Vulnerability and Vigilance: 
Exploring Communication in the Care of Patients with End Stage Renal Disease

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Abstract

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For patients living with End Stage Renal Disease (ESRD), encounters with health care providers are frequent and long-term. Communication forms much of the basis of these encounters and yet little is known about communication in ESRD care. This study was thus undertaken in an attempt to develop some preliminary understandings of helpful and unhelpful communication in the context of the care of these patients.

Interpretive description was the qualitative method utilized in this study, where the investigator posed the question: How do individuals with ESRD explain and describe helpful and unhelpful communication in renal disease care?

Eight people participated in this study. Four women and three men who had been diagnosed with ESRD for at least five years were interviewed regarding their experiences of communication. One family member of a patient with ESRD also participated. Participants had experienced at least one of the four treatment modalities, and several had experienced all four, thereby providing perspectives from the full range of ESRD treatments, where patient-provider communication take varying forms.

Descriptions of helpful and unhelpful communication with ESRD care providers, were grouped into two major themes that illuminate the complexities of communicating while experiencing illness and dealing with a changing and complex health care system. Vulnerability and vigilance were those themes, within which several sub-themes arose. Specifically, being ill, recognizing that care is fragmented and that not all providers are
helpful communicators were contributors to vulnerability. In an effort to mediate this vulnerability, participants undertook vigilant behaviors, such as getting educated in order to monitor the activities expected of providers, and creating networks of health care allies who were supportive and helpful. Participants thus functioned, in varying ways, as coordinators of their own care and utilized their health care allies to provide advice, emotional and political support, depending on what was necessary in the moment.

However, the work of vigilance proved to be considerable. The communication and responsibilities involved in coordinating care, maintaining networks and ensuring the appropriateness of care presented unique challenges for participants. The findings of this study suggest that ESRD care providers might benefit from further consideration about the ways in which health care is communicated, organized, and delivered in order to make illness management less burdensome for patients.
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Chapter 1: Background to the Problem

Until the latter half of this century, the diagnosis of end-stage renal disease (ESRD) was considered a death sentence. Within the last forty years, however, medical improvements in the treatment of ESRD have resulted in survival for many years and, in exchange for life, patients and families with renal disease are required to embark on a journey of dependence on technology, strict medical regimens, and longstanding relationships with renal care providers that can last for decades.

Renal disease can arise out of numerous causes, but most commonly occurs as a secondary result of chronic conditions such as diabetes mellitus, hypertension, infections and autoimmune disorders (Parker, 1998). Diabetes mellitus now accounts for nearly 30% of the incidence of ESRD (CIHI, 2001), followed closely by hypertension, both of which require a significant commitment to medication, diet and other treatment considerations. Consequently, the majority of patients develop renal disease out of pre-existing chronic health conditions that have likewise imposed varying degrees of intrusiveness, treatment and regular health care encounters. It is thus fair to say that the many patients with ESRD arrive in the renal care arena with a significant amount of prior experience with the health care system.

As many patients with ESRD have also self-managed a pre-existing chronic health condition, sometimes for many years, the diagnosis of renal disease and its associated treatment regime often creates a doubly burdensome illness experience.

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1 ESRD refers to the stage where renal function has irreversibly deteriorated to the point of less than 10-15% function, and symptoms of toxin build up and fluid and electrolyte imbalance begin to occur (Parker, 1998).
2 The word “patient” is acknowledged as a problematic term, however, it has been chosen as a more succinct form of referring to individuals living with ESRD.
Specifically, many patients must assume the additional ESRD treatment requirements over and above those of the original condition. Patients with diabetes mellitus, for example, must add the renal-specific diet restrictions, medications, and renal replacement therapy to their already complex regime of diabetes management. Those with hypertension must similarly add further dietary restrictions and supplementary medications to their program of blood pressure management. These additional constraints imposed by renal disease onto pre-existing conditions can create significant challenges for individuals and their families.

Furthermore, apart from the self-management requirements, the nature of renal disease care involves frequent monitoring by care providers and necessitates hospital or clinic visits that can range from thrice weekly with hemodialysis, to quarterly or more frequently, with renal transplantation and peritoneal dialysis. The regularity of these health care encounters, combined with the significant responsibility assigned to clients to self manage the ESRD treatment regime, makes it essential that clients and renal care providers enjoy effective communications and develop trusting and close working relationships.

These trusting health care relationships are an essential part of living with a chronic illness such as renal disease. However, according to many clients that I have encountered over the years, communication with health care providers remains problematic for a number of reasons including conflicting expectations of care, different views on what information is important, an over-emphasis on compliance and judgments that accompany clients' choices that ignore professional advice. These communication problems in renal disease care are supported by the general literature on health care

Unfortunately, despite the voiced concerns of patients with renal disease, within the ESRD health care community there has been little research in this regard. Although a few studies have measured patient satisfaction with care in various renal replacement settings (Bartucci, 1985; Ferrans, Powers & Kasch, 1987; Wuerth, Finkelstein, Kliger & Finkelstein, 2000), or focused on educational needs of patients making decisions about treatment modality (Breckenridge, 1997; Caress, Luker & Ackrill, 1998; Goddard, & Powers, 1982; Lelie, 2000; O’Donnell & Tucker, 1999) or examined health care relationships (Curtin & Mapes, 2001; McCormick, 1997; O’Brien, 1983; Sloan, 1999), I was unable to find any studies that focused specifically on communications with renal care providers. Hence, it is imperative that research be conducted that focuses on this topic.

Problem Statement

For patients with renal disease, health care includes frequent and ongoing encounters with health care providers and self-management of a complex regimen of diet restrictions, medication and renal replacement therapies such as dialysis and transplantation. These health care requirements, on top of those presented by the pre-existing chronic condition, create a context in which effective communication is
essential. According to many renal patients I have encountered in my practice, whose views are supported by the literature on health care communications, there are problems with the existing patient-provider relationships within renal disease care. As there are few studies regarding communication with renal care providers, it is important that we know more about effective and ineffective communication in this specific context. Research is necessary to contribute to our understandings about communication in the context of renal disease care.

**Purpose of the Study**

The purpose of this study was to explore, from the patient perspective, communication in renal disease care. Specifically, learning how patients view communications with providers, what is deemed necessary and timely, and what constitutes helpful and unhelpful communication will guide renal care providers in offering appropriate communication at the appropriate times.

**Research Question**

The question that I sought to explore was: *how do individuals with ESRD describe and explain helpful and unhelpful communications in renal disease care?*

**Significance of the Study**

This study provides some insights into the nature and quality of communications in renal disease care, and will assist renal care providers to better support patients and family members with ESRD as they journey through the complexities of a lifelong commitment to a treatment regime, and, by necessity, a lifelong commitment to relationships within the health care setting. The findings of this study contribute to the establishment of preliminary work intended to assist in the creation of effective
communication standards in renal disease care. However, it is necessary to acknowledge that the results of this study, due to time and resource limitations, cannot represent anything more than the perspectives sought within the sample. Therefore, it is necessary to interpret the findings as located within the constraints of this thesis project.

Assumptions

The following assumptions underlie this study and have shaped my thinking about the nature of communications in renal disease care:

1. Individuals with renal disease consider communications with renal care providers to be important.
2. Individuals with renal disease are willing and able to speak to the researcher about their experiences of communications with renal care providers.
3. Among individuals with renal disease, there may be common elements regarding experiences of communication with renal care providers.
4. Experiences of communication may also differ according to treatment modality, length of illness and experiences of health care encounters for pre-existing conditions.

Summary

Renal disease treatment involves a complex regimen of dietary restrictions, medications and dependence on technology in order to survive. Accordingly, most patients with renal disease must engage with renal care providers regularly for the duration of their lives. Communication with renal care providers is therefore an important aspect of treatment, and makes a solid understanding of effective communication a necessity. Establishment of what, according to the patients themselves, makes
communication helpful is an important step in creating a care setting responsive to the needs of patients.
Chapter 2: Literature Review

Patients with renal disease must rely on health care providers to assist them in managing their health concerns over long periods of time. According to many renal patients in my own practice, encounters with health care providers can be both rewarding and frustrating. In health care encounters, communication is central, and yet, within the ESRD community, little is known about the nature of ESRD communications. What makes a health care encounter successful for patients and families? How might this contrast with encounters that leave patients feeling let down or negatively received? What aspects of the interaction itself are important for patients and their professional caregivers? What do patients and providers bring to the interaction that might affect the perceived effectiveness of the communication?

In order to establish some understanding of the existing knowledge about communications in ESRD care, I undertook a literature search of both general and ESRD-specific health care communications. I limited my search to include research and articles from the last ten years, as health care communications have been widely described, particularly in the last decade. In reviewing the selected literature, I came up with the following results: within the ESRD literature, I found little specific content regarding communication, but there is ample evidence of research concerned with quality of life, compliance with medical regimen, and patient experiences of renal disease. This indicates an interest among researchers that patient perspectives are important, and from this interest, one can infer that health care encounters are considered a significant aspect of experiences of ESRD. As I was unable to find specific research describing ESRD-related communication, it was therefore necessary to examine other bodies of ESRD
literature in order to make inferences about communication in ESRD care. These studies will be described in detail in the latter half of this chapter.

Despite my inability to find literature specific to ESRD and communication, there is a significant body of literature on general health care communications. I was able to find numerous articles and research exploring aspects of physician-patient encounters, as well as a small number focused on nurse-patient interaction. These works will be summarized in the following section.

**General Health Care Communications**

Health care communications have been extensively studied, particularly in the fields of the social sciences, nursing and medicine, and, within the selected literature, predominantly reflect the perspective of the health care provider. Virtually all of the authors of the selected articles identified some concern about the difficulties of health care communications, all agreeing that the present situation is problematic in some way (Arborelius, 1996; Assal, 1999; Bartz, 1999; Bakker et. al, 2001; Bensing, Verhaak, van Dulmen & Visser, 2000; Kettunen et.al, 2000; Kruijver et.al, 2000; Kleinman, 1988; McWilliam et. al, 2000; Ong et.al, 1995; Osborn, 2000; Stewart, 1995; Takman & Severinsson, 1999; Thorne, 1993; Thorne, Nyhlin & Paterson, 2000; Thorne & Paterson, 2001; Van den Borne, 1999; Witte, 1994). These authors indicated that time constraints, expectations, power imbalances, an over-emphasis on information-giving, and varying perceptions of roles and scope of practice appear to take their toll on effective communication. As Stewart, specifically addressing physician communication, put it:

In general terms, communication difficulties can be described with reference to problems of diagnosis, a lack of patient involvement in the discussion or the inadequate provision of information to the patient. Studies have shown that 50% of psychosocial and psychiatric problems are missed, that physicians interrupt an
average of 18 seconds into the patient's description of the problem, that 54% of patient problems and 45% of patient concerns are neither elicited by the physician nor disclosed by the patient, that patients and physicians do not agree on the main presenting problem in 50% of visits, and that patients are dissatisfied with the information provided to them by physicians. These studies point to the conclusion that problems in physician-patient communication are common and worthy of our attention (1995, p. 1424).

Among the selected studies, there is considerable emphasis on the content of health care communications, and three types of communications have been widely identified: affective, instrumental and information sharing, and socio-emotional (King, King & Rosenbaum, 1996; Kruijver et. al, 2000; Ong et. al, 1995; Ong et. al, 2000; Roter, Hall & Katz, 1988; Stewart, 1995; van den Borne, 1999). Affective communication refers to the tone of the interaction, whereas instrumental communication refers to the asking of questions, giving directions, information-giving and counseling. Socio-emotional communication includes showing concern, social behavior and verbal attentiveness (Ong et.al, 2000). These categories of communication are explicitly or implicitly referred to within the literature, and are predominantly concerned with the content of the provider's communication.

Patient perspectives have been sought in a few of these studies (Kruijver et al, 2000; Ong et. al, 2000; Stewart, 1995), however, they have largely relied on surveys and other quantitative tools aimed at measuring outcomes such as recall, quality of life, satisfaction, compliance, knowledge and coping. Moreover, as Roter (2000) points out, the studies that attempted to measure the content of communication were not longitudinal, and were largely based on single, primary care encounters. Consequently, these studies, while useful for primary care providers, do not offer information about the cumulative effect of health care communication, nor do they provide adequate reflection
of the typical trajectory of chronic illness, where the involvement of multiple health care providers over long periods of time is common.

Perhaps one of the reasons that health care communications continue to be problematic is that little research focus has been placed on the context of health care, particularly in the following categories: power dynamics, critical examination of the goals of medicine/health care, the realities of communication while experiencing illness, and specifics of what clients actually want from their care providers. Far fewer researchers attended to these issues, which undoubtedly contributed to satisfaction or dissatisfaction with health care encounters. Hence, it is difficult, from the selected literature, to ascertain what effective communication might be, particularly from the perspective of patients.

Of the research that did attend to contextual factors, some interesting insights emerged. Specifically, a few authors acknowledged the effects of power imbalances on communication (Kettunen et.al, 2000; Roter, 2000; Stewart, 1995). Stewart (1995) argued that power and control, particularly with reference to decision-making on the part of physicians, is of considerable concern. Roter (2000) suggested that the medical focus on biochemical and pathophysiological processes has led to a decline in the centrality of communication in the care process. Kettunen et.al (2000) proposed that the directive quality of nurses' communication creates an asymmetry whereby patients are not afforded the opportunity to explain the effects of illness on their lives and thereby provide a greater understanding of the health concerns and issues. These authors call for more research on the patient side of communication, as the power and control demonstrated by
the providers in their study was strongly evident, and viewed as an inhibiting force in effective communication.

