SOCIAL INFORMATION BEHAVIORS IN THE CONTEXT OF CHRONIC KIDNEY DISEASE: INFORMATION SEEKING AND DISCLOSURE IN ONLINE SUPPORT GROUPS

Kaitlin Light Costello

A dissertation submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the School of Library and Information Science.

Chapel Hill
2015

Approved by:

Barbara M. Wildemuth

Claudia J. Gollop

Gary Marchionini

Mi-Kyung Song

Tiffany Veinot

ABSTRACT

Kaitlin Light Costello: Social information behaviors in the context of chronic kidney disease: Information seeking and disclosure in online support groups
(Under the direction of Barbara M. Wildemuth)

People diagnosed with chronic illnesses are increasingly turning to the Internet to search for information about their health. In some cases, these individuals also disclose personal health information. In fact, these two information behaviors are often linked. This is particularly true in online support groups. However, we do not currently understand how and why people diagnosed with chronic diseases undergo these activities – although they are becoming increasingly common as the Internet becomes more ingrained in everyday life.

This dissertation uses constructivist grounded theory to examine health information seeking online, personal health information disclosure, and the relationship between these processes. Constructivist grounded theory is an ideal research method for examining phenomena, behaviors, and processes that have not yet been fully explored, as is the case in this study.

In this study, twelve participants diagnosed with chronic kidney disease were recruited in three different online support groups for chronic kidney disease. Chronic kidney disease was chosen as the illness context in this study as it is a non-stigmatized, incurable, life-long condition that requires patients to manage their treatment over time. Two telephone interviews were conducted with each participant and their comments to online support groups were collected. Data were collected and analyzed using inductive analysis, the constant comparative method, memoing, and theoretical sampling strategies. Trustworthiness of the analysis was obtained using multiple methods, including peer de-briefing and member checking.

A model of information seeking, personal health information disclosure, and similarity assessment in online support groups was derived from the analysis. The model highlights one of the central contributions that this study makes to our current understanding of information behavior: similarity assessment, or the process of finding people who are similar in online support groups both as human sources of information and as people with whom to disclose. The assessment of similarity changes over time as experience and knowledge evolve. The findings presented in this dissertation add to our theoretical understanding of information behavior; they also intersect with theories from other disciplines, including communications and nursing. They also have practical implications for healthcare providers and designers of information systems.

ACKNOWLEDGMENTS

This research would not have been possible without my generous participants, who lent their invaluable insights and knowledge to this project over the course of two years. I am forever indebted to them for sharing their thoughts about their own information behaviors, their health, and other topics, both with me and online.

Many people throughout my doctoral program provided support and advice, including my advisor Dr. Barbara Wildemuth, who taught me how to be a true scholar by example, and my excellent committee, Drs. Claudia Gollop, Gary Marchionini, Mi-Kyung Song, and Tiffany Veinot. This dissertation is much stronger thanks to their input. I also received a great deal of help from my fellow doctoral students; in particular, Alex Chassanoff, John Martin, and Leslie Thompson read drafts, lent their insights as peer de-briefers, and opened up unexpected avenues in my work. I also want to acknowledge my father, mother, and brother, who have frequently said, “You know Kait – she always has a theory.” Thank you for fostering my curiosity.

Many people and organizations were very generous with opportunities for funding my work throughout the doctoral program, including the Dr. Eugene Garfield, Dr. and Mrs. Thomas S. Royster, and Thomson Reuters, who all provided me with funding for my dissertation research. I also want to thank Drs. Merle Mishel, Helen Tibbo, and Cal Lee, who all served as principal investigators on various training grants during my doctoral coursework.

Finally, I must thank my inquisitive and thoughtful students; they taught me so much about information behavior. Working with them was a highlight of my time at UNC-SILS.

TABLE OF CONTENTS

LIST OF FIGURES

LIST OF TABLES

LIST OF ABBREVIATIONS

CKD	Chronic kidney disease
DD-MM	Disclosure decision-making model
ESRD	End-stage renal disease
eGFR	Estimated glomerular filtration rate
GFR	Glomerular filtration rate
HD	Hemodialysis
HHD	Home hemodialysis
neph	Nephrologist
OSG	Online support group
PD	Peritoneal dialysis
PKD	Polycystic kidney disease
RRT	Renal replacement therapy (dialysis or transplant)
tx	Transplant

CHAPTER 1: INTRODUCTION

Five years ago, Steve,[1] a single father of three, turned on his computer and navigated to Google to search for information about kidney disease. He had searched for health information online in the past, whenever his kids weren't feeling well, and now he was sick himself. He stumbled upon an online support group (OSG) where many people were posting about their own kidney issues, or the kidney issues that plagued their loved ones. He decided to create an account, and he spent the rest of the day – nearly eight hours, save some time to pick his children up from school and to help them with dinner and their homework – reading the forums. In the evening, he posted the following comment in the general dialysis sub-forum, titled "I wish someone had told me":

> I have been reading many of the posts and am finding a wealth of information – things I never had even heard of. It is going to take a while (I know; I have the time now) to get through all these threads. What I am asking the people who have been through this longer than me is: What did you learn too late? What did you wish someone had told you? I am looking for any tidbits of knowledge that may help me make decisions in the future. Thank you, Steve.

Steve received 55 replies over the course of six weeks from 34 unique users who urge Steve to learn about specific topics including the different dialysis modalities and how the transplant list operates, to more general advice like how to interact with healthcare providers, become his own health advocate, stay positive, and continue visiting the OSG for support and information.

On the surface, Steve's initial post is simply a request for information about living with CKD. But he also shares a fair amount about himself: he discloses his age, the age of his three children, his general geographic area, and tells a harrowing story about his diagnosis: "On March

---

[1] Participant names are pseudonyms.

23, I thought I had pneumonia, so I called my doctor and he suggested I go to the ER for a chest x-ray. I was wrong… They informed me that I was in Stage V renal failure. I had no idea! I was stuck in the hospital for 17 days.” He then tells readers his dialysis schedule and gives some intricate details about his dialysis access, closing with the phrase: “I am very new to all this and am trying to learn as much as possible. This sudden transition to my new life has been difficult.”

In his post, Steve is searching for information, looking for social support, and disclosing personal information about himself and his health; these activities are interwoven within his post and throughout his follow-up comments in the thread. Although we know that Steve is not alone –these activities occur regularly in OSGs (Fox & Duggan, 2013) – a better understanding of these processes and their relationship is necessary for several reasons. Healthcare providers are concerned about patients using the Internet for health questions because of safety and credibility issues, and may discourage them from using the Internet outright (Chung, 2013a). Issues of credibility and safety may be exacerbated in OSGs, which are often moderated not by health professionals but by patients themselves (Costello, 2015; Coulson & Shaw, 2013). Furthermore, we do not know whether searching for and/or disclosing health information in OSGs helpful or harmful to patients – or, perhaps more accurately, in what contexts these behaviors are helpful, and in what contexts they are detrimental for patients (Weitzman, Cole, Kaci, & Mandl, 2011).

While there are many theories in various disciplines that relate to these activities – uncertainty in illness theory in nursing (Mishel, 1988), social support frameworks gleaned from psychology (S. E. Cohen & Wills, 1985), models of personal health information disclosure in communications (Checton & Greene, 2012), and theories of information behavior from information science (Johnson & Case, 2012) – none of these models or frameworks adequately address how and why patients search for health information online, what information they are looking for, what information they are sharing with others, what motivates some of them to share their personal health information on the open web, and what influence these activities have on the health outcomes of patients. This study uses constructivist grounded theory methods to explore these phenomena and the relationship between them (Charmaz, 2014). In grounded theory, there is no central research question; instead, a phenomenon of interest is selected for exploration with the intention of creating a model or theory of the phenomenon. In this study, the central phenomenon being explored is the relationship between health information seeking and personal health information disclosure in online support groups for patients diagnosed with chronic kidney disease.

For the purposes of this study, searching for information, or information seeking, is defined as a purposive activity wherein participants search for information related to their health. Disclosure is defined as purposeful online sharing of information about one's diagnosis, the lived experience of the disease and/or treatment, and other information that may be found in one's personal health record such as laboratory values, weight and diet specifications, and details about one's emotional well-being and coping strategies. OSGs are defined as Internet-based forums geared towards patients with a specific disease or who are undergoing a specific treatment; in this case, groups for patients with chronic kidney disease or end-stage renal disease of any etiology, groups for patients on dialysis, and/or groups for people who are preparing for or have had a kidney transplant.

Chronic kidney disease was chosen as the illness of interest for several reasons. First, CKD is a non-stigmatized illness. Although we understand a fair amount about health information disclosure of stigmatized illnesses, such as HIV/AIDS, to date there has been little work that examines how people disclose non-stigmatized conditions to others (Chaudoir &

Fisher, 2010). CKD is also increasing in prevalence – up to 1 in 10 adult Americans have been diagnosed with the illness, and this number is rising particularly because the two most common causes of kidney disease are high blood pressure and diabetes (Coresh, Stevens, & Levey, 2008). CKD also requires a fair amount of self-care. It is also a disease for which multiple treatment options exist; the patient often, but not always, chooses their treatment modality type. Patients either have the option of dialysis or a transplant, if they can find a match; most commonly, patients are on in-center hemodialysis, which they receive three times a week, and they may also be put on a waiting list for a deceased donor kidney transplant. According to the United Network for Organ Sharing, as of July 3, 2015, there were 101,318 candidates on the wait list for a kidney, and there are over 450,000 people on dialysis. Because the prevalence of CKD in the United States is rising (Coresh et al., 2007, 2008), an understanding of how patients with this illness behave online will also be a welcome addition to the literature for practitioners in nephrology.

In the following chapters, I will introduce the literature that has been written about health information seeking, personal health information disclosure, and social support. Next, I will discuss the ways in which I used grounded theory methods to build a conceptual understanding of the above phenomena. Finally, I outline the main results of this study, discuss those results, and illustrate the implications of the findings by presenting a model of the information behaviors exhibited by participants in OSGs for CKD.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This review provides an overview of four topics, all introduced in the previous section of this dissertation. First, chronic kidney disease (CKD) is introduced as the illness context for the health information behaviors examined in this study. The diagnosis, symptoms, and treatment of kidney disease are covered in this section of the review. Next, an overview of the literature on social support in health is offered, with a focus on how social support affects patients diagnosed with CKD. Next, information behaviors in health are addressed. The information needs of patients with CKD are presented; health information seeking is then covered, highlighting the sources that patients with CKD use for information. Finally, a discussion of how patients use information – in particular, how they disclose information about their health to others – concludes the literature review.

2.2 Chronic Kidney Disease

The kidneys are complex organs with two main functions: they filter and excrete waste found in the bloodstream, and they regulate levels of some hormones, electrolytes, and nutrients within the body (Eaton & Pooler, 2009). Each kidney is made up of over one million nephrons; each nephron contains a glomerulus, which is a network of blood vessels and cells that filters blood plasma (Higgins, 2009). To assess kidney function, the rate that fluid filters through the glomeruli is measured. This is called the glomerular filtration rate (GFR). In a healthy adult, the GFR is commonly around 125 ml/minute; a GFR above 90 is considered normal (Eaton & Pooler, 2009).

