.

Study findings suggest that participants were adjusting well to a new normal. Despite the overall tendency to believe that the self was experiencing a fairly high level of emotional well-being, many participants also reported some psychosocial distress. Assessments of hemodialysis patients' psychosocial distress and emotional well-being should be a significant part of daily nursing care. Nurses need to recognize and respond to the tremendous psychosocial and emotional impact that ESRD and hemodialysis has on patients and family members. Thorough assessments of needs will enable nurses to implement effective interventions and anticipate direction that individuals may need for a positive adjustment. As well, identifying and enforcing effective coping strategies may help individuals deal with stressors before they become distressful. Specifically, helping individuals enhance their problem-oriented coping may be effective for their overall adjustment to the illness and treatment. Nurses must ultimately provide hemodialysis patients and their families with effective informational, tangible and emotional support which may promote a more positive adjustment to the illness and treatment.

Finally, study findings also indicate that individuals with more positive perceptions of hemodialysis (i.e., illness and treatment experiences, social supports, and adjustment to a new normal) were also more likely to have a higher quality of life. Emotional well-being emerged as best predictor of overall quality of life. Although achieving an acceptable quality of life is individual specific, nurses can implement appropriate and timely interventions that can help individuals manage the uncertainties and struggles of living with ESRD and hemodialysis. Study findings also suggest that lower stressor levels and satisfaction with support networks influence quality of life. Therefore, nurses must engage in supportive relationships with hemodialysis patients to help them reduce stressors and maintain effective coping to improve quality of life.

Education

The current findings indicate that the presence of fewer stressors, and greater satisfaction with social supports and confidence with knowledge about the illness and treatment were associated with greater emotional well-being for study participants. Educating hemodialysis patients and their family members about the illness and treatment is a very important nursing intervention. It is imperative that patient and family education be enhanced to include information about possible illness- and treatment related- stressors. This enables individuals to anticipate and respond more effectively to stressors if they surface, thus enhancing well-being. Nurses can also focus on teaching patients and their family members effective strategies for seeking support, which in turn will strengthen support systems and help to improve well-being.

Nursing curricula and continuing education programs must include information about the effects of chronic illness, such as ESRD, on individuals and their family members. Given the challenges of ESRD and long-term dependence on technology for survival, it is imperative that nursing students and practicing nurses develop a greater understanding of key factors facilitating positive adjustment and quality of life.

Educational programs that provide a thorough knowledge base of common stressors for hemodialysis patients may help nurses better identify potential areas of concerns, thus enabling implementation of appropriate and timely interventions. As well, acquisition of the knowledge needed to develop and strengthen clinical communication and assessment skills is crucial to delivering effective nursing care.

Nurses working with hemodialysis patients can also increase their knowledge base by completing certification courses in nephrology nursing and remaining current with ongoing research on ESRD. This comprehensive knowledge can promote excellence in nephrology nursing practice that will contribute positively to quality health care. Ongoing education is necessary for practicing nurses to more effectively fulfil their roles as preceptors for students, mentors for new practitioners, and caregivers for hemodialysis patients and their families.

Conceptual frameworks that facilitate understanding of the factors that influence adjustment and quality of life for hemodialysis patients should also be incorporated into nursing curricula and continuing education programs. Application and testing of models, such as LESRD-H, may enhance quality of nursing practice and help refine model assumptions so they are more relevant for hemodialysis patients.

Research

The current study findings provide insight into how illness and treatment experiences and social supports influence adjustment to a new normal for individuals receiving hemodialysis. Study findings also support the influence illness and treatment experiences, social supports, and adjustment to a new normal have on quality of life. Ongoing research is needed to better understand the factors that affect adjustment and overall quality of life for these individuals. The majority of research studies in this area are cross-sectional and consist of small and stable samples. Longitudinal studies that document variations in illness and treatment experiences, availability and usefulness of supports, adjustment to a new normal, and quality of life in response to changing health status and concomitant treatment requirements over time, would give nurses greater insight into the key aspects of individuals' perceptions of ESRD and hemodialysis. The use of more qualitative methodologies would also help identify other key factors that influence adjustment and quality of life for these individuals. Studies are also needed that will test the effectiveness of nursing interventions in order to efficiently assist hemodialysis patients adjust to ESRD and hemodialysis (i.e., reduce psychosocial distress and improve emotional well-being) and enhance their quality of life.

As well, study variables were found to predict only 36.4%, 46.5%, and 61.9% of the explained variance in psychosocial distress, emotional well-being, and quality of life for individuals receiving hemodialysis, respectively. This indicates that other key factors may be influencing adjustment and quality of life. Thus, more research is needed to investigate the predictive power of illness and treatment experiences and social support for adjustment to a new normal, as well as the predictive power of experience, support, and adjustment variables for quality of life.

Study findings only partially support the LESRD-H model, thus more research using this model is warranted with hemodialysis patients. Data obtained from the current and future research could help make the appropriate revisions to the LESRD-H model, making it more relevant for nursing practice with hemodialysis patients. Interpretations of the logic of the LESRD-H model in the larger national study will be strengthened by using longitudinal data and relying on path analysis versus multiple regression. Future research should examine the applicability and usefulness of conceptual models for guiding nursing care with hemodialysis patients. Finally, psychometric testing of existing instruments, such as the PPHS, and the use of qualitative methodologies would help identify the key factors that exert separate and interactive effects on individuals' perceptions of adjustment and quality of life.