Just as there was little research that attended to power imbalances in health care encounters, so, too, was there little research attending to the unique communication needs of patients with chronic illnesses. As noted earlier, communications in the context of chronic illness are complex and long term, requiring a skill level on the part of patients that is dissimilar to those with acute, and thereby short-term, illnesses. Several authors, however, did consider the implications for communication over lengthy periods (Assal, 1999; Bensing et. al, 2000; King et.al, 1996; Kleinman, 1988; Thorne, 1993; Thorne et.al, 2000), arguing that care of the growing number of chronically-ill people requires a paradigm shift from reductionist curative endeavors to awareness of the social context of illness, maintenance of long-term health care relationships, a stronger emphasis on partnerships and shared expertise with patients. According to these authors, until the health care system is able to respond to those with chronic illnesses, the limitations of medical science with its primary focus on pathophysiological processes will continue to impoverish opportunities for effective communication and understanding the scope of illness experiences.

The current limitations in understandings of health care communications have arisen out of a focus that perhaps too readily attends to provider perspectives. The emphasis on content of communications, and attempts to link communication with outcomes such as quality of life, recall, compliance and so on have provided some important insights. However, as few of the studies examined the specifics of what kinds of communication patients really want from their health care providers, a large part of the
equation has not yet been adequately explored. Apart from four qualitative studies (Bakker et.al, 2001; Kettunen et. al, 2000; McWilliam et.al, 2000; Thorne & Paterson, 2001), I was unable to find other research that specifically addressed the question of expectations of patients.

Among these four qualitative studies, some common themes arose. McWilliam et.al (2000), in examining physician-patient interactions in cancer care, found that positive experiences of communication arose when physicians took a leadership role in opening conversations up to patients. Not appearing rushed and taking time to explain matters was important, as was maintaining hope. Bakker et. al (2001), also studying cancer patients, found that patients considered it helpful to have their efforts to inform themselves supported by the health care provider. Also helpful were having a sense of connection, trust, a feeling of partnership and validation of patients’ experiences. Thorne and Paterson (2001), in a study of diabetic patients, noted that those health care providers who were able to view the science of diabetes care as limited, and who showed a willingness to use strategic experimentation with patients were considered helpful, whereas those who adhered too closely to the compliance model were eventually viewed as unsupportive. These authors suggested that solely providing information was insufficient, rather, patients needed to also learn how to use the information in day-to-day decision-making. Moreover, as their own expertise increased, patients needed different kinds of support from health care providers. Specifically, in the beginning of the illness experience, patients took a more passive role and relied heavily on instruction. Passive obedience was often followed by rebellious times, where patients indicated a need to resist the impact of the disease and treatment, that eventually evolved into a reasoned and
competent phase of self-care and self management. Support, via communication, from health care providers was viewed as an essential element of learning to self manage the diabetes (Thorne & Paterson, 2001).

It is evident that the patients involved in these four studies were seeking more than information about their disease management from health care providers. Specifically, support, openness, recognition of the scope of the illness experience, taking time to listen, and recognition of changing needs as patient expertise grew were identified as important. Finally, assistance with developing decision-making skills, or gaining experience in illness management was considered a necessary part of health care communication. It is interesting to note that, according to the patient participants, recall, compliance and clinical outcomes were not indicated as important aspects of health care encounters.

However, in the selected research on health care communication, there is evidence that, according to health care providers, communications outcomes such as patient recall, knowledge, and particularly, compliance, are paramount. This may reflect an unspoken agenda that underpins much of health care, and could, in fact, form some of the basis upon which patients may negatively experience certain health care communications. Specifically, if communication on the part of providers is intended to exact a certain behavioral response from patients, that of compliance, then it should come as no surprise that conflict might arise. Hence, it is necessary to explore the intentions and expectations that might underlie provider communications in order to establish what is known about compliance behaviors and consider the growing critique of notions of compliance as a cornerstone of illness management.
Patient Compliance and Health Care Communication

I found it necessary to examine and interpret the compliance-related body of literature because of the enormous implications it has on health care communication, particularly in the context of chronic illness. Witte (1994), rather provocatively, names all health communication research as an effort to establish what means can be found to best manipulate patient behaviors, arguing for recognition of medicine’s desire to influence patients’ actions and instead seek more ethical use of manipulation strategies. Many of the authors explicitly name compliance or adherence as the desired outcome of health care communication (Arborelius, 1996; Boon & Stewart, 1998; Buchmann, 1997; 1998; King et.al, 1996; Ong et. al, 1995; Ong et. al, 2000), while others implicitly argue that successful communication results in better adherence to the medical regimen. Consequently, it is difficult to discuss health care communications without acknowledging the ideological underpinnings of compliance.

Compliance is a concept that generally refers to the degree to which patients follow the advice of health professionals (Playle & Keeley, 1998), and, I will argue, comprises much of the focus of health care communications. According to Trostle, the popularity of the compliance discourse can be best understood as an ideology: “compliance is an ideology that transforms physician’s theories about the proper behavior of patients into a state of research strategies, research results and potentially coercive interventions that appear appropriate, and that reinforce physicians’ authority over health care (1988, p. 1300)”.

Compliance, along with its more recent term, adherence, rests on the notion that patients will simply follow orders, that health care providers have enough expertise to
judge what is best for patients (Hess, 1996; Playle & Keeley, 1998; Trostle, 1988), and that adhering to proven regimens is the only rational response for patients (Thorne, 1999). Consequently, controlling non-compliance is perceived as necessary to solve problems in following orders, and much of compliance research aims to create strategies that will address non-compliance.

However, there is a growing awareness that non-compliance is often a result of reasoned and skilled decision-making on the part of patients, or a result of the complex interaction between personal, social and economic realities of living with illness (Conrad, 1987; Roberson, 1992; Thorne, 1990; Thorne, 1999; Thorne & Paterson, 2001). It is therefore necessary for health care providers to reconsider the professional norms and expectations underpinning compliance/adherence rhetoric and undertake research efforts that further explore the realities of illness management for patients. If compliance is the desired outcome of much of health care communication, then communication will be problematized early in the health care relationship, for compliance beliefs, if held uncritically, set up expectations that may result in mistrust, competing agendas, and ultimately, miscommunication.

I have argued that unexamined assumptions about compliance transcends much of the health care communications literature and is markedly evident in the culture of renal disease care, where daily the word “non-compliant” crops up in conversations among staff. From here, I intend to turn to the ESRD-specific literature that pertains in some way to health care communications, beginning with a review of the literature about compliance.
ESRD-Specific Literature

Compliance in ESRD care is a major topic of interest, due to the fact that much of renal disease management requires patients to accept major lifestyle changes such as diet and fluid restrictions, a complex medication protocol, and for dialysis patients, regular treatments ranging from several times a day with peritoneal dialysis, to thrice weekly for hemodialysis patients. As the bulk of responsibility for following the regime rests with patients, many ESRD care providers put a significant emphasis on compliance when delivering health teaching and health communication. Additionally, apart from the adoption of major lifestyle changes, patients are subjected to regular lab work, conducted as a means of evaluating the treatment effectiveness, including compliance with medications and diet restrictions. Consequently, compliance is both expected and closely monitored, and a great deal of ESRD communication occurs around compliance behaviors. Beliefs about the need for compliance are so strong that they appear regularly in most nephrology medical and nursing textbooks\(^3\) and occur daily in conversations in the clinical setting. Additionally, despite the last decade of critical examination of the compliance discourse outside of the nephrology setting, I was able to find a number of recent ESRD studies specifically aimed at uncritically identifying contributing factors to non-compliance (Curtin, Svarstad & Keller, 1999; Sherman, 1996; Vives, Pujolar, Flores, Cordovilla & Izquierdo, 1999; Woodcock, 1999). These studies explored patient compliance using means such as pill counts, subjective disclosure, and electronic monitoring of pill bottles, often concluding that compliance rates need to be improved

\(^3\) For examples of uncritically held beliefs about compliance behaviors in ESRD textbooks, see Henrich, 1999; Gutch, Stoner & Corea, 1999; Levine, 1997; Parker, 1998; Smith, 1997)
through increased education, motivational techniques and enhanced communication. None of these studies accounted for the context of chronic illness management in their designs, nor did they reflect the growing critique of compliance models.

I was able to find only three studies that accounted for the complexities of compliance in self-management of renal disease. O’Brien (1983; 1990), in a nine-year study of dialysis patients and ESRD professionals, highlighted the complexities of dialysis unit culture, including both staff and patient coping, and conflicting beliefs about compliance that influenced patient-staff relationships. Similarly, Curtin and Mapes (2001), explicitly argue that:

Dialysis care providers are likely to stress the importance of patient compliance and may be more likely to perceive dialysis patients’ attempts to manage aspects of their own disease and its treatment as risky and inadvisable. These attitudes of health care professionals make it more difficult for dialysis patients to successfully effect self-management (p. 386).

Patients in this study reported sophisticated decision-making about gauging when to report symptoms to providers, and when to adopt alternative therapies, often without ESRD provider knowledge. Further, patients reported interacting with ESRD care providers in a manner that consciously involved managing the impression they gave to providers in order to ensure that they received the best care possible, hoping to avoid sanctions for non-compliance or self-modification of treatment. The authors conclude with a call for improved communication to permit patients to intercede on their own behalf and communicate their opinion about approaches to their own care.

Similarly, Rittman, Northsea, Hausauer, Green and Swanson (1993) argued that the process of taking on a new understanding of being renders “non-compliance” to a natural part of the change process, concluding that health care providers need to recognize that time and repetition of information are necessary for adoption of the regime
into daily life. Interestingly, none of the three studies acknowledge that “non-compliance” can occur as a reasoned, strategic and effective means of managing illness. Notably, both O’Brien (1990) and Curtin and Mapes (2001) observe that the more “non-compliant” patients showed a tendency to live longer than those who strictly followed medical advice. While undoubtedly more research on this topic is necessary, the proposed link between non-compliance and longevity is highly intriguing, and health care providers might benefit greatly from learning more about the strategies that long-term ESRD patients adopt to effectively manage their treatment.

To summarize, I have argued that uncritical compliance beliefs underlie much of ESRD care provider perspectives, where expectations that patients will unquestioningly assume a large part of the treatment responsibility predominate. Although often hidden, these beliefs filter into communication with patients with renal disease, and can function as a barrier to effective interactions. Specifically, compliance beliefs, if held uncritically and too rigidly, can interfere with providers’ abilities to listen to and learn from patients who successfully choose to manage their illness using alternative strategies. As a result, communication can rapidly break down where patients learn to hide their so-called non-compliant practices (Curtin & Mapes, 2001), inhibiting trust and respect for both parties.

Despite the fact that critical examination of compliance beliefs has been inadequately explored in the ESRD setting, other aspects of patients’ experiences are receiving considerable attention. Specifically, quality of life, patient decision-making, patient educational needs, patient experiences of aspects of treatment for ESRD, and satisfaction with care are topics that have been variously explored in the ESRD literature. The following sections explore each category in further detail.
Quality of Life

Measurement of quality of life with ESRD has received increasing attention over the last decade (Cagney et. al, 2000; Parsons & Harris, 1997), particularly among medical practitioners. Interest in quality of life has been linked to the high cost of renal replacement therapy (Parsons & Harris, 1997) and to concerns about how increased longevity due to improved technology has impacted patients with ESRD (Cagney et. al, 2000; Molzahn, 1991; Winsett & Hathaway, 1999). Quality of life with ESRD has proven difficult to quantify due to the vastly differing forms of renal replacement therapies, ranging from the highly invasive dialysis modalities (hemodialysis and peritoneal dialysis) to renal transplantation, that largely relies on medication therapy once surgical recovery has occurred (Parsons & Harris, 1997). Additionally, quality of life instruments have proven difficult to apply to ESRD, as an ESRD specific instrument has yet to be tested and validated. Instead, most instruments used were generic rather than ESRD-specific, and according to Cagney et. al (2000), who reviewed 78 research articles on ESRD and quality of life, have resulted in less than reliable findings. As Molzahn (1991) argues, quality of life has been conceptualized and measured in so many different ways that it is difficult to compare the often-contradictory results. However, Parsons and Harris (1997) were able to identify common areas among studies, concluding that transplantation provides the highest levels of functional ability, employment and subjective quality of life. They found little difference between peritoneal dialysis and hemodialysis, and among diabetics, the largest group of ESRD patients, there was evidence of lower overall scores than non-diabetics.

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4 It is beyond the scope of this project to examine and critique quality of life instruments. Rather, I simply wish to note that quality of life has received considerable attention in ESRD care, with mixed results.
Quality of life measurement indicates an interest, on the part of providers, in the well being of ESRD patients. Although it is not specific to health care communication, this attention to quality of life issues points to a growing awareness among providers of the non-biological aspects of living with renal disease and its treatment. Apart from quality of life research, there are a number of research studies examining aspects of illness experiences such as coping and psychosocial adjustment that I will discuss in more detail.

Coping and Psychosocial Adjustment

It is widely recognized among ESRD care providers that living with renal disease requires a significant psychosocial adjustment on the part of patients and families. I found a few studies that attempted to measure aspects of coping and adjustment. Specifically, adjustment and acceptance (Keogh & Feehally, 1999), rehabilitation (Peters, Hazel, Finkel & Colls, 1994), coping strategies and gender (Blake & Courts, 1996), and psychosocial adjustment and home hemodialysis (Courts, 2000) were explored using quantitative research methods. It is difficult to compare results, again, due to the fact that there are few similarities between studies and respondents. Moreover, it is important to note that, apart from Courts (2000) these studies had relatively small samples and used vastly different scales to measure results.

To summarize, quality of life and coping and adjustment have received some interest among renal care providers, indicating an awareness of the socio-emotional factors in living renal disease. However, these particular studies are quantitative in nature, and vary significantly in terms of instruments, topic of study, and renal replacement modality, making it difficult to synthesize findings.
Unlike quantitative approaches that pre-limit the focus to particular categories, general experience of renal disease is a growing area of interest, particularly to nurses. Within the nursing literature, authors have become much more prolific in examining experiences of renal disease. In the following section, I will provide a detailed discussion of the growing body of research about experiences of living with renal disease.

**Research Attending to Patient Experiences of ESRD**

Molzahn (1993) reported on a review of the nephrology nursing research literature from 1979-1989. In that survey, Molzahn found that much of the research pertained to medical or biomedical research, and that nurse-patient interactions had not been examined at all. Since the date of the Molzahn review, there has been an encouraging growth of nursing research attending to patient experiences of the various aspects of renal disease and treatment factors.