CKD is diagnosed when the estimated glomerular filtration rate (eGFR) drops below 90. The glomerular filtration rate is the speed at which the kidney filters thee blood; it is difficult and expensive to measure and is therefore often estimated (Higgins, 2009). There are five stages of CKD (summarized in Table 1). Many individuals never progress to Stage V; most people are in Stages I through III (Coresh, Stevens, & Levey, 2008). The incidence or rate of progression for individual patients relies on a variety of factors, including the underlying cause of kidney failure, the presence or absence of comorbidities (additional medical problems, such as hypertension or cardiovascular issues), ethnicity, socioeconomic status, and other factors (Post & Rose, 2012). End-stage renal disease (ESRD) is a term used for patients with CKD who are currently being treated with dialysis or a kidney transplant (Levey et al., 2003). This classification exists because ESRD patients are eligible for Medicare (Schreiner, 2000). It is important to note that ESRD

Table 1

Classification of CKD

Stage	Description	eGFR ($mL/min/1.73m^2$)	Action*
I	Kidney damage	≥ 90	Diagnosis Treating comorbidities Slowing progression
II	Mild kidney damage	60-89	Estimating progression
IIIa	Mild to moderate	45-59	Evaluating and treating complications
IIIb	Moderate to severe	30-44	Evaluating and treating complications Preparation for renal replacement therapy (RRT)
IV	Severe	15-29	Preparation for RRT Beginning RRT
V	Kidney failure	< 15	RRT

* Includes actions from preceding stages. Table adapted from 2013 CKD clinical practice guidelines International, 2013).

does not define a level of kidney function; instead, it is an administrative term used by the United States government to indicate that a patient is currently being treated with renal replacement therapy (RRT) (Schreiner, 2000).

The most recent data on ESRD indicates there were 636,905 people in the United States with ESRD at the end of 2012. Of these individuals, 402,514 ESRD patients were receiving hemodialysis, 40,605 were being treated with peritoneal dialysis, and 175,978 had a functioning kidney transplant. The mortality rate for patients on dialysis is much higher than that of the general population. Furthermore, kidney disease is generally more prevalent in African-Americans, Asian-Americans, and Latinos than in Caucasians in the United States (United States Renal Data System, 2014).[2] This is due to a variety of both social and biological factors, including the higher prevalence of diabetes and hypertension in minority populations, a higher likelihood of genetic predisposition to ESRD in minority populations, and socioeconomic disparities (Crews, Liu, & Boulware, 2014).

CKD can result from either an acute injury that causes damage to the kidney, or from any number of underlying diseases that cause progressive failure. Broadly speaking, there are two types of underlying diseases that cause kidney insufficiency that may lead to CKD and ESRD: glomerular diseases and interstitial or vascular diseases (Rahman & Smith, 1998). The two most common glomerular diseases that progress to ESRD are diabetic nephropathy and glomerulonephritis; hypertension and polycystic kidney disease are the most common vascular diseases that eventually progress to ESRD (Shafi & Coresh, 2010).

2.2.1 CKD symptoms and treatment. The initial decline of kidney function is asymptomatic. This can make it difficult to diagnose and treat until patients begin to experience

---

[2] The data reported here have been supplied by the United States Renal Data System (USRDS). The interpretation and reporting of these data are the responsibility of the author and in no way should be seen as an official policy or interpretation of the U.S. government.

some of the common manifestations of the disease; these often occur no matter what the cause of kidney failure (Shafi & Coresh, 2010). As kidney disease progresses, patients begin to experience a variety of symptoms and complications (Post & Rose, 2012). These are listed in Table 2 below.

In earlier stages of CKD, treatment is focused on diet and medications that slow the progression of kidney failure. In the final stages of CKD, RRT is often recommended. CKD is a lifelong, chronic illness and there is no cure. The most effective RRT is transplantation; however, it is not a cure for CKD – it is simply the most effective treatment currently available. This section of the review discusses the basic treatments for kidney disease: conservative management through diet and medication; and RRT in the form of hemodialysis, peritoneal dialysis, and transplant. It is important to note that there is not one standard course of treatment for CKD patients; it depends largely on the individual patient, the etiology of their kidney

Table 2

Complications of renal failure

Complications	Associated symptoms
Anemia (decrease in red blood cell count)	Weakness Fatigue Shortness of breath
Hypertension (high blood pressure)	Heart strain Heart attack Stroke
Hyperkalemia (excess potassium in bloodstream)	Muscle weakness Heart palpitations or arrhythmia General malaise
Metabolic acidosis	Weight loss Bone pain Decreased visual acuity Headaches
Volume overload (excess fluid in blood)	Swelling in arms and legs (edema) Shortness of breath Difficulty sleeping Congestive heart failure

disease, and the symptoms they are experiencing (Taal et al., 2011).

2.2.1.1 Diet and medication. There is little available information on medications prescribed to and used by CKD patients and research in this area is surprisingly unsystematic and difficult to find (Winkelmayer, 2010). This is partially because kidney patients experience a range of symptoms and comorbidities; medication is generally prescribed to help manage these issues, which vary widely. Some of the more common medications used for CKD patients are erythropoietin or iron supplements, which help stimulate red blood cell growth in patients with anemia; diuretics, which reduce the amount of water in the body and are helpful for patients with hypertension and edema; ACE inhibitors, used to regulate blood pressure and to reduce the amount of protein in the urine; and various electrolyte medications to help manage the balance of minerals excreted by the kidneys, like magnesium and potassium (Taal et al., 2011).

Managing and modifying one’s diet can also help to mitigate some of the complications that arise from CKD, although it may not slow the progression of the disease. The most important dietary change is the reduction of salt in order to control hypertension; many researchers also recommend the reduction of dietary protein in order to reduce the accumulation of waste in the blood (Bircher & Woodrow, 2014). Other dietary restrictions, such as reducing the amount of potassium or phosphate ingested, may be recommended, depending on the complications experienced by the patient. Finally, because many of the complications of CKD can result in the loss of appetite, it may also be important for patients to ensure that they are ingesting enough calories to prevent malnutrition (Berns, 2012).

2.2.1.2 Dialysis. Dialysis is a treatment that filters the blood, removing excess water and waste. Dialysis imitates the function of the glomerulus in the kidney by filtering the blood through a semi-permeable membrane either outside of the body, in hemodialysis; or inside of the body, in peritoneal dialysis. It is a common treatment for ESRD patients who are waiting for a kidney transplant or who cannot have a kidney transplant due to contraindications such as severe heart disease or some forms of cancer. There are three main types of dialysis: hemodialysis, peritoneal dialysis, and hemofiltration. Hemofiltration is used almost exclusively to treat acute renal failure in intensive care units (Dennen, Douglas, & Anderson, 2010); it is therefore out-of-scope for this review.

Hemodialysis is the most widely-used type of dialysis in the United States (United States Renal Data System, 2014). It is usually done at outpatient dialysis clinics on a routine basis – typically three sessions a week, for four hours each session – although the amount of time and number of sessions may vary (National Kidney Foundation, 2001). In hemodialysis, patients are hooked up to an external artificial kidney known as a hemodialyzer that filters their blood using diffusion through a semi-permeable membrane. Blood flows on one side of the membrane, and dialysate – a mixture of purified water and electrolytes – flows on the other side (Yeun, Ornt, & Depner, 2011). Hemodialysis requires vascular access, which allows for the vein to be cannulated – stuck with a dialysis needle – repeatedly. Arteriovenous fistulas that join an artery and a vein together in the wrist or forearm are the preferred access method; this requires a short outpatient surgical procedure and about six weeks to heal and mature before it can be used. Catheters placed in the jugular or femoral vein are also used in emergency situations or when the patient is waiting for their fistula or graft to mature.

Once an access method is created, patients will receive hemodialysis either in an outpatient clinic or at home. Outpatient dialysis clinics are vastly more popular than home hemodialysis: at the end of 2012, 7,923 of the 402,514 patients on hemodialysis dialyzed at home, and 91% of the dialysis patients in the United States (including patients on peritoneal dialysis) received hemodialysis in a center (United States Renal Data System, 2014). In-center dialysis is often described as a passive form of treatment: it requires only that the patient visit the clinic at the appointed time to have the procedure performed by technicians. In-center dialysis also allows for frequent observation of the patient by healthcare providers. This is in contrast to at-home hemodialysis or peritoneal dialysis, both of which require active patient participation.

There are multiple types of peritoneal dialysis; the most common is called continuous ambulatory peritoneal dialysis (CAPD). After in-center hemodialysis, it is the second most widely-used type of dialysis in the United States; in 2012, 40,605 people were using peritoneal dialysis as their mode of RRT (United States Renal Data System, 2014). In CAPD, patients have a permanent catheter surgically placed in the abdomen. Once it heals, this catheter is connected to a bag of dialysate that the patient carries throughout the day. Manual exchanges of the bag are performed multiple times a day in CAPD, while in automated peritoneal dialysis (APD) fluid exchanges are performed using a machine while the patient sleeps. In peritoneal dialysis, the peritoneal membrane acts as the semi-permeable filter for the blood. It functions similarly to hemodialysis, except the semi-permeable membrane that the blood filters through is part of the patient's body rather than part of a machine outside of the patient's body.

CAPD requires that the patient actively manage his or her care and dialysis regimen on a daily basis. It allows for more freedom, because patients do not have to visit a clinic multiple times a week for treatment. It is also less expensive to implement than in-center hemodialysis (Berger, Edelsberg, Inglese, Bhattacharyya, & Oster, 2009; Liu et al., 2014). Furthermore, there is no significant difference in mortality between modality choices (Chiu et al., 2011). However, there are several drawbacks to peritoneal dialysis: it is less efficient than hemodialysis, and there may be a risk of peritonitis – an infection of the peritoneum – or infections at the entrance or exit sites, regardless of which type of PD modality (CAPD or APD) is chosen (Lan et al., 2014).

Because hemodialysis and peritoneal dialysis are roughly equivalent in terms of survival rates, most researchers recommend that “clinical judgment, socioeconomic and cultural factors, and the patient’s choice should continue to play the most important roles in deciding the type of replacement therapy to be initiated” (Correa-Rotter, Cueto-Manzano, & Khanna, 2011, p. 2369). Individual patients may prefer different modes of dialysis for a variety of personal reasons, including the ability to travel or the desire to not be actively involved in the dialysis process; therefore, involving the patient in dialysis modality decision-making is vital (Winterbottom, Bekker, Conner, & Mooney, 2012). Decision aids have been developed to help providers aid patients in this process (e.g., Fortnum, Smolonogov, Walker, Kairaitis, & Pugh, 2014).

2.2.1.3 Transplant. A kidney transplant is another type of RRT for ESRD patients. Not all patients are eligible for transplant; in particular, patients with short life expectancies or those with proven history of noncompliance are often ineligible (Ramos & Klein, 2012). In a kidney transplant, the working kidney is removed from a living or deceased donor and is transplanted into the ESRD patient during an inpatient surgical procedure that takes roughly three hours. Usually, the recipient’s existing low- or non-functioning kidneys are left in place, because a nephrectomy – removal of the kidneys – increases the risk of surgical morbidity (Darby, Cranston, Raine, & Morris, 1991). There are two main sources for kidneys: deceased (cadaveric) donors and living donors. Although kidney transplants from living donors typically last longer than transplants from cadaveric donors, research shows that this is related to the amount of time patients are waiting for an available organ – as pre-emptive cadaveric transplants are very uncommon – and is not related to the source of the kidney (Liem & Weimar, 2009; Simforoosh, Gooran, Tabibi, Bassiri, & Ghraati, 2011). Deceased donors have been declared brain-dead, usually due to head trauma or stroke (Israni, Zaun, Rosendale, Snyder, & Kasiske, 2015).

In the United States, kidneys from deceased donors are allocated to individuals using a waiting list, which is managed by the Organ Procurement and Transplantation Network (OPTN), which is in turn managed by the non-profit organization, the United Network for Organ Sharing (UNOS). UNOS also develops donation and allocation policies, and maintains all the data about transplants performed in the United States. There are currently 58 federally designated organ procurement organizations (OPOs) in the United States. When a kidney becomes available, the OPO notifies UNOS and a list of potential candidates in that region is made. Blood type and antigen match between the donor and recipient are evaluated first; if a match is found, antibodies between the donor and recipient will also be tested (United Network for Organ Sharing, Organ Procurement and Transplantation Network, 2015).