Summary

The results of this study indicate that individuals with ESRD and receiving hemodialysis were generally positive about illness and treatment experiences, social supports, and adjustment to a new normal. As well, most participants were quite satisfied with their overall quality of life. In addition, individuals with more positive illness and treatment experiences, greater satisfaction with social supports, and more positive adjustment to a new normal perceived a greater overall quality of life. Testing of the LESRD-H model has explained that multiple variables influence individuals' perceptions of experiences, supports, adjustment and quality of life. Although the findings cannot be generalized to other hemodialysis patients, they do provide useful comparison data for previous and future research, and they generate knowledge which can be included in nursing practice, education, and research.

References

Anderson, K. L. & Burckhardt, C. S. (1999). Conceptualization and measurement of quality of life as an outcome variable for health care intervention and research. *Journal of Advanced Nursing, 29* (2), 298-306.

Baldree, K. Murphy, S., & Powers, M. J. (1982). Stress identification and coping patterns in patients on hemodialysis. *Nursing Research*, *31* (2), 107-112.

Barrett, B.J., Parfrey, P.S., Morgan, J., Barre, P., Fine, A., Goldstein, M.B., Handa, P., Jindal, K.K., Kjellstrand, C.M., Levin, A., Mandin, H., Muirhead, N., & Richardson, R.M.A. (1997). Prediction of early death in end-stage renal disease patients starting dialysis. *American Journal Of kidney Diseases*, *29* (2), 214-222.

Barrett, B.J., Vavasour, H.M., & Parfrey, P.S. (1990). Clinical and psychological correlates of somatic symptoms in patients on dialysis. *Nephron*, *55*, 10-15.

Beddhu, S.B., Bruns, F.J., Saul, M., Seddon, P., & Zeidel, M.L. (2000). A simple comorbidity scale predicts clinical outcomes and costs in dialysis patients. *The American Journal of Medicine*, *108*, 609-613.

Bihl, M. A., Ferrans, C., & Powers, M. J. (1988). Comparing stressors and quality of life of dialysis patients. *American Nephrology Nurses Association*, *15* (1), 27-36.

Burton, H., Lindsay, M., Kline, A., & Heidenheim, P. (1989). Quality of life in peritoneal dialysis patients: Instruments and application. In K. Nolph (Ed.), *Peritoneal dialysis* (pp.429-446). Dordrecht: Klumer Academic Publishers.

Canadian Institute for Health Information. (2001). Dialysis and Renal Transplant Database. *Canadian Organ Replacement Registry*. Ottawa; Canadian Institute for Health Information.

Cagney, K.A., Wu., A.W., Fink, N.E., Jenckes, M.W., Meyer, K.B., Bass, E.B., Powe, N.R. (2000). Formal literature review of quality-of-life instruments used in end-stage renal disease. *American Journal of Kidney Diseases*, *36* (2), 327-336.

Christensen, A. J., Smith, T. W., Turner, C. W., Holman, J. M., Gregory, M. C., & Rich, M. A. (1992). Family support, physical impairment, and adherence in hemodialysis: An investigation of main and buffering effects. *Journal of Behavioral Medicine, 15* (4), 313-325.

Cohen, S., Mermelstein, R., Kamarck, T., & Hoberman, H.M. (1985). Measuring the functional components of social support. In I.R. Sarason & B.R. Sarason (Eds.), *Social support: Theory, research, and application.* Hague: Martines Niijhoff.

Cormier-Daigle, M. & Stewart, M. (1997). Support and coping of male hemodialysis-dependent patients. *International Journal of Nursing Studies, 34* (6), 420-430.

Devins, G.M., Dion, R., Pelletier, L.G., Shapiro, C.M., Abbey, S., Raiz, L.R., Binik, Y.M., McGowan, P., Kutner, N.G., Beanlands, H., & Edworthy, S.E. (2001). Structure of lifestyle disruptions in chronic disease: A confirmatory factor analysis of the Illness Intrusiveness Ratings Scale. *Medical Care, 39* (10), 1097-1104.

Devins, G.M., Mandin, H., Beanlands, H., & Paul, L.C. (1997). Psychosocial impact on illness intrusiveness moderated by self-concept and age in end-stage renal disease. *Health Psychology, 16* (6), 529-538.

Devins, G.M., Mandin, H., Hons, R.B., Burgess, E.D., Klassen, J., Taub, K., Schorr, S., Letourneau, P.K., & Buckle, S. (1990). Illness intrusiveness and quality of life in end-stage renal disease: Comparison and stability across treatment modalities. *Health Psychology, 9* (2), 117-142.

Dijkers, M.D. (1999). Measuring quality of life. *American Journal of Physical Medicine and Rehabilitation, 78* (3), 286-299.