Much of this research is qualitative and researchers have attempted to inductively describe patients' reports of living with renal disease, including both physical and socio-emotional aspects. For example, Lindquist, Carlsson and Sjoden (2000) described patients' wish for normalcy as the primary focus in experiencing renal disease, whereas Gregory, Way, Hutchinson, Barrett and Parfrey (1998), using grounded theory, indicated that developing a "new sense of self" reflected the overall process. Rittman et. al (1993) identified taking on a new understanding of being, hope and dwelling in dialysis as constitutive patterns in experiencing dialysis, arguing that focus on the highly technical dialysis environment often prohibits ESRD care providers from understanding lived experience. Weil (2000) similarly found hope to be a major factor in experiences of hemodialysis, suggesting that nurses ought to foster hope for dialysis patients whenever
possible. These qualitative studies, although not generalizable, provide some insights into experiences of renal disease and treatment, indicating a growing interest among health care providers, in the insider perspective of experiences of illness.

I found two other topics where insider perspectives have been considered relevant to a larger understanding of the ESRD challenge. A few studies examined patient perceptions of quality of care in various treatment settings, and four articles explored nurse-patient relationships. These topics will be summarized in the following section.

Patient Perspectives of Quality of ESRD Care

Wuerth et al. (2000), conducted semi-structured interviews of 30 peritoneal dialysis patients affiliated with a particular clinic, finding that the most important factors influencing satisfaction were attention to individual patient concerns, a personal atmosphere, and overall quality care. Ferrans, Powers and Kasch (1987) surveyed 416 hemodialysis patients and found that satisfaction with medical and nursing care, nurses’ understanding of personal concerns and nurses’ management of emergencies were primary factors in patient satisfaction with care, followed closely by physician concern about patients and time spent by nurses talking with patients. Interestingly, these authors also found a correlation between dissatisfaction and education and length of time on dialysis. Specifically, the longer a patient was on dialysis, and the higher the level of education, the more likely dissatisfaction occurred. It might be worth further investigation to explore this link between experience with treatment and dissatisfaction to see where expectations of care might change. Finally, Bartucci (1985) explored patient perceptions of transplant care in order to evaluate how use of a nurse in primary care differed from that of physician care. Although this study was not conducted to elicit

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5 A definition of quality of care was not provided.
patient expectations of care, there was some indication that the time spent with patients during clinic visits and accessibility between visits was an important aspect of care to patients.

Although there are relatively few published studies eliciting patient perceptions of care, they may be occurring with greater frequency than is reflected in the literature. Some ESRD investigators may elect not to publish their findings, although this is regrettable in that interesting and helpful results may go unshared with other renal care providers. In the absence of published studies, it is difficult to evaluate the extent to which patients' views are being sought regarding perceived quality of care. Hopefully, ESRD care providers will begin to put more emphasis on this type of research.

Communication and Staff-patient Relationships

The ESRD-specific literature that I believe most closely reflected health care communication is that of research exploring staff-patient relationships. I was able to find four such publications that in various ways examined this topic. Oberley (1991) conducted three focus groups attending to issues of patient-staff relationships, finding that continuity of care, staff turnover, insufficient input into care decisions and not enough educational support were concerns of the patients involved. Timing of educational support was also viewed as critical: “In my case, a lot of that information that I got, it was not to the point. I didn’t want it. I was so angry-I’d throw it in the trash. What do I want this for? Why? It always came up: why me? (1991, p. 26).”

O’Brien (1983) similarly took an interest in patient perceptions, and specifically interviewed and observed both patients and staff, concluding that staff-patient relationships involved control (primarily on the part of staff), and bargaining, testing,
manipulation and dependence (primarily on the part of patients). Nurses reported a dual role: both the physical/technical and psychosocial aspects of care, aimed primarily at helping patients adapt to hemodialysis. Interestingly, O'Brien noted that the staff showed a tendency to use physical parameters to mark progress in adaptation, a habit that continues to this day in many ESRD programs, and may reveal assumptions about adaptation that accord with health care provider priorities.

Goddard and Powers (1982), in exploring differences in nurse and patient expectations of education, proposed a link between adequate communication and appropriate education. "When information is presented without first determining what educational issues are of greatest concern to the patient, the communication process is bound to falter (p 578).” However, despite saying this, the educational topics used to develop the scale were largely biomedical, ranging from medications, blood pressure and diet/fluid restrictions to how hemodialysis works. Not surprisingly, nurses rated information on blood pressure and diet much higher than patients, who reported the most important concern (of the limited topics) as that of caring for fistulas. Interestingly, the authors attribute lack of patient interest in diet and fluid restrictions to denial and excessive gain from the sick role.

Sloan (1999) conducted a study using Thorne’s (1993) framework of guarded alliance relationships to verify whether there is evidence of such relationships in ESRD care. Although the framework seemed somewhat uncritically applied to the ESRD setting, the author found evidence that nurse-patient relationships ranged from naïve trust to disenchantment and guarded alliance. However, Sloan takes note of the differences in

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6 A fistula is a surgically created connection between an artery and a vein, usually in the arm, in order to increase the size of the vessel for the purposes of needling and supporting the hemodialysis procedure.
relationships with the variety of care providers typical of ESRD treatment. Specifically, patients have regular access to physicians, nurses, technicians, dietitians and social workers. Different types of relationships occurred simultaneously with different providers, revealing some of the complexities of ESRD care. Sloan calls for greater consistency, honesty and trust on the part of providers in order to improve health care relationships.

Finally, Morehouse, Colvin and Maykut (2001) explored 22 nurses’ perceptions of nurse-patient relationships in hemodialysis. Nurses in the study reported that they perceived relationships with patients to resemble that of the psychotherapeutic patient-therapist connection, in that listening and counseling were a major focus. The study further explored what kept these nurses in the specialty, finding that learning about the complex interaction between technology, physical effects and maintenance of health served to keep nurses interested in the field. The long-term nature of dialysis nursing also factored into nurses’ perceptions of relationships, where opportunities for two-way supportive interactions were more possible than perhaps in other specialty areas. However, the authors conclude: “In order for a nurse to help a patient comply with dietary and medical regimens, nurses need to be teachers, behavioral therapists, and supportive counselors (2001, p. 299).”

Summary

Although there is an encouraging growth of qualitative and quantitative research focused on general health care communications, as well as a growing body of research on quality of life, coping and adaptation, and insider perspectives of ESRD experiences, there is much work to be done. Nearly ten years after Molzahn (1993) published a
review of nephrology nursing research, calling for more research on nurse-patient relationships, I was still unable to find much literature attending to this topic. Similarly, communication research is notably lacking, and yet, forms such a vital element of health care relationships, particularly in the context of the highly technical, closely-monitored environment of ESRD care.

Although there has been an emphasis on the content of health care communication, little is known about the context of communication, and still less is known about patient preferences and expectations of communication, particularly in the context of chronic illnesses such as ESRD. Similarly, the underpinnings of compliance beliefs on the part of health care providers are strongly evident in the research reviewed in this chapter, indicating a need for further examination of how such beliefs may influence patients’ experiences of communication. Thus, it was timely to consider the study of communication in ESRD care from a perspective removed from assumptions that the primary aim of communication is patient compliance. In this research project, I sought to uncover how a selected group of patients with ESRD described their experiences of communication in ESRD care in order to develop a beginning understanding of what they considered helpful and unhelpful, and when and how specific communications ought to occur, from their perspective.
Chapter 3: Method

My goal in this research project was to explore ways in which patients with ESRD explained and described their communications with ESRD care providers. As there have been few (if any) studies of communication in ESRD care, it was helpful to begin with an inductive approach that could offer some descriptive insights into patient experiences of communication. Interpretive Description, as presented by Thorne, Reimer Kirkham and MacDonald-Emes (1997) was the qualitative method through which these descriptions were investigated. Interpretive Description utilizes an inductive, interpretive approach to research, recognizing that human experiences, including experiences of illness, are a complex interaction between psychosocial and biological phenomena, and “acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities (1997, p. 172)”.

Interpretive Description has been adapted from other qualitative methods in order to facilitate use in applied or practical sciences, such as nursing, for the purposes of clinical practice. It draws upon the practices of analytic frameworks, theoretical sampling, constant-comparative analysis and rigor in order to provide enough guidance to permit the researcher to reach conclusions in a manner that incorporates context as well as individual experiences. The ontological and epistemological stances of this method are constructivist and interpretive (Crotty, 1998; Lincoln & Guba, 1985), and provides a suitable fit for the constructed and contextual nature of health care communications. A specific description of the study design is provided below.
Analytic Framework

There is a common conception among health care providers that chronic illnesses have much in common and can therefore be generalized into a collective illness experience. However, not all chronic illnesses are alike, and many involve varying degrees of intrusiveness and impact on daily living. It is necessary to explore the distinctions, as well as the commonalities, among chronic illnesses, particularly those that involve a greater degree of management. ESRD is one such chronic illness that requires a significant amount of daily management, and therefore it was assumed that experiences of ESRD would differ from other, less invasive chronic illnesses. Because of the intrusiveness of the disease and the need for regular and ongoing medical management, communication with ESRD care providers is frequent and extensive, making communication very important to patients and families. Patients with ESRD thus offered important insights about their experiences of health care communications in this particular clinical context. Moreover, conducting research specific to ESRD provided some description of what aspects of communication are unique to ESRD care settings, in addition to those that may be held in common with other chronic illnesses.

Study Design

This project drew, in part, on a larger ongoing study being conducted by Thorne and associates (in progress), who are involved in researching health communications with patients experiencing three distinct diseases: Type 2 diabetes mellitus, fibromyalgia and multiple sclerosis. Thorne and associates have been using interview and focus group methods to collect data exploring patients' descriptions of health care communications in
order to help develop preliminary conceptualizations of themes and patterns within accounts of helpful and unhelpful communications with health care providers. Interpretive Description is the method utilized in this larger study driving the data collection and analysis. Because the Thorne study is intended for chronic illness research and is generating some success in describing experiences of communication, in my study I replicated their design and research question with another patient group: ESRD.

Recruitment

Eight individuals with longstanding experience with ESRD took part in this study. In this case, longstanding experience was defined as having lived with ESRD for at least five years. Individuals were recruited using the assistance of established contacts in a local hospital and by word of mouth. Specifically, patients were approached by clinicians who offered patients the information and consent form (see Appendix 1) and briefly explained the study. Interested patients then contacted me directly to discuss their interest in participating, at which point I provided a more detailed description of the project.

Sample Selection

Interpretive Description employs purposive, theoretical sampling for participant selection (Thorne et.al, 1997). This ensures that individuals in the study represented a range of personal coping styles, treatment experiences and health care encounters. Within the ESRD patient community, there are a number of different treatment modalities that involve varying degrees of regular contact with ESRD care providers. Specifically, patients who are receiving dialysis treatments may view their communications differently than those in pre-dialysis or transplant care, who tend to
access health providers less frequently, and whose treatment regimes are for the most part self-administered and significantly less intrusive. Therefore, I selected patients from each of four treatment groups: progressive renal insufficiency (PRI), peritoneal dialysis, hemodialysis and transplantation, in order to explore both the similarities and differences in their experiences. Furthermore, those closer to the experience of diagnosis, such as patients in PRI care, or newer dialysis patients were considered likely to view their communication differently than those who were veteran ESRD survivors who had experienced multiple treatment modalities.

Four women and three men with ESRD, and one partner, participated in the study. One participant had experienced only one type of ESRD treatment, whereas the rest had experienced from two to all four treatment modalities. At the time of the data collection, one participant was in PRI care, two participants were undergoing peritoneal dialysis, one was on hemodialysis, and three had received renal transplants. Those with renal transplants had each experienced one or both dialysis modalities. Several of the participants had additional concurrent chronic illnesses, including diabetes, chronic hypertension, cardiac disease, and gastrointestinal disease. Several of the participants had been recipients of health care for decades.

Data Collection

The primary source of data in this research was face-to-face interviews. The interviews were minimally structured, followed in two cases by telephone interviews for expansion and clarification. A list of non-directive, open-ended trigger questions is included in Appendix 2. At the beginning of each interview, consent was obtained and demographic factors such as age, details of ESRD treatment modalities, family status, etc
were collected. Efforts were made to ensure a comfortable, private environment that facilitated open discussion. Hence, most of the interviews took place in the participants' homes. As discussing experiences of health communications were sensitive for some individuals, and because I am, myself, an ESRD care provider, I ensured that participants were aware that discussions of negative or particular experiences would in no way affect subsequent care that patients received and that I would not be discussing the particulars of the interviews with any other ESRD care providers.

I conducted each interview. Interviews were audio-taped and field notes completed immediately afterwards to summarize the substance of the interview. Each interview was then transcribed verbatim by a qualified transcriptionist and, when possible, reviewed prior to the next participant interview.

**Data Analysis**

The strategy for data analysis was inductive, using constant comparative analysis, which permits the researcher to seek patterns and relationships as they emerge in the data (Morse & Field, 1995). Rather than a focus on coding and classifying data into ever-reduced elements, Interpretive Description relies on maintaining a sense of the whole by asking questions such as “what is happening here?” and “what am I learning from this? (Thorne et. al, 1997, p. 174).” In this way, the analytic structure emerges from repeated immersion in the data prior to beginning to create linkages, with an emphasis on synthesizing, recontextualizing, and theorizing.

In reviewing transcripts and during the data collection process, I followed the process of reading/listening for themes arising out of the patients' words. I kept my early analysis as tentative as possible in order to prevent premature formation of themes, and
kept a journal in order to track my impressions and development of theories. After reading each transcript and field note, I made tentative comments on the margins and developed a summary of the salient points. With each interview, I used the comparative analysis method to consider differences and similarities among the transcripts, and continually reviewed earlier tentative ideas with my evolving reflections. As commonalities occurred, I made an effort to not only note the similarities, but attempted to account for the differences as well.