There are currently 101,318 candidates on the waiting list for a kidney, based on OPTN data as of July 3, 2015. Typically, these patients are already on dialysis and are waiting for a transplant. The number of candidates increases each year, and the donation rate remains relatively steady, which means that the wait time on the list is increasing. Currently, the median waiting time on the list is about 4.5 years. However, this varies considerably by factors like blood type, region, age, and race. Kidneys are allocated based on a variety of factors, including wait time and antibody matching. A new allocation system was recently put into place that gives priority to people who have been on the waiting list for longer, children, candidates waiting for multiple organs, candidates with no antibody mismatches with a potential donor, and sensitized candidates (that is, people with high levels of antibodies, who are typically much harder to match). Additionally, waiting time now begins at the initiation of dialysis or at the time patients have an eGFR of 20. Patients who were already listed but who were on dialysis before they were listed have had that time retroactively added to their wait-time, giving them increased priority on the list (Matas et al., 2015). Unfortunately, it is impossible to predict exactly when a deceased donor kidney will become available, which can be challenging for patients and caregivers as they must remain in a constant state of readiness while on the list (Danovitch, 2012).

Transplants from living donors are also possible, and they are often recommended by healthcare providers because of the deceased organ donor shortage (Shapiro & Brennan, 2012). Living donor transplants can be done preemptively; that is, they may be performed without the patient needing dialysis first. They last longer than deceased donor kidneys, which have a median survival of 9.7 years from the time of transplant. Living donor kidneys have a median survival time of 13.8 years (Organ Procurement and Transplantation Network, 2011). Living donor kidneys can either come from a related or an unrelated donor, although related donations are more common.

In 2014, of the 5,536 kidney transplants from living donors, 2,683 were from related donors and 696 came from spouses or life partners. There were 2,109 living donor transplants from unrelated donors.[3] Of the unrelated donors, most of them – 1,273 in total – were unrelated directed donations, meaning that the donor chose to donate their kidney to a specific unrelated recipient. There are several other methods used to allocate living donor kidneys, including paired exchange, where willing donors who are incompatible with their potential recipient are matched with other people in the same situation; and a daisy chain, which involves more than two recipients and donors, forming a chain of donations; these often involve multiple hospitals and it can take months to complete the chain (M. A. Rees et al., 2009). Finally, altruistic donors exist –

---

[3] 48 of the living donor transplants in 2014 did not provide data about the source of the kidney. All data in this section is based on OPTN data as of March 20, 2015.

individuals who wish to donate a kidney to any recipient – although they may be regarded with suspicion by healthcare professionals (Tong, Chapman, Wong, & Craig, 2013). Despite this, the number of unrelated altruistic donations is growing – partially because some individuals are successfully using the Internet to find kidney donors (Costello, 2012). There has been considerable progress in the number of kidney transplants performed from nonrelated donors in the last 13 years. In 1999, unrelated donors gave 483 kidneys – compared with the 2,109 living donor kidneys transplanted in 2014.

For a kidney transplant to be successful, the immune response of the recipient must be suppressed using immunosuppressive therapy. This is because the immune system is designed to "discriminate self from nonself" (Sayegh & Chandraker, 2011, p. 2469) in order to prevent and manage issues like infections and tumors in the body. Without suppressing parts of the immune system, the recipient's body recognizes the transplanted tissue as foreign; it attacks the transplant, also called a graft, causing rejection. While researchers are working to develop treatments that allow the recipient's body to tolerate the transplant without maintenance immunosuppressive therapy, currently almost all patients must take immunosuppressive drugs on a regular basis (Matas et al., 2015). No optimal drug protocol or regimen has been established for kidney transplant recipients; instead, a variety of major immunosuppressive drugs are used in different combinations.

2.2.2 Challenges and burdens experienced by CKD patients. CKD and ESRD patients face a variety of challenges related to their illness. This section describes three of these challenges: self-management of one's health, uncertainty, and social isolation. All of these issues may be mitigated by the topics discussed in subsequent sections of this review. It is important to note that many of these psychosocial issues contribute to the high prevalence of depression in this population (Hedayati, Yalamanchili, & Finkelstein, 2012; Kimmel, Cukor, Cohen, & Peterson, 2007). Depression is significantly associated with and is a predictor for mortality in patients with dialysis (Farrokhi, Abedi, Beyene, Kurdyak, & Jassal, 2014).

2.2.2.1 Self-management of health. CKD and ESRD both require a high degree of self-management: patients must visit the doctor regularly, undergo habitual screening and testing to track the progression of their disease, take their medication on time and correctly, monitor their symptoms and side effects, and regulate and track their diet and fluid intake (Curtin et al., 2008). Furthermore, CKD usually involves the management of comorbidities like diabetes or hypertension, adding an extra layer of complexity to self-management (Thomas-Hawkins & Zazworsky, 2005). Depending on modality, dialysis patients must either visit the clinic multiple times a week, disrupting their employment or social life, or be responsible for maintaining their dialysis treatment at home (Gudex, 1995). Often, patients will choose a dialysis modality based on the impact it has on their lifestyle (Tong et al., 2009; Winterbottom et al., 2012). These complex medical regimens are difficult for patients to manage, as are the side effects from medication. This is true both pre- and post-transplant (Martin, Stone, Scott, & Brashers, 2010).

Self-management has a large impact on health outcomes: CKD and ESRD patients who are more able to manage their care are able to slow the progression of their illness (S. Chen et al., 2011), are less likely to be hospitalized with complications (McMurray, Johnson, Davis, & McDougall, 2002), are able to prolong the initiation of dialysis (Binik et al., 1993), are better able to manage their comorbidities (Doulton, Farmer, & Stevens, 2015; O'Toole, Fan, Yaqoob, & Chowdhury, 2012), have more confidence in their health-related decision-making and treatment choices (McCarthy, 2014) and experience higher quality of life and well-being – both of which are related to morbidity and mortality in CKD and ESRD patients (Curtin, Mapes, Schatell, & Burrows-Hudson, 2005).

2.2.2.2 Uncertainty. CKD and ESRD patients also experience uncertainty throughout their illness, particularly during times of transition such as deciding on a dialysis modality or waiting for a transplant (Pelletier-Hibbert & Sohi, 2001). Uncertainty in illness is defined as "the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 225). In many cases, uncertainty can negatively impact the patient's quality of life, their ability to self-manage their care, and their decision-making capabilities. It is the largest contributor to stress in peritoneal dialysis patients (Madar & Bar-Tal, 2009), and patients waiting for a transplant while on dialysis are likely to feel uncertain as they continue to wait (Martin et al., 2010). The theory of uncertainty in illness explains how patients make and determine meaning throughout their illness experience (Mishel, 1981). While this theory was initially developed in cancer research, there is a growing body of literature that successfully applies the theory to patients with ESRD and CKD (Madar & Bar-Tal, 2009; Maikranz, Steele, Dreyer, Stratman, & Bovaird, 2007; Martin et al., 2010; Russell & Brown, 2002; Scott, Martin, Stone, & Brashers, 2011; Stoeckle, 1993; Tong, Lowe, Sainsbury, & Craig, 2008; Weems & Patterson, 1989).

CKD and ESRD patients experience a variety of illness-related uncertainties, such as the inability to predict how one will feel from day-to-day, when and if a donor kidney will become available, concerns about medical procedures and outcomes, and the potential for death have all been identified by CKD and ESRD patients as issues contributing to uncertainty (Pelletier-Hibbert & Sohi, 2001; Schell, Patel, Steinhauser, Ammarell, & Tulsky, 2012). Uncertainty is born out of a lack of information and is exacerbated by lack of communication with health care providers and support from friends, family, and other patients. Furthermore, decline in kidney disease is not always linear, and estimates of the progression of decline are difficult to calculate and are often imprecise (Kaushal, Naimark, & Tangri, 2015). Waiting for a transplant is “a constant state of expectancy” (Stoeckle, 1993, p. 11) and kidney disease itself has been described as both complex and liminal (Molzahn, Bruce, & Sheilds, 2008) . Patients on dialysis are likely to feel uncertain as they continue to wait for a transplant (Martin et al., 2010). Patients on dialysis while waiting for a transplant have expressed that their uncertainty is mitigated by support and encouragement from healthcare providers, family, and friends (Weems & Patterson, 1989). Often, the support and encouragement activities take the form of information seeking and sharing (Ormandy, 2008). These topics will be discussed in subsequent sections of the review.

2.2.2.3 Social isolation. The decay or loss of social support structures is common in ESRD patients. Social isolation is a common complaint for ESRD patients, particularly those on in-center hemodialysis (Kierans, 2005; McLaughlin, Manns, Mortis, Hons, & Taub, 2003). Fatigue can also prohibit patients from their usual social activities like playing sports and exercising (O’Sullivan & McCarthy, 2007). Dietary and fluid restrictions may also make it more difficult for patients to socialize with friends. Patients may also have to interrupt their education or employment (Tong et al., 2009). Finally, some immunosuppressant drugs cause changes in one’s physical appearance, weight gain, and mood swings, which may also contribute to social isolation after transplantation (Muehrer & Becker, 2005). CKD patients may isolate themselves in order to “put on a brave face” or to “cover up” their sickness so as to not burden others (Molzahn et al., 2008, p. 18). Furthermore, because CKD patients often do not appear to be sick, they must decide to disclose their illness to family members, friends, employers, and other people in their social network. This decision places a great burden on the patient, which will be discussed in greater detail in the section on disclosure. The stress from this decision can also contribute to social isolation (Tong et al., 2009).

Both CKD patients and their spouses may also experience marital dissatisfaction. This is largely related to the intrusiveness of the illness and treatment plans (Jiang et al., 2014) and can be compounded by sexual dysfunction, which is commonly experienced in ESRD patients on dialysis (Schmidt & Holley, 1998) and often persists after transplantation (Muehrer, Lanuza, Brown, & Djamali, 2014). Marital dissatisfaction can contribute to depression in both the spouse and the patient (Daneker, Kimmel, Ranich, & Peterson, 2001). It also has an effect on medication compliance, perception of illness, and health outcomes: "an unhappy marriage and increased marital conflict may have serious consequences for health in ESRD patients, including death" (S. D. Cohen et al., 2007, p. 340). These issues will be discussed in greater detail in the section on social support.

2.2.3 CKD conclusion. This section of the review provided a brief overview of some aspects of CKD and ESRD. While there is no one underlying cause or treatment for either CKD or ESRD, there are many common symptoms experienced by patients, including anemia, high blood pressure, fluid retention, headaches, nausea, and general malaise. Treatment of early-stage CKD relies on managing these symptoms with a variety of medications and dietary changes tailored to each specific patient's needs. If an individual with CKD progresses to Stage V CKD, RRT is required, often in the form of dialysis or a kidney transplant. There are two main types of dialysis: hemodialysis and peritoneal dialysis. The choice of which modality to employ should be done as a team, with the patient and provider taking the patient's lifestyle and preferences into account. Kidney transplants are also possible; eligible patients may receive a kidney from a deceased or living donor. Most transplant patients must take medication for the rest of their lives in order to prevent rejection of the kidney. Patients diagnosed with CKD experience a variety of challenges, including difficulties managing their care, medical uncertainty, depression, and social isolation.