DiMatteo, M.R. & Hays, R.D. (1980). The significance of patient's perceptions of physician's conduct: A study of patient satisfaction in a family practice center. *Journal of Community Health, 6* (1), 18-34.

Edgell, E.T., Coons, S.J., Carter, W.B., Kallich, J.D., Mapes, D., Damush, T.M., & Hays, R.D. (1996). A review of health-related quality-of-life measures used in end-stage renal disease. *Clinical Therapeutics, 18* (5), 887-938.

Faber, S. (2000). An investigation of life with end stage renal disease: sociocultural case studies analysis. *CANNT, 10* (3), *24-34.*

Ferrans, C., Powers, M.J., & Kasch, C.R. (1987). Satisfaction with health care of hemodialysis patients. *Research in Nursing and Health, 10*, 367-374.

Ferrans, C. (1996). Development of a conceptual model of quality of life. *Scholarly Inquiry for Nursing practice, 10* (3), 293-304.

Ferrans, C. & Powers, M.J. (1993). Quality of life of hemodialysis patients. Psychometric assessment of the quality of life index. *American Nephrology Nurses Association Journal, 20* (5), 575-582.

Ferrans, C. & Powers, M.J. (1992). Psychometric assessment of the quality of life index. *Research in Nursing and Health, 15*, 29-38.

Ferrans, C. & Powers, M.J. (1985). Quality of life index: Development and psychometric properties. *Advances in Nursing Science, 8* (1), 15-24.

Fox, E., Peace, K., Neale, T.J., Morrison, R.B., Hatfield, P.J., & Mellsop, G. (1991). Quality of life for patients with end-stage reanl failure. *Renal Failure, 13* (1), 31-35.

Fuchs, J. & Schreiber, M. (1988). Patients' perceptions of CAPD and hemodialysis stressors. *American Nephrology Nurses Association Journal, 15* (5), 282-285.

Gill, T.M. & Feinstein, A.R. (1988). A critical appraisal of the quality-of-life measurements. *Journal of the American Medical Association, 272* (8), 619-625.

Gregory, D.M. (1998). *Patients' perceptions of their experiences with end-stage renal disease (ESRD).* Unpublished master's thesis, Memorial University of Newfoundland, St. John's, Canada.

Gregory, D.M., Way, C.Y., Hutchinson, T.A., Barrett, B.J., & Parfrey, P.S. (1998). Patients' perceptions of their experiences with ESRD and hemodialysis treatment. *Qualitative Health Research, 8*(6), 764-783.

Gurklis, J. A., & Menke, E. M. (1988). Identification of stressors and use of coping methods in chronic hemodialysis patients. *Nursing Research, 37* (4), 236-239, 248.

Gurklis, J. A. & Menke, E. M. (1995). Chronic hemodialysis patients' perceptions of stress, coping, and social support. *American Nephrology Nurses Association Journal, 22* (4), 381-388.

Haas, B.K. (1999). A multidisciplinary concept analysis of quality of life. *Western Journal of Nursing Research, 21* (6), 728-742.

Harrison, M.B., Juniper, E.F., & Mitchell-DiCenso, A. (1996). Quality of life as an outcome measure in nursing research. *Canadian Journal of Nursing Research, 28* (3), 49-68.

Johnson, M., Wright, S., & Weinman, J. (1995). Health status and health related quality of life. In Anonymous, *Measures in health psychology* (pp.3-7). *Berkshire: Nfer-Nelson.*

Jones, L. & Preuett, S. (1986). Self-care activities and processes used by hemodialysis patients. *American Nephrology Nurses Association Journal, 13* (2), 73-79.

Julius, M., Hawthorne, V.M., Carpentier-Alting, P., Kneisley, J., Wolfe, R.A., & Port, F.K. (1989). Independence in activities of daily living for end-stage renal disease patients: Biomedical and demographic correlates. *American Journal of Kidney Diseases, 13* (1), 61-69.

Keogh, A.M. & Feehally, J. (1999). A quantitative study comparing adjustment and acceptance of illness in adults on renal replacement therapy. *American Nephrology Nurses Association Journal, 26* (5), 471-478.

Killingworth, A. & Van Den Akker, O. (1996). The quality of life of renal dialysis patients: Trying to find the missing measurement. *International Journal of nursing Studies, 33* (1), 107-120.

Kimmel, P. L. (2000a). Psychosocial factors in adult end-stage renal disease patients treated with hemodialysis: Correlates and outcomes. *American Journal of Kidney Diseases, 35* (4), s132-s140.

Kimmel, P. L. (2000b). Just whose quality of life is it anyway: Controversies and consistencies in measurements of quality of life. *Kidney International, 57*, s113-s120.

Kimmel, P. L., Peterson R. A., Weihs, K. L., Shidler, N., Simmens S. J., Alleyne S., Cruz, I., Yanovski, J.A., Veis, J. H., & Phillips, T.M. (2000). Dyadic relationship conflict, gender, and mortality in urban hemodialysis patients. *Journal of the American Society of Nephrology, 11*, 1518-1525.

Kimmel, P. L., Peterson R. A., Weihs, K. L., Simmens S. J., Alleyne S., Cruz, I., & Veis, J. H. (1998). Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney International, 54*, 245-285.