As themes emerged, they were explored in subsequent interviews. This gave me an opportunity to validate my emerging themes and gain further insights into the commonalities and variances in the interview data. Thus, synthesizing, theorizing and contextualizing, rather than coding and classifying, formed the basis of the analysis. Once the interviews were completed, the data were again reviewed and themes were grouped according to their relationships to each other and according to their contribution to a sense of the whole.

Rigor

Rigor is of utmost importance in qualitative research, and for this project, rigor was addressed in the following manner. According to Lincoln and Guba (1985), rigor in qualitative research must fit with the emergent nature of the data, and measures of trustworthiness are necessary. Specifically, auditability, fit, credibility and applicability (Morse & Field, 1995; Thorne et. al, 1997) were the criteria used to maintain rigor.

In order to provide a suitable audit trail, I kept a reflective journal, thus tracking my decisions, reflections, insights and emerging analysis. Similarly, field notes were completed immediately after each interview in an attempt to capture my initial
impressions and observations during the interview. I also followed Sandelowski’s (1986) recommendations for a clear decision trail, including how participants were selected, the impact of my actions as a researcher on the interview, the nature of the interview settings, data inclusion criteria, details of my analysis process, and checks for credibility and applicability.

Interpretive Description provides an alternative to “member checks” which can be fraught with difficulties (Sandelowski, 1993), in that it permits the researcher to evaluate the fit, consistency and applicability of the emerging analytic framework through subsequent participant interviews. Specifically, ideas were corroborated or discarded by later participants, who provided their perspective on the analytic process. Apart from gaining the participants’ perspectives on my tentative themes, I also took advantage of the perspectives of my colleagues and my committee in seeking out evidence where my biases may be interfering with analysis, and considering the manner in which my emerging themes resonated or seemed credible.

According to Sandelowski (1986), applicability in qualitative research refers to the “fit” between results and contexts outside the study situation are similar, and the results are meaningful for both readers of, and participants in, the research. To address applicability, I relied upon my committee to confirm the fit of the findings with other ESRD and chronic illness contexts. Additionally, I confirmed my findings with other patients with ESRD in order to assess the degree to which my findings applied in meaningful ways to experiences of ESRD communications.
Ethics

Approval for research with human subjects was received from the University of British Columbia and the Vancouver General Hospital. All participants were informed of the purpose and nature of this project (see information and consent form, Appendix 1). As mentioned, having an agency contact establish the initial communication with potential participants, who then contacted me directly, protected the rights of participants. At that time, I answered any questions and gave a full description of the project and interview process, including the right to withdraw at any time. I obtained written consent from participants, and protected the privacy and confidentiality of participants by keeping specific details of the interview anonymous, removing names from transcripts and the final report, and by keeping the tapes and transcripts locked in separate file cabinets. Upon completion of the study, the tapes were destroyed. Finally, participants were offered a summary of the findings once the project was completed.

Study Limitations

As mentioned, the fact that I am an ESRD care provider may have inhibited some freedom of discussion for patients. Similarly, the fact that ESRD care is my clinical background may have blinded me to some of my assumptions, as I am enculturated in the ESRD care setting. Nonetheless, I attempted to be as open in my interviewing style as possible and, during data collection and analysis, looked for evidence that I may be using this ESRD care provider lens so that I might consider how it may have influenced my analysis.

The constructed nature of stories, which change in the telling and re-telling (Sandelowski, 1993), can only function as a “snapshot” of the experience, which will
continue to evolve over time. This will inevitably create limitations in that the findings obviously remain static and can only attempt to capture a description of the patient reports. Moreover, the small sample size and method only offer an interpretation of the experiences of the particular individuals involved. Therefore, there was no attempt to generalize findings to the greater ESRD community or to chronic illness experiences. Instead, the findings simply function as a beginning description of how these specific patients characterized their health care communications, and to invite consideration of the findings among health care providers.

Summary

The method of this study was interpretive description, which employs the use of open-ended, minimally structured data collection, constant comparative analysis and theoretical sampling in order to provide an inductive approach to the research of human experiences. As interpretive description permits consideration of the contextual factors that typically occur in clinical settings, it was chosen as the method suitable to research health care communication. Procedures to protect confidentiality and the rights of participants were followed, and efforts to sustain the rigor of this project were undertaken in order to ensure the results were as trustworthy as possible.
Chapter 4: Findings

My purpose in this study was to examine the ways in which patients with ESRD describe and explain helpful and unhelpful communications with their health care providers. In reviewing the interviews and transcripts, it quickly became obvious that experiences of communication are highly dynamic and individual. Specifically, perceptions about a health care encounter are heavily influenced by expectations, fears, anxieties, physical status and previous experiences. However, there were a number of commonalities among participants that permitted me to provide an overall description of ESRD communications for this particular group of patients. In this chapter, I will offer an account of the study findings that, in my view, best describe and explain the participants’ experiences of their health care communications.

There were two overarching themes arising from the data. These two themes appeared to underscore much of the participants’ reports, and were sufficiently prominent in each interview that I found it useful to organize my findings around them. The two themes were vulnerability and vigilance, both of which featured prominently in the data, although in divergent ways, and therefore appeared to form much of the contextual basis of these particular experiences of ESRD communications. I found it necessary to attend to these two contextual themes because of their usefulness in explaining the ways in which being vulnerable and being vigilant both shaped and were shaped by the subsequent communications. I will begin with a description of vulnerability, including some of the related sub themes that arose out of the data, followed by an overview of vigilance and its related sub themes, whereupon I will conclude with an exploration of
the relationships between helpful and unhelpful communication and vulnerability and vigilance.

**Vulnerability**

Each of the participants referred in some way to the vulnerability they experienced in their health care communications. This vulnerability appeared to arise out of a number of factors, not the least of which was the physical illness itself. A diagnosis of ESRD, because it involves the failure of a vital organ, brought out fears of mortality, fears of a lifetime illness and the associated lifestyle changes. Furthermore, the participants were very clear that they were in a position of needing care, and were aware that they would need that care for the duration of their lives. It was thus apparent to them that developing relationships with ESRD care providers was an important endeavor, and that maintaining those relationships might involve some negotiating within power dynamics and expectations of providers. One participant rather poignantly illustrates this vulnerability:

If you care what people think and you rely on them for your help, that can be very scary to speak your truth because you're afraid that you might upset them and if you upset them will they give you the same level of care, will they be kind to you, will they become upset with you and then not be as mindful of what they are doing?

Another participant acknowledged the power imbalance inherent in ESRD care, particularly around the incongruous amount of information held by providers and the cognitive limitations she experienced with her illness:

It's such an imbalance. Here you have someone who got their 10 years of education, you know it all, and here's the little patient who might even be sick at the time is being asked to make a decision...and your mind doesn't function very well when you're on dialysis. Let me tell you!
Vulnerability, apart from arising out of the illness experience, also occurred in response to lack of familiarity with the health care system, where jargon and unexplained assumptions and routines were prevalent. Being unfamiliar with the routines and customs of the system, participants discussed feeling disadvantaged and sometimes mystified about what was happening with their care and recovery. Moreover, participants occasionally encountered health care providers that were curt with them, or unhelpful in ways that further exacerbated feelings of vulnerability and concern.

Thus, according to the participants, vulnerability was a significant operating factor in ESRD communications, and appeared to be influenced by communicating while ill, the institutional context, and unhelpful communications with individual health care providers. Each of these factors will be explored individually and in detail below.

Communicating During Illness

All of the participants referred in some way to the fact that their illness played a major inhibiting role in their ability to communicate effectively with providers, particularly around the time of diagnosis and initiation of dialysis therapy, when the blood toxin levels were the highest and most troublesome:

I think at the beginning stages I was just so ill that it was hard for me to remember or take in a lot because I just felt so horrible so much of the time. In a lot of pain, and nauseated and vomiting and just so tired and my head [felt] funny...I couldn't take in information. People would say something like "walking your dog" and I would say, "I don't understand", they'd say it again and I still couldn't understand. Somehow my brain wasn't functioning.

For many participants, the effects of illness impaired their ability to process information, learn, ask questions and communicate effectively with providers, particularly around treatment planning in the early stages of the disease. Several of the participants reported feeling rushed into treatment decision-making at a time when they were physically and
emotionally unable to process information in an effective manner, and three of the participants indicated they believed they had made the wrong choice, which set them back in their recovery process for a considerable amount of time and may have had a negative effect on trust-building with providers:

At the time I was sick...I didn't know anything about it and it was difficult... I really felt pressured to make a decision that I didn't feel I was healthy enough to make but I was being told...they made it sound so great that I decided to do it.

Additionally, those who subsequently experienced complications from their treatment regime that required hospitalizations or complicated recovery reported that feeling sick again had a negative effect on their communications, as they often found they did not have the energy to advocate on their own behalf, or even respond to unhelpful communications. One participant described her process for choosing when and how to respond as dependent on her energy levels and the degree of illness:

It depends how...how fed up I am. It depends on how powerless I feel; it depends who it is...This admission I spent five days in emerg...I had five days of fighting and that was when I was really sick...really fighting this system. And so by the time I got up here, I had no energy left to fight anyone so then I had a nurse withhold my insulin and I was sputtering; I was furious. But I didn't do anything...I went to the head nurse the next day. So part of it is trying to stay focused on what's really important and I'm sorry if people are such...there are people who are just total idiots...and when I'm that tired and sick I don't have any energy. It all depends on how much that I have, what my physical status is, how long I've been dealing with this, how much support, on the good side, there has been, and just how fed up I am.

Similarly, a number of the participants reported frequently letting unhelpful communications go unchallenged, as they did not wish to antagonize their care providers, identifying feeling ill and vulnerable as a contributing factor:

I was afraid to speak up. 'Cause they're caring for you and you don't want to upset them and I cared for what people thought at that time and they were very loud at times and would come and keep talking to me...I was so tired...I had no energy and that wasn't helpful either.
Participants thus indicated that, in the context of communication, feeling ill was a powerful influence on the success or failure of their health care interactions, acknowledging the effects of the disease (as well as the insensitivities of health care providers) as an inhibiting factor. Consequently, the ability to advocate or inquire on one's own behalf was hampered, and required conscious decision-making regarding where to conserve or expend energy around communicating effectively.

**Communicating in the Institutional Context**

Apart from feeling ill and experiencing cognitive changes, participants reported that the unfamiliar health care system presented challenges that made communications difficult at times. These challenges had a direct impact on feelings of vulnerability, as not only were the participants ill at the time, they also had less information and expertise than their care providers, who were operating in a system that, while familiar to providers, was quite foreign to patients. The participants reported that it took some time to find out what to ask, how to find out information, or where to seek support. A number of the participants indicated that information about these resources were not necessarily provided at the outset, and they had to engage in a process of learning that not everything would be handled as comprehensively as they might like, and that they would need to take on some of the work of coordination themselves.

Consequently, apart from the fact that they had a great deal to learn about the illness and treatment, it also became apparent to the participants that they had to learn to navigate the system, which included the power dynamics of patient-provider interactions, dealing with authority and expertise, and the gaps in care that can often occur in our current health care setting. Specifically, experiences of provider authority and
fragmented care were the most common sub themes evident in the participants’
descriptions of the challenges in their communications within the institutional context,
each adding another dimension to experiences of vulnerability.

Experiences of provider authority. Although the participants’ descriptions of the
ways in which provider authority impacted their communications varied, it appeared to
play a significant role. Specifically, there was a range of responses, where some
participants indicated a complete and somewhat passive trust, while others expressed
reservations about the advice and expertise they were offered by ESRD care providers.
Perhaps this had something to do with years of experience with the system, as those with
less experience seemed much more inclined to reiterate the information that they had
received from providers during the interviews. For example, those who were earlier in
their illness experience tended to focus on biomedical parameters in their descriptions of
their communications, particularly when reporting their expectations. Three of the
participants, who were relatively new to the treatment, tended to focus on their
understanding of diet restrictions and lab values during the interviews. For example, one
participant and spouse discussed their expectations of ESRD communications that
appeared to reflect a fairly circumscribed view of health communications and a high
reliance on medical authority:

P: Well, if they see on your chart that something is wrong they should tell you.
I've heard some people say they don't believe their blood tests but I think its very
important to get the blood test. The doctor sees what's going on...you see what's
going on.

Spouse: It's really important...levels...man! It's what its all about, isn't it?

These participants indicated that their expectations of communications largely rested on
providers monitoring their status and informing the participants of transgressions and
potential complications, thus demonstrating a relatively unquestioning perception of provider authority. On the other hand, those participants with more experience tended to view their caregivers’ communications, including caregiver advice, with reservation, particularly when they believed they had a more comprehensive outlook on their illness than the caregiver, or the caregiver was new to them:

I want to be listened to...I don’t necessarily want to be agreed with...its a negotiation... so I want to be not only acknowledged, but really listen to me because I do know and there are things that I know more than my providers know as well as things they know, too...the way I see it we each have our own areas of expertise and so, you as a nurse, you give that to me and I, as the patient, give that and then we come up with some kind of plan.

Clearly, perceptions of provider authority involved some expectation of what should be communicated and how it should be done. Despite the range of responses among participants, perceptions of provider authority were a factor in whether communication was perceived as helpful, or not, and whether that authority rendered participants more, or less, vulnerable.

Experiences of fragmented care. Beyond the fact that participants felt ill and needed to navigate the power dynamics of institutional authority, it was also apparent that communicating with a large number of health disciplines presented challenges. The course of ESRD is often unpredictable and involves a great deal of comorbidity, and patients with ESRD seldom experience lengthy stable periods, instead going through numerous ups and downs and physical, social and emotional sequelae that, of necessity, bring them into frequent contact with a number of different health care providers. Moreover, many patients with ESRD experience multiple system or organ involvement, and it is not uncommon for patients to be accessing general practitioners, cardiologists, endocrinologists, gastroenterologists, nephrologists, dermatologists, nurses in dialysis
units, nurses in clinic settings, social workers and dietitians and so on. This became apparent with the study participants, who reported frequently having to access diverse health care providers within and without of the renal team. According to the participants, this led to frequent duplication of diagnostic procedures, miscommunications among the disciplines, inappropriate medication prescriptions and oversights in the treatment planning and implementation process. One participant describes her process of information seeking and decision making in order to circumvent this fragmented approach to her care:

I'm quite demanding that way with "what exactly will that do?" or "why do we have to do that?"...and so I really do demand a lot of information which has actually been quite helpful at times because when someone walks into the room and I can just say "well, I already did that" or "no, I'm not giving another blood test or x-ray" or whatever, because mistakes do happen and there have been a few times I've had to bring attention to ..a nurse or doctor's attention that I either did or didn't get some treatment that I wasn't supposed to. So it pays to pay attention and know what's going on with your own medical history.