2.3 Social Support and CKD Patients

This section of the review begins with an overview of how social support is linked to health, including definitions of key terms and constructs. This is followed by a section discussing the two approaches to understanding social support: functional, or examining perceived and enacted support; and structural, or viewing support as a network effect. The components of support are then discussed, including a section on the four common types of support: emotional, informational, and tangible, and network; and common sources of social support, including family, friends, and patient peers. An explanation of supportive behaviors as they occur online is then presented, which includes a discussion of both general online social networks and online support groups for health. The defining characteristics of online support groups are also examined. Finally, the section concludes by linking social support with CKD: the effects on outcomes and treatment, common sources of support for kidney patients, and online support groups for kidney patients are all discussed.

Social support is defined as the purposeful provision of aid during a time of need or crisis (Caplan, 1974). It also can be used to describe one's sense of belonging in a community (Cobb, 1976). It has been linked to health outcomes and generally has a positive effect on health (S. E. Cohen & Wills, 1985). Because of this, it is a useful construct to study when investigating the behaviors of chronically ill individuals communicating with one another about their illness. Social support is inherently relational and requires some form of communication with others

(Burleson, Albrecht, & Sarason, 1994). It is an integral part of support groups, which are not only sources of support but are also sites of information exchange.

Social support has a direct effect on health and also acts as a buffer for stress and coping. Faced with a stressful situation, such as the diagnosis of a chronic health condition, individuals appraise that situation and determine whether or not it demands a coping mechanism (S. E. Cohen & Wills, 1985). In these situations, the perception of social support helps people both appraise and cope with the stressor. When individuals appraise a health situation, they may decide they need to seek social support from the people that they predict will be supportive, if they perceive that there is support available. In a study of social support for 14 various chronic health conditions, three major correlates to seeking support were identified: health care salience, patient characteristics, and the burden of the condition (Davison, Pennebaker, & Dickerson, 2000). Salience is comprised of factors like whether the cause of the illness is known, whether the patient must manage the disease and treatment, how disabling the disease and treatment are, how costly treatment is, the patient's general attitude, and whether or not the disease is terminal. Patient characteristics include general demographic variables that pertain to the individual, like age and gender. Finally, the social burden of the condition plays a role: is it disfiguring or embarrassing, are the symptoms noticeable, or is the disease stigmatized? These three correlates are assessed during appraisal and help the focal individual to determine whether they need support. In addition to predicting whether an individual will seek illness-related support, these factors help determine both who support may be sought from and the type of support that might be needed (B. E. Hogan, Linden, & Najarian, 2002).

When individuals appraise a health situation, they may decide they need to seek social support from the people that they predict will be supportive. There are two types of support appraisal: enacted support and perceived support. Enacted support is an assessment of how much support people actually receive from their network; perceived support investigates how much support individuals think they will have if they need it (Sarason, Sarason, & Pierce, 1990). Some research suggests that enacted support is mediated by perceived support; that is, the effect of support that is received actually depends on how much support the focal individual expected to receive in a given situation (Barrera, 1986; Sarason et al., 1990; Wethington & Kessler, 1986). These discrepancies between perceived and enacted support, which stem from inaccurate perceptions of either the amount or quality of support, can have either a positive or negative effect on health outcomes, depending on the direction of the discrepancy (Dunkel-Schetter & Bennett, 1990). It is possible that low estimations of perceived support is one motivating factor for people to search for supportive patient peers in online support groups. People who perceive they have higher levels of social support are better able to cope in a health crisis without actually drawing on the support they believe is available (Gottlieb & Bergen, 2010). Conversely, people who don't perceive they have enough social support suffer from social isolation, which can lead to depression, stress, and other negative health outcomes (Dunkel-Schetter & Bennett, 1990).

2.3.1 Types of social support. Generally, there are three types of enacted social support recognized in the literature: emotional support, tangible aid, and informational support (e.g., S. E. Cohen & Wills, 1985; House, Kahn, McLeod, & Williams, 1985; Langford, Bowsher, Maloney, & Lillis, 2008). While these types of support are often discussed as separate concepts, in practice they often overlap (S. E. Cohen & Wills, 1985), and sometimes the concepts are so closely related that they may be redundant when applied to specific problems or situations (Cutrona & Russell, 1990).

Emotional support is defined as support that gives the focal individual a feeling that they are cared for, or the provision of "empathy, caring, love, and trust" (House, 1981, p. 24). Emotional support strengthens the focal individual's sense of self-worth and belonging to a group (Schaefer, Coyne, & Lazarus, 1981). Informational support is the provision of information or advice with the intent of giving the focal individual a means to help themselves (Langford et al., 2008; Schaefer et al., 1981). Sometimes, the information is given to help the individual make a decision or solve a problem (Gottlieb, 1978); in other cases, it is offered in order to help the focal individual evaluate their circumstances without a specific problem in mind. In some cases, researchers have labeled this latter type of support appraisal support (House, 1981), although many researchers do not make this distinction (e.g., Cutrona & Russell, 1990). Finally, tangible support is the provision of goods or services to a focal individual (House, 1981). Examples of tangible support include financial help, rides to the doctor, providing housing, or cooking meals. It is the easiest type of support to recognize, and is more easily separated from the other two types of support discussed (Schaefer et al., 1981). Other types of support are present in a few typologies, such as network support, which is defined as the availability of supporters in one's network. It is closely related to perceived support (Cutrona & Russell, 1990).

Many authors posit that emotional support is the most important type of support (e.g., House, 1981). Perhaps this is because all supportive activities are intended to be helpful and are thus emotionally charged in some way. Many researchers have noted the difficulty in distinguishing emotional support from informational support, particularly because informational support often comes in the form of emotionally laden advice (House, 1981; Tardy, 1985). Tangible support has also been linked to emotional support, particularly when the intent of giving the focal individual a gift is done to indicate caring and not out of a sense of obligation (Schaefer et al., 1981). Finally, some researchers have found that all types of support are perceived as emotional support by focal individuals (e.g., Gottlieb, 1978), further complicating the typology of support in research.

2.3.2 Supportive behavior in relationships. Social support is inherently relational, but the focal individual only considers some relationships supportive. While most of the literature on support sources focuses on role-based relationships, particularly among immediate kin, relationships are actually complex, interpersonal processes that change over time. Relationships and their supportive functions, therefore, should ideally be understood not from a simple, role-based perspective, but by locating supportive people within one's network at a specific point in time (Reis & Collins, 2000). In North America, kin are generally expected to give and receive support and are members of the "inner circle" (Wellman & Wortley, 1990). People also identify friends, neighbors, co-workers, and acquaintances as supportive individuals, although these people are not often identified as "core members" of one's supportive group (Antonucci, Birditt, Sherman, & Trinh, 2011; Kahn & Antonucci, 1980). Throughout the lifespan, people closer to the focal individual provide both more perceived and enacted support, and are also more likely to provide more types of support than people who are not in the inner circle of one's support network, which is also called a convoy (Antonucci & Akiyama, 1987; Gottlieb & Bergen, 2010). Furthermore, these members provide more support over the long-term compared with people in the outer circles, who often give support on a short-term basis (Heaney & Israel, 2008). Emotional and informational support are both exchanged within all members of the convoy, but tangible aid is frequently only present within members of the inner circle, particularly parents and spouses (Antonucci et al., 2011).

The most obvious type of tangible support given by family is caregiving (Swanson et al., 1997). Caregiving encompasses many activities and is not just the provision of tangible support:

caregivers also act as proxies in searches for health information (Fox & Jones, 2009) and also offer emotional support (Swanson et al., 1997). One of the reasons that tangible support from people outside of the “inner circle” of one’s social network may not be as common as other forms of support is that people generally do not like asking others for help, irrespective of their health situation (S. E. Cohen & Syme, 1985). Asking others for information or for advice, however, places less of a burden on the person being asked: it requires only time or compassion, not physical effort. This may be a reason for people to search for health information in online support groups: members of OSGs are already there, and may not have to expend much additional effort to provide support to the focal individual.

Sharing disease commonality is thought to foster mutual support (Hoey, Ieropoli, White, & Jefford, 2008). Systematic reviews and randomized clinical trials demonstrate that online support groups have a positive effect on health and wellness outcomes in cancer (Hoey et al., 2008; McAlpine, Joubert, Martin-Sanchez, Merolli, & Drummond, 2015), depression (Griffiths et al., 2012), rheumatoid arthritis (Allam, Kostova, Nakamoto, & Schulz, 2015), mental illness (Barak, Hen, Boniel-Nissim, & Shapira, 2008), and HIV/AIDS (Mo & Coulson, 2013), both directly and as a cushion during stressful, illness-related events, known as the buffering effect. Not all studies of peer support groups show a positive benefit for participants – for example, a systematic review indicates a mixture of both positive and negative effects for participants (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004). This research should be repeated, however, as the proliferation of health-related online support groups has increased considerably since 2004.

Peer support may help patients who are concerned about harming existing relationships by relying on people they already know for support. Some types of stress, including illness, can negatively impact one’s social network and deteriorate perceptions and enactment of support; this is sometimes called a “social network crisis” (Lepore, Silver, Wortman, & Wayment, 1996). Concerns about the availability and quality of support are particularly salient when convoy members do not understand the situation, minimize problems, or expect the focal individual to “return to normal” (Helgeson & Gottlieb, 2000; Rosland, Heisler, & Piette, 2011). Illness situations, particularly those that are chronic, actually force the focal individual to redefine themselves, forging a “new normal” (Mishel, 1999) by simplifying their lives, reordering their conception of time, and learning how to pace themselves and juggle tasks (Charmaz, 1993). Relationships with patient peers allow for people to form these new identities with other people experiencing similar struggles (Markle, Attell, & Treiber, 2014; Mead, Hilton, & Curtis, 2001).

Support groups foster reciprocity of support, an essential component of supportive activity (Antonucci & Jackson, 1990). They also promote disclosure, with the assumption that disclosing personal health information to others who may share similar problems is therapeutic, possibly reducing stress via the buffering effect (Helgeson & Gottlieb, 2000). The subject of disclosure will be discussed in a future section, but it is useful to note here that disclosure is an essential component of relationships with patient peers, leading to a warm, inviting atmosphere that encourages emotional support exchange among members.

However, there is variability in the efficacy of patient peer groups. One potential reason for this is that the content of discussions is variable and depends largely on the individual particulars of group members. For example, people who are generally predisposed to negativity may incite fear and anxiety in their peers. Furthermore, discussing negative feelings may not necessarily reduce distress unless the discussion contains concrete ways for managing those feelings in the future. This can be difficult to do without trained moderators present.

Furthermore, when patient peers provide concrete suggestions for managing problems, it can make them feel unduly burdened. Although support is reciprocal, there is a danger that some patient peers will feel that they are not receiving as much support as they are giving to others (Helgeson & Gottlieb, 2000). It is also possible that participating in a peer support group might negatively impact one's interactions with their existing convoy, either by changing the way that focal individuals think of support or by otherwise disrupting those relationships (Helgeson, 1999). Negative downward comparison can also be a problem, or the frustration experienced by seeing other patients coping more successfully. Unfortunately, it is currently difficult to understand why some groups appear to work and some do not, because most support group intervention research is not theoretically based (Helgeson & Gottlieb, 2000). Without a theoretical underpinning, understanding the mechanisms at work in peer support groups is difficult, if not impossible. Future research that aims to build a theory of support from patient peers is necessary, especially given the recent explosion of online support groups for health.