Kimmel, P. L., Peterson, R. A., Weihs, K.L., Simmens, S.J., Boyle, D.H., Cruz, I., Umana, W.O., Alleyne, S., & Veis, J.H. (1995). Aspects of quality of life in hemodialysis patients. *Journal of the American Society of Nephrology*, *6* (5), 1418-1426.

Kimmel, P. L., Peterson R. A., Weihs, K. L., Simmens S. J., Boyle D. H., Umana W. O., Kovac J. A., Alleyne S., Cruz, I., & Veis, J. H. (1996). Psychological functioning, quality of life, and behavioral compliance in patients beginning hemodialysis. *Journal of the American Society of Nephrology*, *7* (10), 2152-2159.

Klang, B. & Clyne, N. (1997). Well-being and functional ability in uraemic patients before and after having started dialysis treatment. *Scandinavian Journal of Caring Science, 11*, 159-166.

Kovac, J.A., Patel, S.S., Peterson, R.A., & Kimmel, P.L. (2002). Patient satisfaction with care and behavioral compliance in end-stage renal disease patients treated with hemodialysis. *American Journal of Kidney Diseases, 39* (6), 1236-1244.

Kutner, N. (1987). Social worlds and identity in end-stage renal disease. In P. Conrad and J. Roth (Eds.), *The Experience and Management of Chronic Illness. Research in the Sociology of Health Care Vol 6* (pp.33-71). Greenwich, CT: JAI Press.

Kutner, N.G. (1994). Assessing end-stage renal disease patients' functioning and well-being: Measurement approaches and implications for clinical practice. *American Journal of Kidney Disease, 24* (2), 321-333.

Lev, E.L. & Owen, S.V. (1998). A prospective study of adjustment to hemodialysis. *American Nephrology Nurses Association Journal, 25* (5), 495-506.

Lok, P. (1996). Stressors, coping mechanisms and quality of life among dialysis patients in Australia. *Journal of Advanced Nursing*, *23* (5), 873-881.

Lubben, J.E. (1988). Assessing social networks among elderly populations. *Family and Community Health*, *11* (3), 42-52.

Moos, R.H. & Moos, B.S. (1986). *Family Environment Scale manual.* Palo Alto, CA: Consulting Psychologists Press.

Nagle, L.N. (1998). The meaning of technology for people with chronic renal failure. *Holistic Nursing Practice, 12* (4), 78-92.

O'Brien, M. E. (1983). *The courage to survive: The life career of the chronic dialysis patient.* New York: Grune & Stratton.

O'Brien, M. E. (1990). Compliance behavior and long-term maintenance dialysis. *American Journal of Kidney Diseases*, *15* (3), 209-214.

Padilla, G.V., Presant, C., Grant, M.M., Metter, G., Lipsett, J., & Heide, F. (1983). Quality of life index for patients with cancer. *Research in Nursing and Health*, *6*, 117-126.

Parfrey, P.S., Vavasour, H.M., Henry, S., Bullock, M., & Gault, M.H. (1988). Clinical features and severity of nonspecific symptoms in dialysis patients. *Nephron, 50,* 121-128.

Parfrey, P.S., Vavasour, H.M., Bullock, M., Henry, S., Harnett, J.D., & Gault, M.H. (1989). Development of a health questionnaire specific for end-stage renal disease. *Nephron, 52,* 20-28.

Patel, S.S., Shah, V.S., Peterson, R.A., & Kimmel, P.L. (2002). Psychosocial variables, quality of life, and religious beliefs in ESRD patients treated with hemodialysis. *American Journal of Kidney Diseases*, *40* (5), 1013-1022.

Polit, D., & Hungler, B. (2000). *Nursing research: Principle and methods* (6th ed.). Philadelphia: J.B. Lippincott.

Rettig, R.A., Sadler, J.H., Meyer, K.B., Wasson, J.H., Parkerson, G.R., Kantz, B., Hays, R.D., & Patrick, D.L. (1997). Assessing health and quality of life outcomes in dialysis: A report on an institute of medicine workshop. *American Journal of Kidney Diseases, 30* (1), 140-155.

Rittman, M., Northsea, C., Hausauer, N., Green, C., & Swanson, L. (1993). Living with renal failure. *American Nephrology Nurses Association Journal, 20* (3), 327-331.

Sacks, C.R., Peterson, R.A., & Kimmel, P.L. (1990). Perception of illness and depression in chronic renal disease. *American Journal of Kidney Diseases, xv* (1), 31-39.

Siegal, B.R., Calysn, R.J., & Cuddihee, R.M. (1987). The relationship of social support to psychological adjustment in end-stage renal disease patients. *Journal of Chronic Diseases, 40* (4), 337-344.

Spanier, G.B. (1976). Measuring dyadic adjustment: New scales for assessing quality of marriage and similar dyads. *Journal of Marriage and Family, 38,* 15-28.

Spitzer, W.O., Dobson, A.J., Hall, J., Chesterman, E., Levi, J., Shepherd, R., Battista, R.N., Catchlove, B.R. (1981). Measuring the quality of life of cancer patients. *Journal of Chronic Diseases, 34,* 585-596.