Another participant commented on a similar need to monitor the treatment, while also expressing concerns about dependence on care providers who may or may not be offering the most effective options:

I've actively sought information out because I cannot make a decision and then I have to rely on everyone else to make a decision about my life which makes me crazy...But its clearly getting that information because then I can question you when you put up...I mean I've had people put up things like an IV [medication] and later the next day the doctor said it was the stupidest thing to put up...Well, if I knew that then maybe I would say something first.

The fragmented approach to care raised concerns about quality, that, in turn, led participants to consider either taking on the oversight of care themselves, or looking for single provider or a small team of providers to function as the locus through which all treatment decisions got channeled or validated. Notably, it was the renal team in which
participants indicated they felt the most trust, perhaps because of the lengthy relationship building process and continual contact.

The overseeing of fragmented care, regardless of whether it was done by the individual patient or team, still involved an enormous amount of work on the part of the participants. These participants reported constantly weighing whether or not information about a treatment or symptom change ought to be passed onto the renal team, and strategizing how they could minimize duplication of tests, procedures and potential or real errors:

Honestly, [having more than one disease] is enough for anybody; two is a lot of work and if I can make my life just a tiny, tiny bit easier, by the fact that I have no veins and I can get away with one test instead of two; if I can do one 24 hour urine instead of two...yeah I try to do that ...that just makes my life easier...So I do it even though its running around, I have more confidence that it will get done because people get busy. Its really important to me and it probably isn't as important to my doctor. He's not itchy. So for me everything becomes really significant and I'm willing to take that on...I'm like a chicken....sometimes I'm paging everyone in the hospital and I'm doing this and I'm trying to find out what kind of tests I need...lets just tack it onto this order....I'm willing to go through all these hoops to try to get the best possible care that I can for me and the most comfortable care.

This same participant goes on to describe the potential impact of not doing this work:

What do people do who don't have the intelligence, the energy, the whatever, the assertiveness to do this stuff...what happens is they get three blood tests. Or do a 24 hour urine and a week later they have to do another 24 hour urine. And again, on one hand no one has died from it, but on the other hand, you know what...I can make a phone call to prevent that, I will. But it's a lot of work. I'm my own case manager...So do I check stuff out? Yes. Is it a waste of energy? A lot of times it is. But the one time its not, I'm very happy...

Thus, despite feeling ill and dependent of the care of others, participants described learning that they had to pay attention to the details of their care and learn as much as possible about the treatment planning and implementation, as mistakes and oversights were not uncommon. As a result, a number of the participants actively engaged in extra
work in order to learn to anticipate, monitor and coordinate their treatment plan once they learned that care is often fragmented and that their care was vulnerable to errors.

The participants thus identified aspects of communicating in the institutional context as challenging and required additional effort to learn how to negotiate within the system. For this group of patients, provider authority and fragmented care appeared the most significant, where it became necessary to not only learn about their illness and treatment, but also learn how to deal with authority figures and find out, sometimes the hard way, that they needed to attend to the actions of providers, who might not necessarily be offering the most comprehensive care.

**Experiencing Unhelpful Communication**

Vulnerability, apart from arising out of illness and dependency on the care and expertise of others, also arose out of experiences of unhelpful communications. In short, unhelpful communications tended to heighten this feeling of vulnerability. Participants identified unhelpful communications as those which included judgment on the part of providers, rushing, giving confusing or conflicting information, and most alarming, those that resulted in a reluctance to convey symptoms or check out concerns. I grouped the participants' reports of unhelpful communications into the following sub themes: being dismissed, fearing abandonment and being judged. Each of the sub themes, which added a further dimension of vulnerability, will be discussed in detail below.

**Being dismissed.** Being dismissed had a negative effect on participants in that they learned that they did not have an open forum in which to discuss concerns or learn how to judge the significance of their symptoms. For some, this dismissal of concerns also had negative health consequences. For example, one participant described an
incident where her concerns about her reaction to antihypertensives were ignored for months until she experienced a serious accident:

"Oh well, you shouldn't worry because that's a very good blood pressure. That's what we want it to be." And I said "yeah but it goes down too fast". "Oh well, don't worry about it...don't you worry your little head about this. We'll look after you, you know." And so, when I finally almost killed myself, then they changed my medication. But you shouldn't have to put up with that.

As another participant points out, being dismissed had the effect of reducing participants’ trust of their bodies’ cues, curbing the expression of fears, and a subsequent reluctance to report symptoms:

I think it’s so important to listen to the patient and to understand that this is a big one even when nothing is wrong. Don’t yell at the patient because when a patient isn’t well and then something happens, they don’t know if its their illness and something serious could be happening and, you know, because they’re kind of faced with their own mortality at times, you know. They don’t know if it's just the flu, if it's just...so they have to report it and at least get it checked out. It's the self-responsible, self-loving thing to do. So if you go in and you're told you're wasting their time or this or that or you're over-reacting, you know that can cause a patient in the future to think, "should I report this, what if he thinks I'm over-reacting, what if I am? Oh, god, what if I am?"

Fearing abandonment. Several of the participants explicitly discussed fears of having their care compromised by providers who did not value the opinions or actions of participants. For example, one participant indicated a fear that his caregivers would abandon him when he made changes to his regime without their consultation:

P: Well, I was a little...I knew I had done something wrong...that I should have contacted them so I learned that the next time I better let them know what I'm doing. Otherwise I won't get the help I need. You know...otherwise they'll just say "oh well, he's going to do his own thing, so we'll just let him go".

R: Do you think they'd do that?

P: Oh, you never know! They've got so many patients. You know if you don't want to work on their rules...I guess there's rules that you've got to go by and things that you've got to do and if you don't obey...if you don't do those...they aren't going to bother with you because they figure you don't want to...you
know...you're not worried about your health so I've learned now that I better let them know what I'm doing if there's a problem.

Other participants indicated a more general concern that angering or alienating providers might have negative consequences for their care, resulting in a reluctance to challenge or question providers, or taking a fairly meek and roundabout approach to inquiring about the care they received.

**Being judged.**

Being sick and being judged was very hard because then I didn't feel safe in that environment—my only environment to go to if I'm ill and I need support, right. Like from the health professionals, that is. I have friends, but when I need to go into the hospital—scary enough for me, let alone when you feel judged. Also it kind of shut me down verbally. It made me not want to share as much. And, I just didn't feel safe in opening up and sharing and I didn't...and it made me feel not as...compassion wasn't coming from them—it made me wonder if they liked me and what kind of care was I getting and it just...it made me more stressed. It made me feel anxious because if you don't feel safe with people you know, then you don't feel as comfortable to be yourself. If you don't be yourself, then your needs aren't taken care of as effectively.

Finally, many of the participants referred in some way to the judgment that occurred when health care providers found fault with patients' level of compliance, indicating this as unhelpful communication. This judgment on the part of providers had the effect of curbing open communication, where participants either felt inclined to be less forthcoming about changing their regime, or felt shame or defensiveness about being considered non-compliant. As one participant explained:

> When someone speaks to you with such disrespect its really maddening. And also it's because you have that medical problem that you're getting that disrespect so it makes one feel even lower in the shame and like there's all these issues around being sick anyway, you know.

This same participant went on to describe how seemingly innocuous statements can sometimes be filtered through old experiences:
So part of that is an old story but part of it is the judgment stuff...people come to me and say "oh your blood sugar is 16. That's really high", or "hey great, it's 6. And those are really judgmental statements...I think. I hear them as very judgmental statements. And I hear the 16, "oh, you were bad, oh, did you do anything, did you have those extra cookies"...I mean, those are the things that are running through my head.

According to participants, being judged was linked to a lack of compassion and understanding of the complexities of managing a lifetime illness. Its effect on communications was troubling for participants, who voiced considerable indignation at having their considerable efforts judged by providers.

Unhelpful communications, particularly those that resulted in being dismissed, fearing abandonment and being judged, contributed, in turn, to feelings of vulnerability that raised concerns about the quality of care. The effects of these unhelpful communications appeared to influence subsequent interactions, where participants described either feeling less trusting of themselves or of their care providers. This mistrust, whether of self or providers, appeared to further increase vulnerability and impairments to open communication.

Consequently, the effect of vulnerability on communications appeared to be an important element of the data, one that appeared to reflect much of the contextual content of the interviews with participants. The various contextual factors that contributed to feelings of vulnerability, namely, experiencing communication while ill, communicating in the institutional context, and experiences of unhelpful communications seemed to have a significant impact on the participants' experience of their ESRD communications.
Vigilance

In response to feelings of vulnerability and experiences of challenging health care communications, participants discussed some of the strategies they developed in order to get their communication needs met. One such strategy, vigilance, appeared to function as a response to vulnerability that provided participants with some measure of control over their interactions with providers. Vigilance appeared to emerge from the knowledge that mistakes occur, that there are many providers involved in ESRD care, that there is often no single provider overseeing care, and that skilled communication and competence, on the part of providers, varies.

This vigilance appeared to include observing the behaviours of providers, asking questions, learning about the illness and treatment, anticipating common problems, being aware of the treatment plan, ensuring that the plan is followed, seeking consensus among providers, looking for potential allies among providers, particularly those with the desired communication styles, and strategizing how and when to use those allies to meet needs. Vigilance, not surprisingly, seemed to temper the vulnerability that the participants experienced. Specifically, by taking an increasingly active role, patients could better ensure that their care was appropriate, current and specific to their situation, and that they were receiving the necessary support. Moreover, it appeared to provide some comfort that, should future and unforeseen complications occur, there was a network in place to assist participants in managing the next event:

To me, it's to make informed choices...I want to be in there as much as I can because, you know what its like...if you're my doctor, right, and you make a mistake, you might feel bad, then you go home to your family, and the next day you're on the golf course. For me, its my life....and so that's where I find that the communication and the education are really important. It's that I can better manage my care, I can keep an eye on who is managing my care. And it makes
me feel happier, and I think I'm healthier for that. You know I've had tests cancelled that I didn't need, I've had procedures cancelled that I didn't need because I'm doing this and I use the resources that I have.

The comments of this participant illustrate both the elements of mistrust of providers and the sense of self-responsibility that seem to underscore this notion of vigilance. Beyond mistrust and self-responsibility, however, vigilance also seemed to reflect the process of learning how to work within the system. One of the ways in which participants learned how to work within the system was by educating themselves.

Getting Educated

Getting educated, according to participants, had as much to do with learning how to manage the system as learning about the illness itself. For example, for one participant, understanding the economic factors involved in providers' recommendations for treatment modalities was an eye-opener, that, to her, indicated a less than altruistic approach to providing care:

I ended up having a ruptured membrane...I had to go back to the hospital and [doctor] examined me and said "we can just redo it"...I remember I had to have enough strength to say to him "no, I don't want it redone, I want hemodialysis". And I was prepared for a fight if it came to that because I didn't realize at the time that the cost difference between peritoneal and hemodialysis was so huge, so of course the medical system is pressured to...get people on peritoneal dialysis. So by this time I knew all this. Talking to people...its amazing what you learn from people you see and you meet and you're chatting in the waiting room or whatever, and fortunately I had a friend who was ahead of me in the whole dialysis process and she told me a lot [about] the system and things I didn't know. So, it was a learning experience that took time.

Getting educated also seemed to arise directly out of the awareness that care is fragmented and that no one care provider is in charge. Consequently, getting educated included actively seeking out honest answers, finding out what to ask about their illness
and treatment and learn what to look for in symptoms, so that participants could keep abreast of their clinical status.

**Seeking honest answers.** All of the participants spoke of their desire for honest communication from providers, including their respect for providers who admitted when they didn't know and showed a willingness to explore options. In speaking of her nephrologist, one participant stated:

I trust what she has to say and there's a lot to be said for that. She puts herself off with an authority...like she really does know what she's talking about and oh! I love that about her. She said, "You know what, the kidney doctors are...we really don't know much. She'll also say when she doesn't know and I love that. It makes me honour and respect her even more. When a person or doctor can say, "I don't know". That's awesome. They're saying, "We're human, how much can we really know about everything?" So, that I love and then when she does know...when she says something that's best, at least she will tell me and then she'll listen to what I have to say about that.

Another participant described the importance of the role nurses played in providing her with honest explanations:

Hemodialysis is quite a frightening experience when you start it. You know there's these machines and tubes and blood running through the tubes and needles and people walking around with masks on and you're just going "where in the hell am I? I'm on f--- Mars". It's very overwhelming at first...I want to know what's going on...what's going into my body...what's coming out...how long does it take...why do I need this and that and the dialysis nurses, for the most part, were very good. Where you could ask questions and you could get information about your treatment and for me that was immensely important...I mean, it's not for everyone but I really take a personal interest in what's going on.

Honesty, however, needed to be tempered for some participants, in that the appropriate amount of disclosure about future complications and prognoses was highly individual. Some participants indicated a wish for the "worst case scenario" at all times so that nothing would come as a surprise:

I don't want to think that I'm getting better and all of a sudden find out that I'm not. I want to know what's the worst-case scenario, then I should be pleasantly
surprised, or not. I won't be surprised anyway. And, you know, my kidney could have rejected. I knew that. And, I wouldn't want to be told that "you get a kidney and then you're going to be just fine", because you're not! And, I guess, I felt I had been lied to too often by doctors. Not that they lie in a sense that...they just felt "well, why bother her with it because it probably won't happen". Well, I don't want that. Some people do!