2.3.3 Online support groups with patient peers. There are two common locations where patients communicate with one another online: general-purpose online social networks, like Facebook and Twitter, and condition- or treatment-specific online support groups (OSGs), which are sometimes called virtual communities or online forums. Patients use general-purpose online social media outlets to communicate health information with friends, other patients, and health care providers (Antheunis, Tates, & Nieboer, 2013; Hawn, 2009). People often use general-purpose sites in two health-related contexts: when they have a specific health goal, such as losing weight or exercising more (Newman, Lauterbach, Munson, Resnick, & Morris, 2011), and when they have a health crisis and need support (Skeels, Unruh, Powell, & Pratt, 2010). These two uses align with main effects and buffering effects hypotheses discussed earlier. On general-purpose sites, people are leveraging their existing or embedded network (Dennis, 2003). However, sometimes one’s embedded social network is not equipped to deal with certain support needs; this is particularly true in health crises (Helgeson & Gottlieb, 2000) but can also occur in a wellness context. When people in one’s embedded social networks cannot meet an individual’s support needs, they may look beyond those networks for support.

On sites specifically created for health purposes, people often post more details and discuss problems more readily than they do on general-purpose social networks (Newman et al., 2011). There are two types of online social networks for health: pan-health sites, which contain multiple forums and groups for a wide variety of diseases, and sites specific to one condition or treatment. They both fulfill the same functional purpose from the patient’s point of view, although pan-health sites may be more attractive for people with multiple conditions because these sites allow for them to aggregate all of their health information and online support in one location. The literature typically calls online social networks for health “online support groups,” because their main purpose is essentially to foster support between patient peers. Although OSGs also exist for topics other than health, the term OSG will be used for brevity and clarity in this review. Some pan-health sites also allow patients to share more detailed data about their health in the fashion of a personal health record, such as PatientsLikeMe (Wicks et al., 2010).

Informational and emotional support are both commonly found in studies typifying supportive activities in OSGs (Braithwaite, Waldron, & Finn, 1999; Chung, 2013b; Coulson, 2005; Eichhorn, 2008; LaCoursiere, 2001; Nambisan, 2011). There is scant evidence in the literature for tangible support online in patient peer OSGs (e.g., Chuang & Yang, 2012; Dennis, 2003). As discussed in the section on types of support, informational and emotional support often occur concurrently in OSGs. One forum post, for example, might contain both information and emotionally supportive text (Braithwaite et al., 1999). Patients prefer to get a specific type of informational support from peers online: experiential information, which is not available from healthcare providers. However, providers are still the primary source for most informational needs (Fox & Duggan, 2013), which will be discussed in section on information behaviors in this review.

As noted above, there are OSGs for virtually every type of chronic health condition: life-threatening diseases like cancer and HIV/AIDS; unexplained illness like fibromyalgia and chronic fatigue syndrome; and chronic disabling conditions such as arthritis and depression (Griffiths et al., 2012; Mo & Coulson, 2013; van Uden-Kraan, Drossaert, Taal, Seydel, & Van De Laar, 2009). Health factors play a large role in participation in OSGs. People with chronic conditions are more likely to use OSGs (Fox & Duggan, 2013), and individuals who perceive their health to be poor, who have more illness-related distress, and who have experience specifically with cancer are more likely to have used OSGs for health support (Chou, Hunt, Beckjord, Moser, & Hesse, 2009). Furthermore, different diseases have different representation online: people with rare diseases or stigmatized conditions are more likely to seek support from OSGs when compared with more common or less stigmatized diseases (Davison et al., 2000; Howard, 2014). People are also more likely to search for information about stigmatized conditions than they are to share information about that condition using a general social networking platform like Twitter (De Choudhury, Morris, & White, 2014). Aside from illness-specific factors, age and education also play a role in determining whether or not a given individual will participate in an OSG. Younger people are much more likely to participate in online support groups, as are people who have completed some college education, but not college graduates (Chou et al., 2009). Finally, gender plays a role in participation in OSGs: men tend to focus on sharing information resources and practical day-to-day tips, while women tend to discuss emotional issues related to illness (Mo, Malik, & Coulson, 2009).

OSGs offer several advantages over classic face-to-face support groups: time, location, anonymity, social presence, and passivity are all features of OSGs that differ significantly from physical support groups (LaCoursiere, 2001). OSGs are not limited by time; that is, anyone can participate, at any time of day or night. Patient peer support is therefore available on a just-in-time basis online, making it more convenient for people with an Internet connection to access. This also allows people to carefully craft their questions and responses to others, unlike a traditional support group, which moves in real-time (White & Dorman, 2001). The therapeutic benefits of writing about illness have been well-established, particularly when patients write over the course of many days or months (Pennebaker, 1997). Writing as a way to cope with health issues will be discussed further in the following section on disclosure.

OSGs also transcend geographic boundaries – anyone with an Internet connection can participate in an OSG, while face-to-face groups can only be attended by people who live nearby. This is particularly helpful for patients who live in rural areas, who are often unable to participate in face-to-face support groups or other activities that are part of the health care system. This isolation can make it more difficult for patients to cope with a chronic illness (Cacioppo & Cacioppo, 2014). The lack of geographic constraints is also advantageous for people with rare diseases: when there is no one local who shares a diagnosis, the opportunity for face-to-face peer support is nonexistent. In a recent survey conducted by the Pew Research Center, about one third of Internet-using patients with rare conditions consulted patient peers online for information or support (Fox, 2011b). Many times, this is because there are no local patient peers available. However, access to OSGs is still a concern, particularly for patients in rural areas; these individuals are less likely to use the Internet for health information (Hale, Cotten, Drentea, & Goldner, 2010) and also may have less reliable Internet access. Also, the 1 in 5 American adults who do not use the Internet cannot benefit from OSGs; research shows that senior citizens, people with less than a high school education, or who live in households that earn less than $30,000 a year are the least likely individuals to have Internet access at home (Zickuhr & Smith, 2013).

OSGs also facilitate anonymity, something that is more difficult to attain in face-to-face support groups – at best, face-to-face groups can promote the illusion of anonymity, as is the case with Alcoholics Anonymous, without being able to offer it in a true sense (Colman, 2011). True anonymity – defined as "losing oneself in the midst of others" (Pedersen, 1997, p. 153) – is not entirely possible in OSGs either, because one develops an identity used for all interactions on the site over time. However, this identity is not necessarily connected to one's real-life persona or identity, meaning that anonymity is greatly enhanced online. Online, anonymity fosters a sense that one can be their "true self" without fear of judgment, paving the way for catharsis and autonomy. Anonymity allows people to escape from traditional social pressures, lending a sense of safety because one is part of a group without fearing retribution from that group (Pedersen, 1997). However, anonymity can also lead to "Munchausen by Internet" syndrome – people either overstating the effects or fabricating illness entirely (Pulman & Taylor, 2012). When revealed, this can cause shame, distrust, and suspicion in remaining members in the OSG (White & Dorman, 2001). Anonymity also impacts disclosure habits; for example, people with stigmatized conditions are more likely to participate in OSGs partially because they can reap the benefits of a traditional support group without having to reveal their identity (Davison et al., 2000; Lawlor &

Kirakowski, 2014). This and other issues revolving around anonymity will be discussed in greater detail in the section on disclosure.

Related to anonymity is egalitarianism; most researchers claim that social context cues are absent online (Walther, Anderson, & Park, 1994). However, this stance ignores the ability for people to create alternative social context cues online; for example, many OSGs print information like the date a member joined, their profile picture, and the number of comments they have made next to each post they make. This information, while not identical to the cues people receive in face-to-face interactions, likely does have the same effect on people as other social context cues. Still, the Internet does provide a different type of egalitarianism between participants: things like age, gender, race, income, and social status are much more difficult to discern online (White & Dorman, 2001). It's also easier to be passive, or to lurk, in an OSG, while it is much more difficult to lurk in a face-to-face support group, which requires more reciprocity from members (Davison et al., 2000). Although reciprocity has been called an essential component of support (Antonucci & Jackson, 1990), this may be different online, as lurkers in OSGs report the same empowerment benefits as non-lurkers (Petrovčič & Petrič, 2014; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). Lurking also raises perceptions of well-being, and while lurkers do not contribute by posting information to OSGs, they still consider themselves to be actively engaged with the OSGs that they frequent (Han, Hou, Kim, & Gustafson, 2014). However, people who post on OSGs receive more enacted social support than people who do not post (Setoyama, Yamazaki, & Namayama, 2011).

2.3.4 Effects of social support on CKD and ESRD. With an understanding of how social support operates systematically and functionally, including the types, sources, and locations of support, we can now turn to a discussion of support and CKD. This section of the review discusses social support and how it affects both CKD and ESRD outcomes and treatments. It also covers different sources of support for CKD and ESRD patients with a focus on patient peer support groups for renal disease. A brief overview of online support groups for CKD and ESRD concludes the section.

2.3.4.1 Social support, health outcomes and treatments for CKD and ESRD. The social support literature about CKD and ESRD patients is largely focused on patients who are undergoing either hemodialysis or peritoneal dialysis, but there is a growing body of literature on post-transplant kidney patients as well. In dialysis patients, social support has been positively linked to mortality (Friend, Singletary, Mendell, & Nurse, 1986; Kimmel, 2000; Untas et al., 2011), quality of life (S. D. Cohen, 2013; Perales-Montilla, García-León, & Reyes-del Paso, 2012), depression (Christensen & Ehlers, 2002; Gencoz & Astan, 2006), compliance with fluid and dietary regimens (Patel, Peterson, & Kimmel, 2005), and lower rates of hospitalization (Plantinga et al., 2010). That is, higher levels of social support reduce mortality rates and depressive symptoms in dialysis patients, while also increasing compliance with dietary and fluid restrictions. Specifically, discrepancies between how much support dialysis patients think they will receive when it is needed and the support they actually receive have a significant impact on whether or not they will survive (Thong, Kaptein, Krediet, Boeschoten, & Dekker, 2007). Reciprocity of support is also important to dialysis patients. Giving support has been linked to mortality in this population; individuals who are not able to continue giving support to people they supported in the past have lower survival rates (McClellan, Stanwyck, & Anson, 1993). This finding holds when controlling for other mortality risk factors. Support reciprocity remains moderately high among dialysis patients, although the symptoms of both ESRD and dialysis treatment do make reciprocating support more difficult (Cormier-Daigle & Stewart, 1997; Jiang et al., 2014).

Social support is particularly important for people on dialysis because the treatment significantly impacts one's psychological state and their social life (Patel, Peterson, & Kimmel, 2005). Dialysis impairs the ability to participate in work and social activities, and the disease can place a significant burden on people in one's social circle, particularly caregivers (Bayoumi, 2014). Depending on the mode of dialysis selected, it can require a fair amount of interaction with others, including providers, patient peers, and caregivers. Therefore, the treatment may have the effect of increasing network support, because it reduces social isolation, a common outcome of chronic illness (McClellan et al., 1993). This is particularly true when patients go to a dialysis center to receive treatment, because centers have social workers on staff; time spent with social workers related to lower levels of depression and higher quality of life in hemodialysis patients (Beder, 2008). Peritoneal dialysis patients also report high levels of social support, largely because peritoneal dialysis requires caretaker management (Plantinga et al., 2010). Perceived social support also has a positive effect on the quality of life of patients on hemodialysis (Khalil & Abed, 2014; Rambod & Rafii, 2010).

Variations in social support are also relevant pre- and post-kidney transplant. Investigations of stress and support in kidney transplant recipients have found that the buffering hypothesis is in effect: patients experiencing high levels of stress related to their transplant are able to cope with that stress more effectively if they perceive that they have higher levels of emotional support (Christensen, Turner, Slaughter, & Holman, 1989). Tangible support is also helpful post-transplant, particularly during the recovery period (Frazier, Davis-Ali, & Dahl, 1995). Post-transplant interpersonal relationships are often a stressor on patients, particularly relationships with family; it is posited that this is because patients are concerned that their illness is a continued burden for family members (Frazier et al., 1995). The ability to provide support to other people within one's network is associated with higher quality of life post-transplant (Cetingok, Hathaway, & Winsett, 2007).