Tarlov, A.R., Ware, J.E., Greenfield, S., Nelson, E.C., Perrin, E., & Zubkoff, M. (1989). The medical outcomes study; An application of methods for monitoring the results of medical care. *Journal of the American Medical Association, 262* (7), 925-930.

Tell, G.S., Mittlemark, M.B., Hylander, B., Shumaker, S.A., Russell, G., & Burkart, J.M. (1995). Social support and health-related quality of life in Black and White dialysis patients. *American Nephrology Nurses Association Journal, 22* (3), 301-3309.

Tilden, V.P., Nelson, C.A., & May, B.A. (1990). The IPR Inventory: Development and psychometric characteristics. *Nursing Research, 39* (6), 337-343.

Walters, B.A.J., Hays, R.D., Spritzer, K.L., Fridman, M., & Carter, W.B. (2002). Health-related quality of life, depressive symptoms, anemia, and malnutrition at hemodialysis initiation. *American Journal of kidney Diseases, 40* (6), 1185-1194.

Way, C, Parfrey, P., & Barrett, B. (1998). Individuals experience with technology and chronic illness: Implications for clinical practice and research. Presented at the Research Forum at Memorial University of Newfoundland, Newfoundland, Canada.

Weil, C.W. (2000). Exploring hope in patients with end stage renal disease on chronic hemodialysis. *Nephrology Nursing Journal, 27* (9), 219-224.

Welch, J.L. & Austin, J.K. (1999). Factors associated with treatment-related stressors in hemodialysis patients. *American Nephrology Nurses Association Journal*, *26* (3), 318-325.

White, Y. & Grenyer, B. (1999). The biopsychosocial impact of end-stage renal disease: the experience of dialysis patients and their partners. *Journal of Advanced Nursing, 30* (6), 1312-1320.

Wise, T.N., Mann, L.S., Jani, N., Kozachuk, W., & Jani, S. (1994). Convergent validation of the Illness Effects Questionnaire. *Psychological Reports, 75,* 248-250.

Zimet, G.D., Dahlem, N.W., & Zimet, S.G. (1988). The multidimensional scale of perceived social support. *Journal of Personality Assess, 52,* 30-41.

Appendix A

Approval from Human Investigation Committee

Memorial
University of Newfoundland

Office of Research and Graduate Studies (Medicine)
Faculty of Medicine
The Health Sciences Centre

1998 04 15

TO: **Dr. Brendan Barrett**

FROM: Dr. Verna M. Skanes, Assistant Dean
Research & Graduate Studies (Medicine)

SUBJECT: Application to the Human Investigation Committee - #98.69

//

The Human Investigation Committee of the Faculty of Medicine has reviewed your proposal for the study entitled "**Living with Hemodialysis: Testing the Patient Perception of Hemodialysis Scale**".

Full approval has been granted for one year, from point of view of ethics as defined in the terms of reference of this Faculty Committee.

For a hospital-based study, it is **your responsibility to seek necessary approval from the Health Care Corporation of St. John's**.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

Verna M. Skanes, PhD
Assistant Dean

cc: Dr. K.M.W. Keough, Vice-President (Research)
Dr. E. Parsons, Vice-President, Medical Services, HCC

SUPPORT
THE OPPORTUNITY FUND

Appendix B

Approval from Health Care Corporation of St. John's

HealthCare
Corporation of St. John's

1998 04 20

TO: Dr. B. Barrett

FROM: George Tilley, Senior VP-Corporate Affairs

SUBJECT: Research Proposal

Your research proposal **HIC # 98.69 - "Living with hemodialysis: Testing The Patient Perception Of Hemodialysis Scale"** has been considered by the Research Proposal Approval Committee (RPAC) of the Health Care Corporation of St. John's at their most recent meeting.

The committee has approved your proposal to be conducted at the General Site within the Health Care Corporation of St. John's. This approval is contingent on the appropriate funding being provided and continued throughout the project and on the provision of regular progress reports at least annually to the RPAC Committee.

GEORGE TILLEY
Senior Vice President, Corporate Affairs

GT/ls

c.c. Linda Purchase, Research Centre

General Hospital
Health Sciences Centre, 300 Prince Philip Drive, St. John's, Newfoundland, Canada A1B 3V6 Tel. (709)737-6300 Fax (709)737-6400
SITES: General Hospital • Janeway Child Health Centre/Children's Rehabilitation Centre • Leonard A. Miller Centre

Appendix C

Consent Form

Faculty of Medicine, Memorial University of Newfoundland,
St. John's, Newfoundland A1B 3V6

CONSENT TO PARTICIPATE IN HEALTH CARE RESEARCH

RESEARCH STUDY TITLE: Living with Hemodialysis: A Theoretical Model of and Scales to Measure Patients Perceptions

INVESTIGATOR: Dr. Brendan Barrett
Telephone:

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Physicians and nurses involved with your care will not have access to your questionnaires or any other information that could potentially identify you as the source.