Other participants indicated they wanted a very specific amount of detail, mostly focused on what was clinically relevant in the moment:

I try not to live too much in the future, but you know, I have some awareness. The transplant was definitely a future-oriented thing. But I don't know that I live too much there because it's too scary; because I don't know...You know I have all these complications from renal, from diabetes...so, I try not to live in the future; that can be very dangerous for me.

Another participant similarly referred to the hazards of forecasting too much:

And so when the doctor says to me "there's no way da da da" and eventually...like I'm told this is going to happen and that's going to happen and then your heart's going to do this and the dialysis isn't going to work and that's going to happen and da da, you're going to die young...that I don't want to hear because I don't want to fit into a box that everyone else fits into; I can't if I'm going to be open to possibilities so I don't want to discount that. And I don't say they are wrong but I don't want to put it in my head as this what I'm expecting. Because I feel that our thoughts are also creative of our reality...What I would say is for a doctor to ask each individual "what information would you like and to what extent would you like it?"

Honesty, then, although highly valued, was subject to individual preferences, as some participants preferred every detail, and others indicated a need for only the relevant information. However, honesty, in general, appeared to increase trust, particularly when providers were able to indicate when they did not have the answers or when the treatment plan was unclear. Moreover, seeking honest answers from providers seemed to serve as a means of reducing vulnerability and vigilance, permitting some measure of security and control over one's health.
Anticipating future developments. Closely related to seeking honesty, finding out what to anticipate appeared to be an important aspect of vigilance. Apart from learning about the relevant clinical conditions that may arise out of ESRD treatment, anticipating future developments also included learning about the medical management, in order to permit participants to ask the right questions of providers should the need arise, and to ensure that the proper procedures were being followed. The following quote illustrates both the importance of knowing what to anticipate, as well as the rather disconcerting lack of communication among providers that could have catastrophic results for patients:

I went up to my nephrologist, said “tell me when I get a second transplant what the protocol is.” So he told me, I got called for a second transplant and I said, “So I’m going to be on this protocol”. He [resident] said “no, no, no”. He said “your first rejection was a technical error.” I said “it was not, it was an acute cellular rejection”. He said, “No, I was told it was…” Anyway, it went back and forth and I said, “Look, I talked to my nephrologist…and I know I’m to get [medication] before I even start.” And the resident agreed, “obviously you know what you’re talking about…I can’t find anyone else so I’ll assume you’re right.” So, because I had that information before, and again, maybe it saved my kidney.

Another participant similarly identified a need to know ahead of time what may occur, after experiencing a common complication that got missed:

You have to be aware of things, like you say, the gatekeeper. I don’t have a problem with them telling me “Well, look, a lot of people get this or that or the next thing”. Its like, well fine, let me read up on it…at least know what the symptoms are.

The intent behind anticipating future developments appeared to involve identifying possible scenarios simply in order to reduce unnecessary surprises, but also involved the need to know the medical management strategies in order to monitor the quality of subsequent care.

Thus, getting educated appeared to go beyond that of simply learning about the illness. Rather, getting educated had a great deal to do with negotiating a health care
system that did not always succeed in providing participants with reassuring and comprehensive care. Participants’ awareness that care is fragmented and that mistakes do occur made it necessary, even wise, to educate oneself in order to be vigilant about one’s own care.

Getting Support

Getting support, like getting educated, was an important communicative endeavor, but for very different reasons. Getting support had more to do with dealing with the emotional and social aspects of living with ESRD, and most of the participants, with a couple of exceptions, reported actively seeking out emotional support from providers. Moreover, this active seeking of support reflected another aspect of vigilance: keeping an eye out for providers who acted in compassionate and caring ways. Some participants linked compassion and caring to moral support, one participant even identifying them as critical elements of relationship building:

I expect you, as a nurse, not to just be able to put me on and take me off and do my blood pressure. I expect you to relate to me as a human being. And that's often very lacking and I understand some of the concerns and burnout concerns...but on the other hand, maybe it is sort of divine, that you can be good at your tasks, right, but the real healing potential, that, I think, all of us in the field have, is about who you are, what you bring to that person, how you relate to that person. And that's what I need to see. And anyone I'm going to trust has to have that.

Notably, although they too emphasized a need for compassion and kindness, the men involved in the study placed less value on emotional support than the women. For example, when discussing his fears about his heart condition, one participant indicated that he did not think health care providers could help him with this. Another participant, although he stated he valued the feeling of being cared for, was very clear that he looked to health care providers for specific support: "Well, I want them to know how I feel."
How I feel medically, not emotionally." It is difficult to speculate why these differences occurred, as it so happened that the male participants were also the newest to renal disease, each being very close to five years with ESRD, and relatively new to the treatment modalities.

Participants further described supportive communications as those that had a calming, if not healing effect. Notably, two of the participants specifically identified supportive communications as important to their healing and recovery from acute phases of the disease process:

Some of the people that made such a difference...even total strangers were, could make your day by just saying something very positive and comforting, that you weren't expecting. And that was a real surprise for me, to start learning about human compassion...you know, it's really out there. And that was surprising and really gratifying to feel some of that. 'Cause that even helped me through the process as well.

Even those who did not link supportive communications with actual healing did discuss the feeling of being cared for and treated as an individual as very important. Moreover, supportive communication, according to participants, offered comfort, reassurance, normalized the illness responses, and made the illness easier to bear: "They really made a genuine effort to ensure that I understood and that I felt as comfortable as possible given the circumstances. I never went away from there wondering what was going to happen next."

Also viewed as supportive were providers who did not appear rushed, and participants indicated that they greatly valued the time providers spend with them. Notably, a number of the participants indicated that they were pleased with the manner in which multidisciplinary renal services are provided; where participants indicated they did
not feel rushed, that providers took adequate time to explain things and work
collaboratively toward a plan. One participant described his pleasure in working with
providers who took the time to answer his questions after years of being followed by a
specialist that did not:

At least you can talk to her and she'll answer you. She'll sit down and talk with me
which is what I like where the other doctor that I had for 10 years, he
couldn't...he'd examine you and everything but when you started asking questions
he'd disappear.

Other participants similarly described the comfort they experienced when health
providers took the time to communicate with them:

...he took his time, and the other surgeons I've dealt with...most of the other
surgeons I've been with were very rushed and very...because their time is so
limited but he had enough time and we were in his office for 1/2 hour and could
ask all the questions we wanted and that was reassuring in and of itself...for me.

P: They really took the time to explain how the kidney functions and what effect
it was having as my kidney function was deteriorating; what sort of symptoms I
would get and expect to encounter along the way. I think it's really great...when
my creatinine has been so high and [nurse] seems to be the first one to get the
results and she's on the phone...Urea's up, phosphate's ok, test ok. How are you
feeling? What are you doing?

R: So what is it about her call that you appreciate?

P: Oh the fact that she's interested in my health...she takes the time to call and
check up on me...it's just comforting to know that they're on top of it and willing
to communicate with you.

Not feeling rushed also seemed to contribute to a sense of being cared for and
treated as an individual, to the extent that one participant called it a "sense of mission"
and another called it "an attitude that it's their job to keep me healthy, happy". It appears
that not rushing was highly valued, and was closely linked with the soothing effect of
having questions answered, allaying fears and anxieties and providing a clear understanding of what to expect from treatment.

A final aspect of getting support that the participants raised was the need for health care providers to acknowledge and consider the cognitive effects of ESRD when delivering information and education. Participants believed that while some health professionals did take this into account, others made insensitive comments that caused extensive damage to relationships:

You know that your mind is affected...you can have a funny feeling like you're drunk...and I remember saying that to my doctor...and she said right in front of us both "Are you stupid?" and we both couldn't believe it and I felt so alone, so invalidated...and here you're seeking to understand why you have this and then when she said that, the kidney doctor...it was getting so bad and I said "I have to write everything down" which I do anyway, like a lot of people do, but she said "Why are you...? Are you stupid that you can't remember?"...and then she called my parents...she asked them "Does your daughter have any schooling?"

This same participant, again, emphasizing the need for providers to show compassion regarding the cognitive changes inherent to ESRD, goes on to suggest:

...I think if I could look back, I think if another patient, let's say if another patient was coming in right now to be treated and I could be there in the whole process, I think I would say to the doctor and the nurses and the dietitian again, please talk slowly with the patient and even ask them to repeat to you what...after it's all done...what it is they need to do, what did they understand about everything so far...And really encourage the patient...make it safe for the patient to ask questions...make it safe for the patient to approach the doctor with anything of concern to them.

According to participants, getting support entailed vigilance around identifying and building relationships with providers who practiced in a compassionate and caring manner, and who could offer the kinds of supportive and empathetic statements that indicated a real interest in participants’ well being, particularly around the socio-emotional aspects of ESRD.
Creating a Network of Health Care Allies

Once participants found providers who acknowledged their efforts to become educated, who were supportive and compassionate practitioners, and who provided helpful communication, they tended to continue to seek access to them. Participants reported actively watching for these types of providers so that they could create a network of allies that would be helpful in future developments. This network of allies ameliorated, to some degree, the need for vigilance. Specifically, when participants had a network in place, they indicated feeling some comfort around knowing whom to call with questions, who would advocate on their behalf, and who would provide a soothing ear when nothing could be done:

I have enough people in the system that I can also call for help and I tend, you know, to ask for intervention. So that's a good way for me to cope with these things and then I just figure out who my allies are...So I just see who my allies are and I use those people...I certainly go to the people, either for just pure emotional support; sometimes for their positions of power and what they can do; it just depends.

Consequently, networking with health care allies who had the desired communication styles appeared to be helpful, further reducing vulnerability and vigilance. For example, having a network of allies created a mechanism for dealing with fragmented care, in that the network could assist participants to strategize, minimize duplication and provided a forum for ensuring that treatment plans were appropriate. Similarly, once a network of allies was established, vestiges of provider authority were reduced, opening the door to more collaborative decision-making processes. Accordingly, the communication became more helpful, and the effects of unhelpful communication reduced, for even if unhelpful interactions occurred, there were enough helpful resources to provide a balance.
This networking, although most explicitly articulated by the more experienced participants, was still apparent among the lesser-experienced participants, who perhaps felt bonded to single or smaller numbers of providers, but still described maintaining a connection on an ongoing basis. For example, all of the participants discussed making phone calls to various providers in order to keep in touch, ask questions relevant to their current needs and clinical condition. However, where they differed was in the level of sophistication, where the more experienced participants might access these resources for a broader range of needs, such as in cases where they needed help negotiating challenges within the wider health care arena.

Thus, creating a network of health care allies involved some vigilance, for keeping an eye out for helpful communicators who could provide some educational, emotional, political or strategic support, including assistance in overseeing care, was a valuable endeavor for many of the participants. Having this network also created a measure of comfort, in that the unforeseen might be less frightening with a network of helpful providers in place.

The effect of vigilance, in its various forms, on health care communication seemed to be an important element of the participants' reports, and appeared as a prominent contextual factor that both shaped, and was shaped by, experiences of ESRD communications. The various facets of vigilance involved getting educated in order to both anticipate, to some degree, future events and monitor the appropriateness of responses of the providers involved. Furthermore, vigilance involved actively seeking out and collecting providers who were able to provide the necessary support, be it emotional or instrumental, to meet the needs of participants.
Summary

According to the descriptions of these particular patients with ESRD, health care communication takes place in a context of illness, institutional authority, fragmented care and prior experiences of helpful and unhelpful communication with providers. This context creates a vulnerability that shapes the meanings ascribed to communication, where, for these participants, communicating from a vulnerable position was viewed as challenging and, at times, distressing. Consequently, participants described taking on vigilant behaviours such as getting educated, anticipating future needs and getting support that assisted them in working within a complex and often foreign health care system, while simultaneously providing some measure of control and predictability that tempered vulnerability. Moreover, by actively seeking out health care allies and resources, participants indicated that their vigilant and strategic efforts to create a supportive network was an effective means of both ensuring that their care was optimum, and that their various other needs would be met both within and without of the ESRD care context.

It thus seems important for health care providers to consider the context of ESRD communications that rendered these participants vulnerable, and recognize the vigilance that helped them to overcome that vulnerability. Unhelpful communication, for this particular group of patients, can thus be described as those that further increased vulnerability, such as dismissal, judgment and ignoring the effects of unfamiliar, and often uncoordinated, institutional practices. Conversely, helpful communications can be described as those that attended to vulnerability and vigilance, including
acknowledgment of the effectiveness of honesty, education, support and working within a network of other health care allies.
Chapter 5: Discussion of Findings

Findings from this study highlighted several aspects of communication in the context of ESRD care. Particularly surprising were the findings that suggested that vulnerability and vigilance highly influenced the communications that occurred between participants and the providers they encountered. What was surprising about this was the emphasis on context rather than content of communication, where I had anticipated that I might hear more detailed descriptions of the types or content of communication that participants found helpful or unhelpful. Instead, I heard participants focus more on the various ways in which the illness, relational and institutional contexts, that created this vulnerability and vigilance, influenced their communication in both helpful and unhelpful ways.

Further, the participants’ overall emphasis on relationship building, rather than anecdotes of communication within individual encounters, was illuminating. This indicates to me that communication in the context of ESRD care, for this group of participants, may have had a greater purpose: that of developing and maintaining health care relationships for the long haul. Consequently, communication took a different shape than perhaps might occur in primary care encounters, or for those with shorter-term health challenges. As a result of the participants’ awareness of the long term nature of their illness and their dependence on ESRD care providers, it appeared necessary to engage in a great deal of work around educating oneself, not only about the illness and self-management, but also about negotiating care within the complexities and power dynamics of the health care system.
These insights contrast with what I consider to be prevailing assumptions of ESRD care providers. Specifically, the culture of ESRD communication is often organized around delivering “pre-packaged” information, with an emphasis on what the providers believe patients with ESRD ought to know. Consequently, much of the communication focuses on medical management and treatment-related parameters. These topics, while helpful and necessary, are clearly not all that participants in this study needed to learn. As a result of the institutional and interdisciplinary gaps in the system, the study participants indicated that they needed, and became resourceful in finding; help with managing their care provision. The findings of this study thus may provide some insights into why health care communications might be particularly challenging for patients with ESRD, and provides some support for the notion that communication is part of a larger endeavor aimed at the development and maintenance of health care relationships. The purpose of this chapter is to explore these insights in further detail.