2.3.4.2 Sources of support for CKD and ESRD patients. Patients often identify family members and spouses as their most important supporters (Jiang et al., 2014). Friends and healthcare providers – particularly nurses – often play an important supportive role but are less important than family; and patient peers are the least important people in one's support network (Cormier-Daigle & Stewart, 1997; Cummings, Becker, Kirscht, & Levin, 1982; McClellan et al., 1993). However, the presence of patient peers in most studies that examine support sources suggests that, although they play a minor supportive role, they are still important sources of support for ESRD patients. Family members are the most important source of support for dialysis patients (Christensen et al., 1992; Cormier-Daigle & Stewart, 1997; Oka & Chaboyer, 1999; Siegal, Calsyn, & Cuddihee, 1987).

Fostering relationships between patient peers with CKD and ESRD is not particularly common in interventions, but it has been encouraged (S. D. Cohen et al., 2007; Friend et al., 1986; Rounds & Israel, 1985). The few interventions in this area employ trained patient peers to convey information to dialysis and/or transplant patients (e.g., Brunier, Graydon, Rothman, Sherman, & Liadsky, 2002; Roy & Atcherson, 1983; Sullivan et al., 2012). It is surprising that there are not more interventions that focus on patient peers, because dialysis patients find "meeting and experiencing support from other patients in the same situation and from the health professionals… as positive and helpful" (Klang, Björvell, & Clyne, 1999, p. 874). In fact, dialysis patients will often seek out information from patient peers before going to healthcare providers, particularly when they are looking for information about experiences (Godbold, 2013a).

2.3.4.3 Online support groups for CKD and ESRD. Several interventions have focused on the use of OSGs for kidney patients (Bers, Gonzalez-Heydrich, Raches, & DeMaso, 2001; Nicholas et al., 2009; Zheng et al., 2010). Interestingly, all of these interventions are geared towards children and young adults; to this researcher's knowledge, there have been no interventions designed for adult renal patients to connect with patient peers online. These interventions demonstrate that support between adolescent patient peers with CKD and ESRD can be fostered online, resulting in meaningful supportive relationships that have a positive effect on health outcomes including medication compliance, depression, and stress. Individuals with CKD and ESRD also join OSGs independently, without being enrolled in interventions. They may be motivated to do so for reasons similar to those identified for patients in online support groups for other health conditions; namely, to seek emotional and informational support (Eichhorn, 2008).

Unfortunately, there is little empirical evidence that describes how kidney patients behave in online forums. However, research suggests that dialysis patients go online to discuss issues like pain management, coping, and other troubling topics (Godbold, 2010b) and that they co-create meaning and engage in collaborative sense-making in online forums for CKD (Godbold, 2013a). Many patients are also interested in learning about the experiences of other patients and not in obtaining medical information when they view videos posted by other patients with kidney disease (Garg, Venkatraman, Pandey, & Kumar, 2015). Individuals waiting for kidney transplants also use Facebook, Craigslist, blogs, and personal websites to communicate with other people in the transplant community (Costello & Murillo, 2014), but our understanding of their motivations for going online and the activities they engage in with one another is also limited. Although the literature on this topic is paltry, there are many active online communities for members of the CKD and ESRD community: patients, caregivers, providers, and donors are all active in online support groups. There is currently a large gap in our understanding of how and why CKD and ESRD patients use the Internet to communicate with patient peers.

2.3.5 Social support conclusion. This section of the review provided an overview of social support as it relates to health. Social support is defined as the provision of helpful resources both throughout one's life and in times of need. Relationships with supportive individuals strengthen one's general health and wellness, or they have a main effect and a buffering effect on health. Individuals appraise how much support they need in a given situation, and rely on their network to provide support if it is needed. How much support people think they have available to them, or perceived support, plays an important role in health outcomes.

There are generally four accepted types of social support present in the literature: emotional, informational, tangible, and network; in practice, however, it can be difficult to distinguish these types of support from one another. People also receive support from a variety of different individuals in their network, and the convoy model of support is one approach to understanding who provides support and what type of support they are likely to provide. Patient peers are one source of support; they often provide emotional support via support groups. OSGs are another location where patient peers can communicate, although people also use general social networks to communicate about health with people from their existing networks. OSGs provide around-the-clock access to support for anyone with an Internet connection, allowing anonymous, egalitarian communication between patient peers; however, their efficacy is largely unknown at this time. There is some exploratory evidence that suggests that kidney patients glean positive benefits from participating in patient peer groups online, although there is more research investigating the benefits of face-to-face peer support for renal disease and support from family members and spouses. Social support has been shown to have a positive effect on health outcomes, particularly in mortality, depression, and medication compliance in CKD and ESRD patients.

2.4 Information Behaviors in Patients with CKD

There are myriad theoretical frameworks and models that attempt to describe and predict information behaviors. These theoretical frameworks help to explain what motivates people to fill their information needs with seeking and use behaviors. People often experience an information need as a gap in their knowledge (Dervin, 1998), exacerbated by a feeling of uncertainty and the desire for information to reduce their uncertainty (Kuhlthau, 1993). When seeking information, people choose different information carriers in order to close the gap and reduce uncertainty based on the characteristics of the carrier: the channel, source, and messages (Johnson, 1997). Many times, these carriers can be other people. When individuals use information, they may engage in information transfer – sharing the information they have found with others in order to make more sense of it or to provide informational support to others who may have similar information needs (T. D. Wilson, 1999). While all of the frameworks are strong, none of them fully addresses questions of health information behavior specifically in a comprehensive manner.

Most of the existing frameworks divide information behavior into three distinct types or phases: information needs, information seeking, and information use. These behaviors are generally understood to occur in a linear progression; that is, people first identify an information need, they then search for information to fill that need, and then they put that information to use

(Case, 2012). These models overwhelmingly focus on information seeking – the easiest of the three behaviors to observe in practice – and are also usually oriented toward a single task where a user has a defined need. In practice, however, these activities often overlap as users grapple with multiple inter-related questions, problems, and gaps (Dervin, Foreman-Wernet, & Lauterbach, 2003) and they may be difficult to distinguish from one another, particularly when one begins to think about information behaviors over time and in context (Savolainen, 2008). It may be more helpful to frame these behaviors as information *practices* – a range of activities that relate to information that take place within a social context (McKenzie, 2003). These practices do not occur in a vacuum: they may be social and dynamic, particularly when they are related to everyday life – as is the case in living with a chronic illness, which requires a great deal of information work (T. P. Hogan & Palmer, 2005).

For the purposes of clarity, however, this review is divided into three sections that align with the traditional linear models of information behavior. Information needs, seeking, and use are discussed as they relate to health information behavior specifically. Information practices are often understood as an important component of coping with a chronic illness; coping can take many forms, including decision-making and uncertainty reduction. Factors that influence behaviors, such as empowerment, health literacy, and channel selection are also covered in this section of the review. Each section concludes with a discussion of the specific needs, seeking strategies, and use patterns of CKD and ESRD patients.

2.4.1 Information needs. Health information is an important component of coping with health-threatening situations (C. Rees & Bath, 2001). General information needs that fit this context include understanding the particular challenges of a health-threatening situation, determining the resources available to manage health, and increasing predictability and reducing uncertainty around health (Lambert & Loiselle, 2007). Many health information needs are associated with the diagnosis of a particular health condition, although they may also occur at several points along the illness trajectory. Research indicates that periods of transition are highly correlated with increased illness-related uncertainty, which requires the individual to develop and maintain coping strategies surrounding their health (Mishel, 1999); these uncertainties likely lead to new information needs related to a given condition throughout one's life.

The concept of an information need is slippery at best, particularly because it can really only be understood after it has manifested in some behavior – usually information seeking (Case, 2012, p. 91). However, most researchers in this area agree that information needs often arise from uncertainties or gaps in knowledge. For example, Belkin explains that information needs come from a recognized but imprecisely defined anomaly, or what he calls a "perceived wrongness" (1980, p. 137). Dervin's (1998) sense-making approach also focuses on gaps in knowledge. For Dervin, these gaps are a constant part of the human condition; information seeking is just one phenomenon that arises from the need to bridge these gaps (Savolainen, 2006). Wilson (1997) argues that information needs are caused by other needs, including the desire to cope with stress. In particular, people who are less tolerant of uncertainty and more vigilant may engage in more active information seeking; this is particularly relevant in the domain of health information (T. D. Wilson, 1997).

Unfortunately, the bulk of the literature on information needs of CKD and ESRD patients is focused on what providers think patients should know, not on what patients are interested in learning (Ormandy, 2008). Many of the studies that assess information needs from the CKD/ESRD patient's point of view are embedded in larger explanations of educational interventions for pre-dialysis or dialysis patients (e.g., Binik et al., 1993; Harwood, Locking-

Cusolito, Spittal, Wilson, & White, 2005; Iles-Smith, 2005; Lee, Gudex, Povlsen, Bonnevie, & Nielsen, 2008); often, information needs as a component of decision-making about treatment are the focus of these interventions (e.g., Groome, Hutchinson, & Tousignant, 1994; Klang et al., 1999; Orsino, Cameron, Seidl, Mendelssohn, & Stewart, 2003). A recent study specifically examining the knowledge gaps experienced by patients with CKD in stages I through IV indicates that patients feel that they do not receive enough practical, specific information from providers about the illness; furthermore, they feel that general practitioners and primary care doctors are not well-informed about CKD (Lopez-Vargas et al., 2014).

From these studies a picture of the specific information needs experienced by renal patients emerges, as described in a systematic review of the literature on this topic (Ormandy, 2008). Newly diagnosed patients are interested in what impact CKD or ESRD will have on their lives (Harwood et al., 2005; Iles-Smith, 2005), their chances of survival (Groome et al., 1994), and the possibility of death if treatment is refused (Orsino et al., 2003). Options for RRT – information about the types of dialysis and information about how kidney transplants work – are another large area of concern (Iles-Smith, 2005; Klang et al., 1999). When making decisions about RRT, patients desire information about the side effects of different treatments, the amount of autonomy a treatment provides, the impact of the treatment on relationships, and logistical information about how the treatment will be delivered (DePasquale et al., 2013). Learning how to interpret blood and other test results is also something patients want to know, as well as understanding what results are normal and what effects may arise from abnormal results (Lopez-Vargas et al., 2014). Newly diagnosed patients with Stage IV CKD are particularly concerned with dialysis-related issues like graft and fistula insertion and care, and having enough money for dialysis treatments (Lewis, Stabler, & Welch, 2010). Information about finances is important to renal patients regardless of where they are in the disease trajectory, as is information about the ability to work (Harwood et al., 2005; Martin et al., 2010). The ability to work is an issue for many CKD and ESRD patients, particularly those that were diagnosed at a young age; it is the subject of several studies on transition of care for pediatric patients (e.g., Cameron, 1985; McDonagh, 2005; Rosenkranz et al., 2005; Watson, 2004).

Knowing what life is like on dialysis is another topic in which newly diagnosed patients express interest (Groome et al., 1994). This is a particularly important need, as patients often gain this information by experiencing dialysis and living in the information world of the dialysis clinic itself (Veinot, Meadowbrooke, Newman, Zheng, & Perry, 2010). In fact, patients in one study expressed a desire to visit dialysis clinics and meet with other patients before beginning dialysis in order to understand the process (Iles-Smith, 2005). This need for experiential information from other patients is also seen in other studies and is present throughout the disease trajectory (Groome et al., 1994; Harwood et al., 2005; Klang et al., 1999).