Purpose of the Study: You are being asked to participate in a research study of patients receiving hemodialysis treatment. The purpose of this study is to develop a screening tool to monitor individuals adjustment to end-stage renal disease and hemodialysis treatment over time.

Description of Procedures and Tests: You are being asked to respond to two questionnaires that will be read to you during one dialysis treatment. You will be asked questions about the history of your illness and treatment, the quality of your supports, for example, friends, family, nurses, doctors, etc., and how you have adapted to a “new self” while receiving hemodialysis treatment. With your permission further information will be taken from your health record, for example, cause of renal failure, presence of other illnesses, etc.

Duration of Participation: The first questionnaire (Patient Perception with Hemodialysis Scale) will take approximately 60 minutes to complete and the second (Ferrans and Powers Quality of Life Index) approximately 30 minutes.

Foreseeable Risks, Discomforts or Inconveniences: There are no expected risks from participating in this study. You may refuse to answer any questions which make you feel uncomfortable, and terminate the interview at any time. All information that you provide will be kept strictly confidential, secured in a locked file, and accessible only to the

Patient ID: ____
Pt. Initials: ____

investigators and research nurses and assistants. Your name will not appear on the questionnaires. The inconvenience is associated with giving 60 minutes of your time for the first questionnaire and 30 minutes of your time for the second.

Benefits: You may not derive any direct benefits from participating in this study. However, the information that you provide may help nurses and physicians plan more appropriate care for you and others receiving hemodialysis treatment.

Other Information: Findings of this study will be available to you and health care professionals upon request. Findings may be published but you will not be identified. The investigator will be available during the study at all times should you have any questions or concerns about your continued participation.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

I,______________________________, the undersigned, agree to my

participation in the research study described.

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been given to me.

______________________________ ________________

Signature of Participant Date

______________________________ ________________

Signature of Witness Date

To the best of my ability, I have fully explained the nature of this study to the participant. I have invited questions and provided answers. I believe that the participant fully understands the implications and voluntary nature of the study.

______________________________ ________________

Signature of Interviewer Date

____

Phone Number

Patient ID: ____
Pt. Initials: ____

Appendix D

Personal Data Extraction Form

ID: ______________

Personal Data Extraction Form

Dialysis Site: St. John's ____ HSC_____ SAGGH _____
Corner Brook ________
Montreal ______ Hamilton ___

Study #: _____

Preferred Language: ____________________

Age (years): ________ Date of Birth: ____________
(d/m/yr.)

Sex:_________

Current Living Arrangements: Living Alone ______
Living with Spouse ______
Living with Parents ______
Living with Another Adult ______

Start Date of Dialysis: ____________
(d/m/yr.)

Cause of End-stage Renal Disease:
Diabetes ____________
Glomerulonephritis/Autoimmune Diseases ____________
Renal Vascular Disease ____________
Polycystic Kidney Disease ____________
Congenital/Hereditary Renal Disease ____________
Other ____________

Presence of comorbid illness:	Yes	No
Heart Disease IHD	______	______
CHF	______	______
Stroke	______	______
Diabetes	______	______
Major Lung Problems	______	______
Cancer	______	______
Severe Arthritis	______	______
Amputation	______	______

Appendix E

Patient Perceptions of Hemodialysis Scale

PATIENT PERCEPTIONS OF HEMODIALYSIS SCALE

The following scale contains a list of items that reference events/situations that you may have experienced since the onset of kidney failure and starting hemodialysis. You are being asked to rate each item on a 5-point rating scales located in the columns to the right. In the first instance you are asked to indicate **'how often you feel this way'** (never, rarely, sometimes, often, or almost always). Finally, you are asked to indicate **'how satisfied, how confident, or how concerned are you**' (not at all, a little bit, moderately, quite a bit, considerably).

Rating Scales

How Often

Never	Rarely	Sometimes	Often	Almost Always
0	1	2	3	4

How Satisfied/How Concerned/How Confident

Not at all	A little bit	Moderately	Quite a bit	Extremely
0	1	2	3	4

1.	How confident are you that you understand the illness events that caused the loss of your kidney function?	0	1	2	3	4
2.	How concerned are you that your health will get worse regardless of what you or doctors do?	0	1	2	3	4
3.	How often do you experience breathing difficulties?	0	1	2	3	4
4.	How often do you feel tired and low on energy?	0	1	2	3	4
5.	How often are you bothered by walking short distances (e.g., tired feelings, breathing problems, etc.)?	0	1	2	3	4
6.	How confident are you that you understand why you need diet or fluid restrictions?	0	1	2	3	4
7.	How satisfied are you with the information that you have about the benefits/side-effects of dialysis?	0	1	2	3	4