**Context Versus Content: Honoring the Narrative**

In the process of conducting the interviews, it was a surprise to me that stories of communication did not come readily to participants. As a group, they seemed much more concerned with the intersection between their ever-changing health needs and the manner in which health care is delivered. Thus, the interviews, instead of solely providing descriptions of incidents where communications were helpful or unhelpful, appeared instead to delineate the participants’ process of becoming more expert, not only in their own illness management, but in working within the system. Hence, the content of communication (what is actually said, or how it is said), which comprised much of the literature reviewed in chapter two, largely took a back seat to the context of
communication with this particular patient group. Consequently, the findings represent quite a turn from the communications literature described earlier.

However, I believe it was important and necessary to follow the direction in which the study participants took the interviews. One of the values of unstructured interviews is the possibility for participants to ascribe whatever meanings are appropriate to their experiences, particularly when the topic is a subject that has not previously been explored (Fine, Weis, Weseen & Wong, 2000; Frank, 1998; Kleinman, 1988). Certainly, all of the participants in this study indicated that they had never been asked about their health communications before. Some of the participants had spent more time reflecting on their communications than others, and yet, every one of them indicated that it was a matter of great importance and warranted greater attention from ESRD care providers. Consequently, in an effort to remain true to the voices of the participants, the findings described in chapter four reflected these contextual, relational and political themes.

Because the findings of this study diverged so greatly from much of the literature reviewed in chapter two, it became necessary to consider a wider body of literature in which to locate the study. Specifically, the findings so clearly speak to the challenges of health care relationships for the chronically ill, including the vast amount of work necessary for achieving satisfying health care encounters and illness management. Despite the fact that the work of illness management and its socio-emotional impact is well documented in the chronic illness literature (for example, Bury, 1991; Miller, 1992; Pollock, 1987; Robinson, 1993; Royer, 1998; Strauss et. al, 1984) the work of negotiating the highly complex health care system is less well-described, with the exception of Thorne (1993, 1999) and Thorne and Paterson (2001). Perhaps the findings of this study
may lend additional insights, particularly for those living with ESRD. The work of “managing the system” will be further discussed in the following section.

The Work of Managing the Health Care System

Much of the participants’ narratives pertained to their gradual awareness that their vulnerability grew rather than diminished as they gained more experience with the health care system. Consequently, the theme of “Getting Educated” had additional responsibilities beyond those of learning about the disease and the day-to-day particulars of treatment. Getting educated had a great deal to do with becoming familiar with, and successfully navigating the health care system, which included monitoring the effectiveness of individual providers of care. Thus, the work of getting educated proved no small endeavor, for not only did participants have to learn a complex and highly intrusive treatment regimen, they also had to familiarize themselves with the unexplained culture and idiosyncrasies of the institutional context.

This theme of getting educated resonates with the work of Thorne (1993) and Curtin and Mapes (2001) where patients with chronic illnesses, and ESRD, respectively, indicated a strong emphasis on learning how to “manage” the care providers in addition to managing their own treatment responsibilities. This took different paths, depending on the type of illness. According to Thorne (1993), health care relationships with individual providers took on particular characteristics largely depending on the individual’s prior experience with health care: those of naïve trust, disenchantment, or guarded alliance. In response to these characteristics, patients later developed relationships based on a guarded alliance that combined mistrust with self-reliance. These types of relationships with individual providers, however, did not necessarily mitigate the ways in which the
larger health care system created obstacles and constraints that limited care in frustrating ways. This study confirms aspects of Thorne’s work, in that relationships with individual providers first presented more disappointments than successes, and relationships with helpful communicators were both sought and nurtured. Further, in this study, the effects of a fragmented system and poor intra and interdisciplinary communication did much to damage confidence in care, making the institutional context a significant factor in health care relationships. Sloane (1999) used Thorne’s framework to investigate its relevance to ESRD patients, confirming that naïve trust, disenchantment and guarded alliances did resonate with participants in her study. Similarly, there was some evidence of such relationships in this study, where awareness of vulnerability led to both disenchantment and a guarded alliance that could resemble aspects of vigilant behaviors.

Curtin and Mapes (2001), in researching the health care strategies of long-term hemodialysis patients, similarly, and perhaps surprisingly, found that descriptions of being a long-term survivor of hemodialysis had much to do with strategic health care relationships. Of particular interest is their finding of “vigilant oversight of care” that reveals similarities to the reports of participants in this study, where vigilance appeared to arise out of awareness that mistakes are commonplace and the competence of providers warranted monitoring. The need for self-advocacy and independent modifications of the treatment were other notable findings resonate with the findings of this study, although Curtin and Mapes do not provide the contextual information that might help explain these activities. Still, the similarity of some of the findings in the two studies lends some support to the notion that vulnerability is in fact an issue for patients with ESRD, as is the need to be vigilant about the care received.
Taking on the task of coordinating care is another aspect of the work of managing the system that resonates with the work of Ravenscroft (1999) where continuity of care arose as an issue, indicating that there may be a wider concern about how care is coordinated, and where the need to advocate for themselves created some challenges for patients. What bears further exploration is a question that neither Ravenscroft nor this study can fully answer: might patients with ESRD take on this task anyway, as they gain additional expertise with their disease management? Is taking on the coordination of care solely a result of the fragmented system and poor interdisciplinary communication, or might this be a function of developing a sense of self-responsibility? Are there elements of both that operate in this finding? There were elements of both in the reports of participants in this study, particularly among those who espoused a high degree of involvement in their care. However, speculating on the root causes of this effort to coordinate care is difficult and requires further analysis.

Certainly, gaining expertise in health care management, apart from the role of coordinating care, involved other elements of work that resonated with other research. For example, the more experienced participants indicated a development of personal expertise to the point where the information and advice regarding diet, lab results and medications (those parameters most closely monitored and focused on by providers) became increasingly irrelevant, as the participants moved their focus onto larger health concerns or getting different types of support. Specifically, the participants indicated an ability to do a great deal of interpretation of their own results, which permitted a focus on other, perhaps more pressing issues, such as developing or future health challenges, becoming acquainted with the overall health plan, and seeking more flexible and
collaborative health care relationships. This finding corresponds with the work of Thorne and Paterson (2001) who, investigating the self-care management of diabetic patients, suggested that as expertise grew, there were corresponding changes in the types of provider support required. Specifically, as patients gained expertise, they were more fully engaged in the complexities of managing the illness, and indicated they both needed and valued relationships with providers that could similarly respond to the complexities and complications of life with a chronic illness. For the participants in Thorne and Paterson’s study, measuring the biomedical parameters became but a small part of the illness management.

Likewise, judgment regarding non-compliance, on the part of providers, created adversarial health care relationships for those in this study. As patient expertise grew, judgment around compliance became increasingly irrelevant, insulting and an impediment to relationships. This finding concurs with a number of studies that call for a re-examination of the power dynamics and ideological assumptions around the notion of compliance. This study, and that of other research, raises questions regarding the usefulness of labeling patients as non-compliant, and suggests that this labeling does little to effectively serve patients’ needs (McCormick, 1997; O’Brien, 1990; Playle & Keeley, 1998; Ravenscroft, 1999; Thorne, 1990; Thorne et. al, 2000; Thorne & Paterson, 2001; Woodcock, 1999). Participants in this and other studies have indicated that they are more satisfied with relationships that can account for the difficulties of living with such challenging health conditions, and similarly indicate that those providers who adhere to a compliance model are soon considered ineffective. Conversely, Morehouse, Colvin and Maykut (2001), in exploring nurses’ perceptions of nurse-patient relationships in the
dialysis setting, conclude that: "In order for a nurse to help a patient comply with dietary and medical regimens, nurses need to be teachers, behavioral therapists, and supportive counselors (p. 299)". This quote reflects what I consider to be the prevailing assumption among nephrology nurses regarding their role in practice, despite the fact that it does not bear up in the literature representing patients' perspectives. However, as the body of research exploring health care relationships expands, perhaps there will be a shift in culture, where more flexible and collaborative partnerships can flourish.

I would suggest that trust/mistrust is at the core of this discussion, and central to the reports of participants in this study. It seemed paramount that participants find someone, or a team of providers, that they could trust, particularly as there was so much evidence that the various causes of vulnerability could lead to mishaps. Trust also entailed learning to trust oneself, which diminished some of the intimidation and vulnerability that came with perceptions of authority. However, the fact that participants were dependent upon the care of providers, regardless of their opinion of that care, made it doubly important that at least some trusting relationships occurred. Once those trusting relationships developed, whole new possibilities of collaborative decision-making arose.

Collaborative Decision-Making: Issues of Timing and Amount of Information

From the reports of participants, it seems evident that there was no expressed need for a fifty-fifty split in input toward decision-making. Rather, it seemed more a matter of working within the constraints of the illness itself, and the varied expertise each party brought to the equation. Specifically, each of the participants indicated in some fashion that the disease created numerous difficulties around recall and processing of information. This, in and of itself, presented challenges for communication and
relationship building. Participants additionally expressed having personal and very different preferences around the amount of information they wished to receive, and the timing of information-provision. For example, some wanted to know everything, and others felt that too much information might create anxiety around future complications. Hence, the amount of disclosure and honesty they wished for, and the desired degree of input varied among participants. As one participant suggested, one of the first collaborative decisions in a health care relationship may be to establish with each individual how much detail they wish to receive, and when.

Collaborative decision making, in this study, was not just valued by those participants with extensive health care experience, which suggests that expertise is not the only element involved in satisfying health care relationships. Each of the participants indicated a wish to be a part of most decisions, or at least, to have input and a chance to feel heard and cared for in the process of decision-making. The findings regarding illness effects on cognition, and the desire for collaborative decision making lends support to the notion of pre-dialysis or progressive renal insufficiency (PRI) care. In these programs, education about renal disease and preparation for renal replacement therapy is ideally provided well in advance of ESRD, when toxin levels make it difficult for patients to learn and take in information (Levin et. al, 1997; O’Donnell & Tucker, 1999, Starzowski, 1986). However, it is also clear that education and information must extend beyond the introductory, and more toward individualized support, both within PRI care and beyond.

There is additional support for the notion of collaborative decision making in other studies occurring in the ESRD care setting. For example, the work of Caress, Luker, and Ackerill (1998), Erben (1999), Lelie (2000), Molzahn, (1996), Nilsson,
Anderberg, Ipsen, Persson and Andersson (1998), Ravenscroft (1998) and Watt (2000) all document the value of shared decision making in ESRD care, suggesting that it is important for both patients and their caregivers to get to know one another prior to making decisions, particularly around choosing a dialysis modality, but also in managing the day to day decisions that are inevitable. Caress et al. used a quantitative design to establish patient preferences around their role in decision making, concluding that there are personal preferences around this, where 45% wished to take a passive role, and 36% a collaborative role, with the proviso that trust in the providers was the major factor in remaining passive, or not. I would suggest that preferences around input into decision making largely depends on what the decision is about, where sometimes the decision will primarily rest with the provider if the patient lacks the expertise to decide, and other times, the patient may make the decision. This suggestion is borne out in this study, where participants indicated that they did not necessarily have to be right, nor in control at all times, but what they wanted was to be heard.

Therefore, the participants’ preferences about collaborative decision-making, degree of disclosure, timing and amount of information were highly individual, which discourage a “one-size-fits-all” approach to education and information sharing, and instead point to individualized, illness-sensitive approaches that incorporate empathy, caring and emotional support.

**Summary**

The findings of this study resonate with those of other research, however, it remains a relatively small body of literature, and further investigation is necessary.
However, the key insights discussed in this chapter highlight some of the considerations ESRD care providers may find useful when reflecting on their communication and relationships with patients. Of particular importance are the notions that communication may be part of a larger relational endeavor and that negotiating and managing the health care team and system involves a great deal of work for patients. Similarly, sensitivity to the illness effects and knowing when and how to collaborate are valuable assets. In light of this research, we, as providers of care, would benefit from some examination of our assumptions and practices regarding communicating with patients with ESRD. The practice, educational and research implications of these findings will be further discussed in the following chapter.
Chapter 6: Summary, Conclusions and Implications

ESRD care is complex and involves a lifetime commitment to health care. Hence, encounters with health care providers and the formal health care system are frequent and long-term. Communication forms much of the basis of these encounters, and yet, little is known about communication in ESRD care. This study was thus undertaken in an attempt to develop some preliminary understandings of the particulars of helpful and unhelpful communication.

Interpretive description was the qualitative method utilized in this study. Interpretive description draws upon analytical frameworks, theoretical sampling and constant-comparative analysis to permit researchers to reach conclusions that incorporate context as well as individual experiences. This qualitative method proved useful in the study of communication because, by its very nature, communication is a complex, dynamic and highly contextual process.

Eight people were recruited into this study by clinicians in the various ESRD treatment facilities, and by word of mouth. Four women and three men, who had been diagnosed with ESRD for at least five years, and one family member, were interviewed regarding their experiences of communication. Participants had experienced at least one of the four treatment modalities, and several had experienced all four, thereby providing perspectives from the full range of ESRD treatments, where patient-provider contact and communication take varying forms. Analysis proceeded with data collection and preliminary insights were proposed to subsequent participants to confirm or dispute findings.
Descriptions and explanations of helpful and unhelpful communication with ESRD care providers, according to the participants in this study, reflect a number of themes that illuminate the complexities of communicating while experiencing illness and dealing with a foreign and complicated health care system. Vulnerability and vigilance were the dominant themes in this study, and primarily arose out of the manner in which the illness, the health care system, and encounters with individual providers intersected to reinforce the experience of being vulnerable. Specifically, being ill, being dependent upon care, realizing that mistakes and gaps in the system can occur, and that not all providers are helpful communicators were components of vulnerability. Consequently, in an effort to mediate this vulnerability, participants undertook strategies that were vigilant in behavior, such as getting educated in order to establish both the treatment plan, and to monitor the activities expected of providers. In short, these participants functioned in varying ways as coordinators of their own care. Aware that they needed allies in this endeavor, however, participants described strategically creating health care networks that functioned to provide advice, emotional and political support, depending on what was necessary in the moment.