Restrictions on diet and fluid intake are also something about which patients want information, particularly because they can impact a patient's quality of life considerably – in fact, patients in Harwood et al.'s (2005) study expressed regret that they did not have this information in the earlier stages of their disease because it could have helped them delay dialysis. Patients feel like they do not receive information about delaying the progression of their CKD from providers, which is often a source of frustration and confusion (Lopez-Vargas et al., 2014). Individuals also want to learn about physical symptoms and their body image, particularly because of problems like fluid retention and medication side effects (Groome et al., 1994). Body image issues are of particular importance to younger patients (Orsino et al., 2003). This concern is echoed in the desire for information about the implications of the disease on family and social life. For younger patients, this often manifests as a desire to learn about the impact of the disease on their fertility (Cameron, 2001) and how they will navigate dating and other social relationships (Martin et al., 2010); older patients are concerned with the impact the disease will have on their family and on their ability to travel (Barnieh et al., 2014; Martin et al., 2010). After the initial shock of diagnosis has worn off, patients report new information needs that are largely psychological: how to manage uncertainty (Martin et al., 2010) and cope with their compromised health (Juhnke & Curtin, 2000). Ultimately, these needs can be roughly split into two categories: those that can be met by getting information from health care providers, and those that can be met by communicating with other patients. Although some needs may be met by both sources equally well, others are best met by only one channel. This will be discussed in more detail below.

2.4.2 Information seeking. In the health domain, there are many definitions of information seeking. All definitions identified in a recent meta-analysis stress the active, purposeful nature of information seeking, and most discuss the channels or sources consulted by the seeker (Lambert & Loiselle, 2007). For the purposes of this review, the most basic definition for health information seeking will be used: "the purposive acquisition of information from selected information carriers" (Johnson & Case, 2012, p. 16). There are many reasons that people seek health information. These reasons are directly related to the type of information need being experienced, as well as the intended use of the information after it is located and processed by the searcher. Some of the more popular reasons for seeking health information in the literature include stress management (Krohne, 1989), coping with illness (Folkman & Lazarus, 1980), to aid in medical decision-making (Longo, 2005), to aid communication with family member and healthcare providers (Morahan-Martin, 2004), to satisfy curiosity about illness-related topics (Li, Orrange, Kravitz, & Bell, 2014), and to reduce uncertainty (Brashers, Goldsmith, & Hsieh, 2002). Individuals may either actively seek information, which is called vigilance; or, they may actively avoid information seeking, which is known as cognitive avoidance (Krohne, 1989). Vigilance and avoidance are analogous to the concepts of monitoring and blunting, which are used in more general threatening information-seeking situations (S. M. Miller, 1987). Not all patients engage with information, however: choosing not to search for information is not necessarily avoiding information. People have many reasons for not searching for information about their health beyond avoidance: seeking can be frustrating, information can be difficult to interpret, comprehensive information about health conditions is very hard to find, and information-seeking is time-consuming (Johnson, 2014). However, this review focuses on the purposive acquisition of health information.

2.4.2.1 Source selection. Individuals with a health issue who do decide to look for health information may consult a variety of sources. These sources are often part of one's existing information horizon – a set of resources that are embedded within a larger perceived information environment. This perceived information environment contains all potential sources that are known to the seeker; the horizon is a part of the environment containing resources that the seeker believes to be significant, with the most significant sources being more proximal to the seeker in this metaphor (Savolainen & Kari, 2004; Sonnenwald, 1999). Three of the most common sources consulted by patients are healthcare providers, other patients, and the Internet (Fox & Duggan, 2013).

2.4.2.2 Healthcare providers. In general, patients prefer to get information from their healthcare providers (Fox & Duggan, 2013; Gollop, 1997; Lenz, 1984). However, in practice they are more likely to go online to seek health information before talking with their provider, both for more general health questions (Volkman et al., 2014) and for concerns related to chronic issues such as multiple sclerosis (Marrie, Salter, Tyry, Fox, & Cutter, 2013). Although people prefer channels that exhibit social presence (Johnson & Case, 2012), it can be expensive and time-consuming to visit the doctor. Access to sources also matters greatly: people with less access to flexible resources like the Internet are more likely to consult their providers for health information (Manierre, 2015). The context of the information need also plays an important role: patients are likely to ask healthcare providers about technical issues, such as prescription interactions and symptoms; they turn to other, more personal channels when they have more personal information needs, like coping strategies (Fox, 2011b).

Although to this researcher's knowledge there are no direct-observation studies of kidney patients trying to elicit information from care providers, many studies do allude to the struggles that patients have in obtaining information from their providers. For example, dialysis patients in an interview study have noted that they don't know what to ask their doctors and nurses, citing a lack of time and the barrier of medical vocabulary used by nephrologists and dialysis technicians (Anderson, Devitt, Cunningham, Preece, & Cass, 2008). Others in this study said that they wanted to know why they got sick, but that asking care providers yielded no satisfactory answers, a finding echoed in another more recent study of patients diagnosed with CKD in stages I through IV (Lopez-Vargas et al., 2014). Unfortunately, a confounding issue is the low health literacy in patients diagnosed with CKD or ESRD; this is present throughout the illness trajectory and has been found in several studies (Devraj et al., 2015; Fraser et al., 2013; Miller-Matero, Hyde-Nolan, Eshelman, & Abouljoud, 2015). It is difficult, therefore, to know whether or not patients do not try to elicit information from their providers or if they do not understand the information that is provided to them by providers.

One issue that patients do discuss with their providers is dialysis modality choice. This may be because the topic is broached by the provider when dialysis is necessary, but patients of all ages and both genders have indicated that the first source that they consult when making treatment decisions about dialysis is their physician (Orsino et al., 2003). However, these patients also consult additional channels, including family, friends, and other patients, when making this treatment decision. If patients have chosen in-center dialysis, they may begin to feel like they do not need to actively seek for health information: one study found that the information they might need was "already there in the clinic" (Veinot et al., 2010, p. 3).

2.4.2.3 Other patients. Individuals also discuss their information needs with other, similar patients. Traditionally, the use of other patients as information sources has been facilitated in face-to-face support groups. Although the research on support groups for CKD and ESRD patients is paltry at best (Patel et al., 2005), a handful of studies have investigated in-person patient peer support groups for CKD and ESRD patients. Although there is not much empirical work focused on how these patients interact with other patient peers, the subject does come up in research on the psychosocial aspects of both CKD and ESRD, particularly in dialysis-based interventions and research (e.g., Goldade et al., 2011; Jablonski, 2004; Leake, Friend, & Wadhwa, 1999; Lee et al., 2008; Leung, 2003; Veinot et al., 2010). This is likely because in-center dialysis patients have an inordinate amount of contact with other similar patients as compared with other diseases, as noted by Veinot et al. (2010). These studies generally find that these relationships have a positive effect on patients, although Veinot et al. (2010) do say that the death of other patients can be a difficult issue for some individuals on dialysis.

In one of the only studies on support groups for dialysis patients, participants were keen to take part in a support group that was administered not by providers but was instead moderated by patient peers (Friend et al., 1986). Unfortunately, no detailed descriptions of the support group topics or discussions were reported, so the role of information seeking and sharing cannot be elaborated upon. Another study on patient peer mentors for dialysis patients found that the mentors were seen as helpful when patients were making decisions about end-of-life care (Perry et al., 2005) Finally, participants in an online peer-mentoring program for young adults with ESRD expressed the desire to seek health information and help in an online support group by getting to know other patients (Zheng et al., 2010).

2.4.2.4 The Internet. The Internet combines information-based sources with user-generated interpersonal communications. Some sites offer only one type of content – that is, they are either static websites, or they are social sites – while some offer a blend of both. In the health information realm, there are few sites that offer both types of content; they are typically either static websites that offer health information from one agent or body, or they are social sites that contain user-generated information. This section discusses both types of sites and their use by CKD and ESRD patients. According to a recent survey, 72% of the Internet users in the United States have searched for health information online; this proportion increases if the user has a chronic illness (Fox, 2011a; Fox & Duggan, 2013). These individuals are known as e-patients, a term coined in the 1990's to describe patients who used the Internet to find and share health information (Ferguson & Kelly, 1999).

2.4.2.4.1 Information-based sites. Some of the sources consulted online are primarily information-based; that is, they are static websites containing general information about a particular health condition. Ideally, reputable authors – often care providers – write the content that is presented on these pages, and the information provided is reliable and accurate. It may be accurate and very similar to the information that a provider would offer during a visit, or the information might be unreliable. In fact, the use of the Internet for health information has been noted as a problem for health care providers, who are particularly worried about the credibility, reliability, and accuracy of online information (Eysenbach, 2005). A recent review of websites for kidney patients focused on authoritative sources of information for kidney patients online, including sites from the National Kidney Foundation, the American Association for Kidney Patients, the American Society of Nephrology, and The National Kidney Disease Education Program (Buettner & Fadem, 2008). Another study conducted in 2004 on static Internet sources for information about CKD and ESRD indicated that proprietary websites, such as those sponsored by dialysis companies, were less reputable than their nonproprietary counterparts (Jaffery & Becker, 2004). A recent study of 40 non-proprietary websites offering information about CKD and ESRD found that the scope and depth of information available on these sites was limited at best, and that there was virtually no information about lifestyle changes or coping on these websites (Lutz et al., 2014). Furthermore, most sites scored poorly on readability and did not offer sources for the information they reported, making it difficult for users to evaluate the quality and credibility of the information they provide. The narrow scope of health information available on static sites is not limited to CKD; a similar review on sites for cancer reported similar findings (Warren, Footman, Tinelli, McKee, & Knai, 2014). This may be because in general, health information is scattered over the Web, with most health-related websites offering multiple general facts with little detail attached to those facts (Bhavnani & Peck, 2010).

Unfortunately, this author is not aware of any research that investigates whether and how kidney patients actually consult static websites for health information. However, over 23% of hemodialysis patients in the United States use the Internet to find health information; those who do not use the Internet are mostly interested in doing so, but they often don't have access to a computer (Schatell, Wise, Klicko, & Becker, 2006). About one third of the 1,768 dialysis patients in this study asked a proxy to conduct Internet searches related to health for them. A similar study conducted in Canada found that 58% of dialysis patients they surveyed had searched for health information online (Seto et al., 2007). Unfortunately, none of these studies discuss the types of sites these patients consult for health information; this would be a valuable addition to the literature. Further research is necessary to determine what sites patients diagnosed with CKD find useful when they search for health information online.

2.4.2.4.2 Online support groups. In recent years, people are increasingly turning to the Internet to find other patients with their disease (Fox, 2011c). These individuals are not just looking for health information, but are also seeking social support from patients with similar diagnoses in order to make sense of their condition, learn about the psychosocial effects of their disease, and understand the impact of treatment options on their quality of life in order to aid decision-making (Ferguson & Kelly, 1999). Participating in patient support groups online makes patients feel more informed about their disease and enhances their sense of well-being, according to a survey of patients with life-threatening, unexplained, or chronic disabling conditions (van Uden-Kraan et al., 2009).

There is little empirical work on kidney patients' employment of online social support groups. The work that exists is mostly intervention-focused (Bers, Gonzalez-Heydrich, & Demaso, 2003; Cantrell, Fischer, Bouzaher, & Bers, 2010; Trisolini et al., 2004; Zheng et al., 2010). Many of these interventions offer multiple components: a social support forum and static educational resources written by healthcare providers. In Trisolini et al.'s (2004) study, patients were eager to use the provided website for information seeking; however, participants chose to participate in the study and were therefore likely to be more interested in using the Internet for health information seeking than non-participants. Bers et al. (2003) found similar results with a population of children on dialysis, although many potential participants declined to take part in the study due to fatigue.

2.4.3 Information use. After individuals have identified an information need or needs and searched for information to fill the need(s), they use the information. However, this process is not always linear. Individuals may return to seeking during or after the use process, and using information might create new information needs. Although there are many ways that individuals may use health information, such as to aid in decision-making or to reduce uncertainty, this section of the review focuses on disclosure and information sharing as types of information use.