8.	How often do you think about what could happen if you did not follow recommended diet and fluid restrictions?	0	1	2	3	4
9.	How often do you experience muscle cramps during or after dialysis?	0	1	2	3	4
10.	How often do you experience a drop in blood pressure during or after dialysis?	0	1	2	3	4
11.	How often do you experience itching due to your kidney disease?	0	1	2	3	4
12.	How often do you feel exhausted after dialysis?	0	1	2	3	4
13.	How often do you feel comfortable after dialysis (e.g., less breathing problems, less swelling, etc.)?	0	1	2	3	4
14.	How often do you feel that dialysis has improved the quality of your life?	0	1	2	3	4
15.	How confident are you about knowing what is required to have a kidney transplant (e.g., waiting period, reasons for not being placed on or coming off the wait-list, etc.)?	0	1	2	3	4
16.	How often do you follow recommended diet and fluid restrictions?	0	1	2	3	4
17.	How often do you pay attention to what nurses do during dialysis (e.g., saline for cramps, checking blood pressure, turning off heparin, etc.)?	0	1	2	3	4
18.	How often do you watch for problems that could occur during dialysis such as bleeding/clotting of access site, cramps, or changing blood pressure?	0	1	2	3	4
19.	How often do you inform the nurse about problems that occur during dialysis (i.e., feeling unwell, problems with access site, etc.)?	0	1	2	3	4
20.	How often does your family try to help you accept your illness and dialysis treatment requirements?	0	1	2	3	4
21.	How concerned are you about becoming too dependent on your family?	0	1	2	3	4

22.	How often do family members remind you about diet, fluid, or activity restrictions?	0	1	2	3	4
23.	How concerned are you about the impact of your illness and treatment on family members? (e.g., decreased social activities, dietary restrictions, time commitments with dialysis, etc.)	0	1	2	3	4
24.	How often do you do things to lessen the impact of your illness and treatment on family members?	0	1	2	3	4
25.	How often do you feel that your family is coping well with your illness and dialysis treatment requirements?	0	1	2	3	4
26.	How often do you experience delays in getting on dialysis or receiving scheduled treatment (e.g., turning off heparin, etc.)?	0	1	2	3	4
27.	How concerned are you that nurses may be too busy to pay attention to what is happening to you during dialysis?	0	1	2	3	4
28.	How satisfied are you with the overall quality of nursing care in the dialysis unit?	0	1	2	3	4
29.	How confident are you that nurses have the knowledge and abilities to know what to do if you became ill on dialysis?	0	1	2	3	4
30.	How satisfied are you with nurses willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
31.	How satisfied are you with the amount of time that nurses take to help you understand your illness and treatment requirements?	0	1	2	3	4
32.	How often do you feel that nurses try to promote a relaxed, family-like atmosphere on the dialysis unit?	0	1	2	3	4
33.	How satisfied are you with the comfort measures provided by nurses during dialysis (e.g., providing a blanket, pillow, refreshments, etc.)?	0	1	2	3	4
34.	How confident are you that dialysis doctors' have the necessary knowledge and abilities to monitor or deal with your overall physical needs?	0	1	2	3	4

35.	How satisfied are you with how quickly doctors respond to your needs when you are on dialysis?	0	1	2	3	4
36.	How satisfied are you with the quality of overall medical care in the dialysis unit?	0	1	2	3	4
37.	How satisfied are you with doctors willingness to listen to what you have to say about your illness and treatment?	0	1	2	3	4
38.	How satisfied are you with the amount of time that doctors take to help you understand your illness and treatment requirements?	0	1	2	3	4
39.	How satisfied are you with the support provided by dialysis social workers to help you deal with illness or treatment-related problems?	0	1	2	3	4
40.	How satisfied are you with the information provided by the dietician about your diet?	0	1	2	3	4
41.	How often do you feel so frustrated with things that you would like to get off the machine and go home?	0	1	2	3	4
42.	How concerned are you for your personal safety while on dialysis (i.e., cluttered or messy environment, germs, etc.)?	0	1	2	3	4
43.	How concerned are you about voicing your needs to nurses or doctors due to the physical closeness of others during dialysis?	0	1	2	3	4
44.	How often are you upset by seeing others become suddenly ill (i.e., worried that it would happen to you)?	0	1	2	3	4
45.	How often do you dwell on your own health problems following the death of another patient?	0	1	2	3	4
46.	How often do you feel depressed (i.e., feeling down, fed-up, frustrated) about your illness and long-term treatment requirements?	0	1	2	3	4
47.	How satisfied are you with your ability to do household or other work activities?	0	1	2	3	4

48.	How often do you experience fears or worries about unexpected illness/dialysis events (e.g., sudden drop in blood pressure, clotting of access site, breathing problems due to too much fluid)?	0	1	2	3	4
49.	How often do you feel that depending on others makes you feel useless (i.e., self-esteem, self-worth)?	0	1	2	3	4
50.	How often do you feel distressed by the severity of your illness and the long-term treatment requirements (e.g., troubled, worried, upset, etc.)?	0	1	2	3	4
51.	How often do you feel stronger as a person because of your illness (i.e., discovery of inner strength, spiritual comfort, courage)?	0	1	2	3	4
52.	How often do you try to maintain a positive attitude towards dialysis?	0	1	2	3	4
53.	How often do you feel good about the ‘special closeness’ among patients during dialysis?	0	1	2	3	4
54.	How confident are you that you will come to terms with your illness?	0	1	2	3	4
55.	How often do you accept dialysis as something you have to do (i.e., scheduled appointment, part of weekly norm)?	0	1	2	3	4
56.	How often do you relax during dialysis?	0	1	2	3	4
57.	How often do you participate in recreational activities (e.g., travel, volunteer work, hobbies, etc.)?	0	1	2	3	4
58.	How satisfied are you with how well you have adjusted to the effects of dialysis (e.g., pain, restrictions, problems with access site, delays, machine functioning, drop in blood pressure)?	0	1	2	3	4
59.	How confident are you that you can manage the financial costs resulting from dialysis?	0	1	2	3	4
60.	How satisfied are you with the amount of quality time spent with family and friends?	0	1	2	3	4
61.	How confident are you that you are coping well with dialysis restrictions?	0	1	2	3	4