Thus, the work of vigilance proved to be considerable. The communication and responsibilities involved in coordinating care, maintaining networks, and ensuring that care is appropriate presented unique challenges for patients with this disease. The findings in this study suggest that ESRD care providers might benefit from further consideration of the ways in which that care is communicated, organized, and delivered. The purpose of this chapter is to provide some exploration of the conclusions and implications of this study.
Study Conclusions

The following represent my conclusions from the findings of this study:

1. Persons with ESRD consider communication to be part of the larger context of health care relationships. Because of this, they are concerned not only with the particulars of individual health care interactions, but also with the context in which communication occurs.

2. The disease-process, the unexplained and foreign culture of health care, the often poor interdisciplinary communication and the large number of health care providers involved in care all contribute to feelings of vulnerability, which, in turn, shape communication.

3. Vulnerability and the need to gain expertise in illness management lead to the development of vigilant behaviors that may become strategic in nature. These strategies involve ensuring that the proper care and support are provided, that supportive health networks are available, and that trusting relationships occur within that network to offset the unhelpful aspects of communication and health care service delivery.

4. Vigilance involves a great deal of work, and although it provides a measure of confidence that care will be appropriate and specific to the needs of participants, it also creates additional challenges for the ill individual.

5. Persons with ESRD describe unhelpful communications as those that result in feelings of being dismissed, fearing abandonment, being judged, and communications that are insensitive to the effects of illness or the ways in which the system creates barriers to confidence in health care. Conversely, they describe
helpful communications as those that are honest and supportive, and that assist patients in getting educated, both about the disease and treatment and the health care system.

6. Persons with ESRD find it helpful if they can create a network of health care allies, who are honest, flexible, supportive and able to listen to their concerns. From their perspective, collaborative decision-making is an important aspect of both communication and relationship building, although personal preferences around how that ought to occur vary.

Implications

The implications of these conclusions are extensive, and require consideration at the individual and organizational levels, as well as in relation to patient education and further research. To provide some context for exploring these implications, I will review the way in which ESRD care is generally organized, recognizing that there will be some variations from institution to institution and from province to province.

People with ESRD typically see a nephrologist once their kidney disease is diagnosed. That nephrologist, or team of nephrologists, then follows them for the duration of their lives. Many patients are encouraged to attend multidisciplinary PRI (progressive renal insufficiency) clinics early in their disease process, where teams of nurses, dietitians, social workers and nephrologists work together to provide education and medical support to the point where ESRD sets in, and a type of renal replacement therapy is commenced. At that stage, patients may lose contact with at least some members of the PRI team, moving on to dialysis or transplantation care teams. Often, the nephrologist, dietitian and social worker continue to work with patients, but in general,
the nurses involved change. It is important to note that those that do remain in contact with patients from the beginning tend to have high caseloads, and may only see patients sporadically.

Once renal replacement therapy (hemodialysis, peritoneal dialysis, or renal transplantation) has commenced, patients interact closely with the nursing staff involved in that therapy, although the degree of contact varies widely, from thrice weekly with hemodialysis to quarterly or less frequently with the other two modalities. The services provided by the nephrology team are focused solely on the renal disease, and those patients with other conditions must interact with those specialty providers separately. Hence, as mentioned in other chapters, it is not uncommon for patients with ESRD to interact with general practitioners, who understand ESRD to varying degrees, and a host of other medical specialists, nurses, dietitians and social workers. The broad coordination of the medical care of a single patient might fall to a nephrologist, a team of nephrologists, or general practitioners who make an extra effort to keep on top of medical developments and referrals. However, the day-to-day particulars of treatment, well-being, questions and clinical status of patients is more likely to become the responsibility of nurses. The treatment modality has a great deal of bearing on how nursing care is delivered. With peritoneal dialysis and transplantation, a small team of nurses follows patients, whereas with hemodialysis, particularly in the larger units, care is diffused among a large number of staff that may or may not have an assigned group of patients to follow.

To further complicate matters, it is typical for a patient with ESRD to experience a number, if not all, of the treatment modalities in a lifetime, thus moving through several
different practice settings. For example, a typical patient may start with the PRI clinic, begin on peritoneal dialysis for a time, then switch to hemodialysis, and perhaps receive a transplant. As transplants often do not always last, patients may find themselves back on hemodialysis and so on. Additionally, if that patient had other conditions such as diabetes or heart disease, which is quite common, care and monitoring of those conditions would be organized and delivered by a completely different set of providers. Because ESRD care is organized around treatment modality, rather than the patients themselves, the effect on developing and maintaining health care relationships can be difficult. Consequently, it is easy to conceive of the challenges this structure might present if you were that patient moving through the various treatment settings where the providers may often be new, and limited in their knowledge of your medical and personal history.

In this study, all of the participants had experienced at least two, and some all four, of the ESRD treatment settings, and several of them had other longstanding health problems that required ongoing treatment. Consequently, I am confident that their descriptions and explanations represent a fairly typical set of experiences. In the following discussion, I explore the research, individual, organizational and patient educational implications of the findings in light of the current structure of ESRD care. **Implications for Further Research**

As the sample in this study was small, further sampling would be necessary to confirm the findings in a manner that permits generalization. Although I did attempt to find patients who were currently experiencing each of the four treatment modalities, it might be helpful to further consider the specific communication and health care relationship issues with larger groups experiencing each modality. This may permit some
differentiation regarding the communication with each, as each modality has particular characteristics, including involvement with the health care team. Hence the needs of each group may well be different, although that did not come through in the findings of this study.

The newly diagnosed were not represented in this study, and it would be helpful to explore the communication needs of this group of patients, who, perhaps, have a unique set of needs regarding health care communications and relationships. The findings in this study suggested that the time of diagnosis and choosing a dialysis modality were particularly vulnerable times for participants. However, this group of participants had gained considerable experience with the health care system at the time this study took place, and their retrospective reflections, through the lens of this expertise, makes it difficult to speculate what the needs of the newly diagnosed, who may not be aware of what resources are available to them, might be.

Further, with one exception, family members did not participate in this study, and family communication with the ESRD care team would be another area worthy of further exploration. Specifically, families might have a large role in assisting patients to navigate the health care system, and consequently, research regarding inclusion of families in health teaching and renal program orientation, the effects of communication on families and ways in which families interact with each other and with the health care team would be important.

Finally, it would seem important to further explore patients’ process of gaining expertise, and the effect that expertise has on the work of managing the health care system. Specifically, how much of an active role might patients take on as they gain
expertise in their illness management, and is this active role directly related to expertise and confidence in self-management? Or, has it more to do with the often-ineffective process of health care delivery? It would be useful to have a greater understanding of this intersection between the effects of the system and growing self-responsibility. Providers could take some direction from this knowledge, particularly in the realm of collaborative decision-making and organization of care.

**Implications for Individual Practice**

Individual practitioners can utilize the findings of this study to consider, or re-consider, their own assumptions regarding the goals of treatment and ESRD care delivery. For example, if patient compliance is considered a goal of treatment, then the findings of this study, among others, might provide some basis upon which to challenge that goal. Clearly, according to the participants, being judged was a major barrier to relationship building, and compliance was not the main focus of their reports. Similarly, concentration on treatment parameters and measures were considered, over time, such a small part of the illness management that participants found that providers who did not look beyond these were not particularly helpful. Instead, cultivating helpful health care relationships with patients with ESRD, at least according to the participants in this study, may involve learning about the individual physical, emotional and social needs of each patient, which often includes being willing to engage in the often thorny complexities of life with chronic illness.

Similarly, as individual practitioners, it is important to recognize that we are but one of many providers coming into contact with patients with ESRD. Consequently, it is important to consider the collective impact of all the health care providers on an
individual's experience. Moreover, once we consider our collective impact and the frequency with which communication gaps may occur, it may be easier to go that extra mile in using our knowledge of the system to better ensure that patients receive answers to the questions they have, or appropriate care for their clinical conditions. In short, follow-through is very important when we consider the potential or actual gaps in the system that make it difficult for patients to trust that they are in good hands. If we do not provide the follow-through, it may be left up to the patient, who may or may not have the capacity or wish to perform this function.

Further, as individual practitioners, it important not to wait for patients to raise their issues with us, for although the participants in this study demonstrated an ability to advocate on their own behalves, not everyone can, or will. For many, the health care system may prove too intimidating or overwhelming, and dealing with the illness alone may be more than enough. It is important to recognize that many patients will not be sufficiently informed about how the system works to even know what to ask, or look for, particularly when toxin levels are high and retention of information is impaired.

Relying on patients to be vigilant about the care they receive and expecting them to correct us when we make mistakes can be dangerous, and can have negative health consequences for patients. The findings of this study raise some troubling issues about the ways in which communication can break down, and can, at the least, create inconveniences for patients, and at the worst, result in devastating complications or failure of treatment. The findings make it particularly important that we, as individuals, be accountable in providing appropriate and timely care, and when the plan of care is not clear or doesn’t appear correct, to obtain clarification on behalf of patients. Moreover, the
findings suggest that listening to patients is a very good idea, particularly when they have taken the time to learn about their individualized health care plan and have gained expertise in illness management. They may well know more than we do about particular aspects of their care.

**Implications for Organizational Structures**

If communication is considered to be a feature of relationship building, then organizational structures ought to reflect that feature, and we, as providers, ought to create structures that support individual relationships. It may well be that the most effective ways of organizing and delivering care is not around treatment modality. Instead, what might be a better option for patients is care organized around a core group of providers who journey through the treatment modalities with the patients. An interdisciplinary team of nephrologists, nurses, dietitians and social workers, who are consistently and closely involved throughout the patients’ journey, may improve the ways in which the institutional context breaks down communication. It is important to note that this model of care may already occurring, or is being considered, in other renal programs, but has not yet reached a wider acceptance. It is certainly not yet occurring in the region where this study took place.

Beyond simply managing the renal replacement therapy, the renal team might expand its role to assist with the coordination of other disciplines as well. For example, acting as a locus through which information and health care planning for other, co-morbid conditions, is funneled, might take some of the burden off patients. It appears that this might be happening in an informal way already, as a number of the participants indicated they used their renal team in this manner whenever they felt they needed
additional support or information. In this way, duplication of tests, procedures, inappropriate treatment planning and mishaps might be less likely to occur, and patients might gain more confidence in their care.

Organizing care around the patient, rather than the treatment, or perhaps a combination of the two, might provide better opportunities for health care providers to come to know individual patients and, together, create health plans that are more congruent with individual needs and available resources. Again, it is premature to suggest that this would be the ideal model, and further research is necessary. However, there was sufficient concern expressed by participants in this study that we perhaps ought to reflect seriously upon the ways in which we are organizing our services.

**Implications for Patient Education**

The findings in this study suggest that learning about the disease and treatment was not all that participants needed. Moreover, participants indicated that they were overwhelmed at the time of their diagnosis or beginning of treatment, when most of the information is provided. This would suggest that the timing, type and amount of information delivery ought to be re-examined.

First, it is necessary to consider the effects of illness on cognition, and recognize that sensitivity about the memory loss and impaired ability to concentrate and learn is an important consideration for teaching. The participants in this study indicated that it sometimes took them years to integrate the information they received. Therefore, as providers, it is important not to judge someone who seemingly has not learned what we have taught. Instead, we need to recognize that learning occurs where and when necessary, and thus providing information ought to take a slower, more longitudinal
approach. Front-end loading information, for example, during PRI care, might not be practical for all patients. Similarly, the findings suggest that “pre-packaged” or group format activities, although practical for economic reasons, might not provide the individualized education that participants indicated was necessary for them to learn to live with their disease.

Further, the content of education might bear some re-examination. Specifically, although disease and treatment information is valuable and necessary, so too is information about the ways in which to navigate ESRD care, and the health care system in general. Including this as a topic of orientation, such as explaining the jargon, the norms and assumptions of care provision might be very helpful. Patients have to learn it regardless, and often the hard way, which makes it particularly important that we facilitate this process in ways that are supportive.

Conclusion

In attempting to explore how patients with ESRD explain and describe their experiences of helpful and unhelpful communication, it became apparent that communication is part of the larger endeavor of health care relationships. A number of contextual features emerged that created or reflected relational, institutional and political challenges in communications. These challenges, in turn, created vulnerabilities and vigilant behaviors that both shaped and were shaped by communications in ESRD care. Although further research is warranted, the findings and implications of this study offer some considerations from which ESRD care providers, and the patients for whom they care, may derive some benefit.
References


I hereby consent to participate in the study on Communication in Renal Disease Care.

__________________________  __________________________
signed                        date

If you have any concerns about your rights or treatment as a research subject, you are invited to contact Dr. Richard Spratley, Director of the Office of Research and Administration, at (604) 822-8598.
Appendix 2

Communication and Renal Disease Care Study
Interview Questions

• Can you tell me something about your experience with this disease (i.e., when you were diagnosed, how your disease has progressed, major events in your illness)

• What are your impressions about the importance of communication between health care providers and people with your disease?

• From your own experience, can you describe examples of helpful communication you have had with health care providers? How/why was this helpful?

• From your own experience, can you describe examples of unhelpful communication with health care providers? How/why was this unhelpful?

• What other examples of communication have affected you (either positively or negatively) during your experience of this disease?

• What kinds of communications are always helpful? Explain.

• What kinds of communications are always unhelpful? Explain.

• What do you think accounts for the difference between helpful and unhelpful communication with providers?

• Are there particular times when communication with health care providers is particularly important? Why? What make communication so important during this time/event?

• Would you say you have different expectations of communication from different kinds of health care providers (doctors, nurses, physio, technicians, etc.)? Explain.

• What do you think health care providers should know/understand in order to be able to communicate effectively with patients?