62.	How often do you feel that you have some control over the ups and downs of dialysis and the effects on your health and well-being?	0	1	2	3	4
63.	How often do you try to weigh the benefits/negatives of different treatment options before making a decision (e.g., home vs hemodialysis, transplant, counselling, time of day or days on dialysis, etc.)?	0	1	2	3	4
64.	How satisfied are you with the amount of self-care responsibilities that you are able to assume on a given day?	0	1	2	3	4

Appendix F

Quality of Life Index and Letter of Permission

ID: ____________

Ferrans and Powers
QUALITY OF LIFE INDEX©
DIALYSIS VERSION

201

PART 1. For each of the following, please choose the answer that best describes how **satisfied** you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Dialysis treatment?	1	2	3	4	5	6
2. Your health?	1	2	3	4	5	6
3. The health care you are receiving?	1	2	3	4	5	6
4. Your physical independence?	1	2	3	4	5	6
5. The efforts made to increase your potential for a successful kidney transplant?	1	2	3	4	5	6
6. Your potential for getting off dialysis (for example, through a successful transplant or medical discovery?	1	2	3	4	5	6
7. Your potential to live a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6

(Please Go To Next Page)

ID: ____________

202

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

(Please Go To Next Page)

ID ___________

PART 2. For each of the following, please choose the answer that best describes how **important** that area of your life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Dialysis treatment?	1	2	3	4	5	6
2. Your health?	1	2	3	4	5	6
3. The health care you are receiving?	1	2	3	4	5	6
4. Your physical independence?	1	2	3	4	5	6
5. The efforts made to increase your potential for a successful kidney transplant?	1	2	3	4	5	6
6. Your potential for getting off dialysis (for example, through a successful transplant or medical discovery?	1	2	3	4	5	6
7. Living a long time?	1	2	3	4	5	6
8. Your family's health?	1	2	3	4	5	6
9. Your children?	1	2	3	4	5	6
10. Your family's happiness?	1	2	3	4	5	6
11. Your relationship with your spouse/significant other?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your friends?	1	2	3	4	5	6
14. The emotional support you get from others?	1	2	3	4	5	6

(Please Go To Next Page)

ID ___________

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
15. Your ability to meet family responsibilities?	1	2	3	4	5	6
16. Your usefulness to others?	1	2	3	4	5	6
17. The amount of stress or worries in your life?	1	2	3	4	5	6
18. Your home?	1	2	3	4	5	6
19. Your neighborhood?	1	2	3	4	5	6
20. Your standard of living?	1	2	3	4	5	6
21. Your job (if employed)?	1	2	3	4	5	6
22. Not having a job (if unemployed, retired or disabled)?	1	2	3	4	5	6
23. Your education?	1	2	3	4	5	6
24. Your financial independence?	1	2	3	4	5	6
25. Your leisure time activities?	1	2	3	4	5	6
26. Your ability to travel on vacations?	1	2	3	4	5	6
27. Your potential for a happy old age/retirement?	1	2	3	4	5	6
28. Your peace of mind?	1	2	3	4	5	6
29. Your faith in God?	1	2	3	4	5	6
30. Your achievement of personal goals?	1	2	3	4	5	6
31. Your happiness in general?	1	2	3	4	5	6
32. Your life in general?	1	2	3	4	5	6
33. Your personal appearance?	1	2	3	4	5	6
34. Yourself in general?	1	2	3	4	5	6

UIC The University of Illinois
at Chicago

Department of Medical-Surgical Nursing (M/C 802)
College of Nursing
845 South Damen Avenue, 7th Floor
Chicago, Illinois 60612-7350
(312) 996-7900

February 6,1998

Dear Ms. Gregory:

Thank you for your interest in the Ferrans and Powers Quality of Life Index (QLI). I have enclosed the dialysis version of the QLI and the computer program for calculating scores. I also have included a list of the weighted items that are used for each of four subscales: health and functioning, social and economic, psychological/spiritual, and family, as well as the computer commands used to calculate the subscale scores. The same steps are used to calculate the subscale scores and overall scores.

At the present time there is no charge for use of the QLI. You have my permission to use the QLI for your study, which includes my permission to make as many copies as you need. In return, I ask that you send me a photocopy of all publications of your findings using the QLI. I then will add your publication(s) to the list that I send out to persons who request permission to use the QLI.

If I can be of further assistance, please do not hesitate to contact me. I wish you much success with your research.

Sincerely,

Carol Estwing Ferrans, PhD, RN, FAAN
Associate Professor