Once patients have located information about their condition, they may want to share it with a variety of other people. This is distinct from sharing information about one's health status (i.e., one's diagnosis or the way they currently feel), which will be covered below. In many cases, both types of information are shared during one exchange, which can make them difficult to distinguish. However, the goal of sharing information that is not about one's health status is to provide information that may not be known by the receiver and that may help them. In this way, information sharing is closely related to informational support (Schaefer et al., 1981)., which was discussed previously in this review. Such sharing can take place either offline or online.

In face-to-face information sharing encounters, patients are sharing information that they have gleaned from one of the channels outlined above. They may share with a variety of parties, including healthcare providers, family and friends, and other patients. When people share with providers, they are often doing so in order to improve their own care (e.g., Diaz et al., 2002; Fox, 2011b; Morahan-Martin, 2004). Patients also share with other patients who have their condition in face-to-face encounters. This typically takes place in waiting rooms or in clinics where multiple patients are receiving treatment at the same time (e.g., Pettigrew, 1999; The, Hak, Koeter, & van der Wal, 2000). Veinot et al. (2010) note that patients diagnosed with ESRD share health information (such as how to cope with dietary restrictions) with one another in dialysis clinics, although the machines were spaced widely apart and many patients napped during their treatment.

Patients also share health information with friends, family, and other patients online. This occurs on general social networking sites like Twitter and Facebook (Hawn, 2009); in general-purpose online groups for health like PatientsLikeMe (Wicks et al., 2010); and in online support groups (OSGs) geared toward their specific disease. However, it is relevant to note here that, although online information sharing among CKD and ESRD patients has not been thoroughly investigated, Godbold's (2010a, 2010b, 2012, 2013a, 2013b) work in this area indicates that information sharing among dialysis patients in OSGs helps participants create and negotiate a shared normality, potentially reducing illness uncertainty through collaborative sense-making. Other work in this area is necessary in order to understand how and why CKD and ESRD patients share information about their illness with other patients, both online and offline.

2.4.3.1 Self-disclosure. While both activities are examples of information use, it is important to distinguish information sharing from information disclosure. Information sharing is a broad term that describes the purposive communication of information to another person or people. Self-disclosure is a more specific type of information sharing; it has been defined as the process of communicating information about the self to another person (Cozby, 1973). This information must be considered personal by the focal individual in order for disclosure to take place. This study is mainly concerned with personal health information disclosure, and examples of more general information sharing will not be discussed as they are out of scope for this review. Self-disclosure concerns information about the focal individual, and it must be purposefully transmitted, often by verbal (Cozby, 1973) or written (Pennebaker, 1997) means. Often, disclosure has a purpose, such as enhancing intimacy, self-expression, relinquishing or gaining control, or relieving a burden (Petronio, 2002; Smyth, Pennebaker, & Arigo, 2009). Although this review focuses on self-disclosure, it is important to note that disclosures need not only involve information about the self: people can disclose information about others, either purposefully or inadvertently. Sometimes, this has an effect on self-disclosure. For example, if the focal individual believes that the person they are disclosing to may already know the information, or that they have a way of finding out the information from another source, this may impact disclosure behavior (Rosenfeld, 2000). However, since this study focuses on patients disclosing their own health, sharing information about others is also out-of-scope and will not be discussed. It is helpful to distinguish between two common understandings of disclosure: some investigators define disclosure as if it is a personality trait (e.g., Jourard, 1959). Others look at disclosure as a state, or a relational and contextual process that may be mediated by a variety of factors. This research is focused on the interpersonal aspects of disclosure: the identity of the individuals in question, motivations to disclose or to keep things private, and interpersonal factors such as liking and reciprocity (Dindia, 2000). This review focuses on the interpersonal aspects of disclosure, as the trait-based research has mostly been inconclusive. Research suggests that disclosure is a state that is mainly influenced by contextual factors, not a long-term trait influenced by personality (c.f. Chelune, 1979; Endler & Kocovski, 2001). An investigation of the dynamic, interactional process of disclosure indicates that there are not trait-like differences in the patterns of disclosure across multiple targets (L. C. Miller, 1990).

2.4.3.2 Models of disclosure. There are many models that attempt to explain disclosure behaviors, including the fever model, which posits that distress causes people to disclose, much like a fever requires medical intervention to be controlled (Stiles, 1987); the cycle of concealment, which suggests that people regulate disclosures by anticipating the response of their target (Vangelisti, Caughlin, & Timmerman, 2001) and conceal when they anticipate a negative response (Afifi & Olson, 2005; Afifi, Olson, & Armstrong, 2005); the disclosure process model (DPM), a goal-based model developed to explain how people with concealable stigmatized health conditions disclose that rests heavily on individual calculations of risks and benefits of disclosure (Chaudoir & Fisher, 2010); and the disclosure decision model (DDM), another risk/benefit model that attempts to explain disclosure of all types of information, not just stigmatized health conditions (Omarzu, 2000).

The disclosure decision-making model (DD-MM) attempts to explain how people decide to disclose a non-visible illness to others (Greene, 2009). It is more comprehensive than the models just mentioned because it does not simply focus on the antecedents of disclosure; instead, it attempts to unite some of the antecedents of disclosure with the effects of disclosure, explaining how the goals and motivations of the focal individual interact with perceived risks and benefits. Until the DD-MM was introduced, much of the theoretical work on disclosure focused either on the antecedents of disclosure, as in the fever model, or on the perceived effects of disclosure, like the cycle of concealment, the DPM, and the DDM. In the DD-MM model, the focal individual assesses five components of their diagnosis when deciding to disclose: its stigma, their prognosis, their symptoms, how prepared they were for the diagnosis or the information, and the relevance of the illness to themselves and others. These five components create a more complex picture of one's health status than previous research on diagnosis disclosure, which tends to focus on stigma alone (Greene et al., 2012). Individuals making disclosure decisions also take three factors about their potential target into account: their relationship quality, the anticipated reaction, and how confident they are in getting their desired response. Finally, the focal individual assesses efficacy – how easy or difficult they feel it will be to disclose the information in question. Disclosure efficacy has not been well-researched, but its inclusion in the model opens an avenue for future work in this area. It is possible that efficacy can be strengthened by practicing disclosures in "safe" locations, such as in a diary (e.g., Pennebaker, 1997) or online (Greene & Magsamen-Conrad, 2010). The DD-MM is linear; that is, individuals first assess the information they might disclose, then they assess relationship factors, and finally they assess their own efficacy in disclosing. However, because disclosure is a complex, multi-faceted, and dialectic process, this model may be overly simplistic in its linearity. Further work that investigates subsequent disclosures may reveal that the linear model is imperfect for describing disclosures, particularly after the initial disclosure of diagnosis has been made.

Research on health and disclosure often concentrates on the topic of diagnosis disclosure: when and how people decide to tell others that they have been diagnosed with a particular condition. One's health status affects others, whether the illness is life-threatening, transmissible, or a chronic-disabling condition. Disclosure of diagnosis is often necessary because it may impede one's ability to work (Frndak et al., 2015; Gignac & Cao, 2009; Stewart et al., 2001), it may be transmitted to others (Derlega, Winstead, Greene, Serovich, & Elwood, 2004; Skinta, Brandrett, Schenk, Wells, & Dilley, 2014), or it may require caregiving (Checton & Greene, 2014; Parrott, Duncan, & Duggan, 2000). Once diagnosis has been disclosed, however, there are further disclosures that may take place related to the condition. In some cases, such as with HIV/AIDS serostatus disclosure, other disclosures related to health may become inevitable or necessary – for example, the disclosure of sexual orientation or intravenous drug use (Greene, Derlega, Yep, & Petronio, 2003). These related disclosures may prohibit people from making the initial diagnosis disclosure, which will be discussed below in the section on risks and benefits of disclosure. Subsequent disclosures about one's prognosis, symptoms, or recovery may also be related to uncertainty about those topics. Preliminary work indicates that uncertainty about both diagnosis and prognosis in patients with chronic disabling heart conditions plays a large factor in subsequent disclosures (Checton & Greene, 2012, 2014); more research is necessary to test these findings and to extend them to other disease types.

2.4.3.3 Social support. Often, research on disclosure after diagnosis links these further instances of disclosure to social support (Checton & Greene, 2014; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). People may ask how the focal individual is coping with the illness or offer help or assistance, which spurs additional disclosures related to their health. These further disclosures are not a focus of the literature on health, social support, and disclosure, which is an avenue for future work in determining how disclosure and health are related over time. This work may also be closely related to research on illness trajectories. Social support is often presented as a benefit to health disclosure (Frattaroli, 2006). Most of the work on health disclosure and support, however, indicates that the relationship is not always positive. Instead, it is complicated and relies on many factors, particularly the specifics of the disease being disclosed and the relationship between the discloser and target. To date, health disclosure and its link to social support has mostly been studied in the HIV/AIDS population. Because of the particulars of HIV – namely, because it is a transmissible and stigmatized disease – these findings may not be generalizable to other health conditions. More work that extends our understanding of disclosure and social support in health conditions that are not transmissible and/or stigmatized, such as heart disease, diabetes, and CKD, is necessary.

As explained in the previous section of this review, social support is either perceived or enacted. Perceived support is the preferred term in the literature, although it may be better characterized as "expected" support. Perceived social support is fostered by the number and strength of social ties in one's network – how much support focal individuals feel they have if they should need it – while enacted social support is the actual support received in a particular situation. Perceived social support has an effect on how well people are able to cope in a health crisis, and individuals do not actually have to draw on the support that they believe is available in order for it to have a positive effect (Gottlieb & Bergen, 2010). Because of this, people may make the decision not to disclose if they anticipate that the disclosure will have a negative effect on their relationships (Kalichman et al., 2003). Instead, they can draw upon the perceived social support that they believe they will receive if they maintain the status quo. In these cases, disclosure may actually hamper the benefits of social support.

Disclosure is often not perceived as having been beneficial in instances where the target is not supportive. For example, women who disclose that they have had an abortion to unsupportive targets experience poorer adjustment than women who disclose to supportive targets and than women who do not disclose at all (Major et al., 1990). This suggests that disclosure can be beneficial when the target is supportive, but does not indicate that disclosure fosters social support. Therefore, disclosure may have positive effects for the focal individual in instances where support is received after disclosure (Chaudoir & Fisher, 2010), but disclosure may not in itself promote support. It is important to note, however, that disclosure is an essential component of enacted support – without disclosure, the options for enacted social support in response to health concerns are limited or nonexistent. People must know that support is needed in order to provide it, and this knowledge hinges on some form of disclosure. More research is necessary in order to understand the link between disclosure and social support, particularly in situations where there are few perceived risks of disclosure. Disclosure is often linked with other concepts related to social support: reciprocity, liking, and relational ties.

Jourard was the first researcher to discuss reciprocity of self-disclosure; he called reciprocity "'the dyadic effect' [and said] disclosure begets disclosure" (1971, p. 66). There are several possible reasons for this effect, including the social obligation to disclose, which is in line with social exchange theory (Derlega & Chaikin, 1977; L. C. Miller & Read, 1987); conversational norms (Greene et al., 2003); modeling, or the process of matching intimacy levels; trust, which often operates simultaneously with modeling (Rubin, 1975); and attraction and liking, which will be discussed below. Results of a meta-analysis of studies on face-to-face disclosure reciprocity indicate that self-disclosure is generally reciprocal for intimates and strangers, but it does not operate immediately on a turn-for-turn basis (Dindia, 2000). Instead, reciprocity occurs over time in conversations and in relationships. Findings from other studies support this; for example, Berg and Archer (1980) note that self-disclosures are often met with expressions of concern, which may actually foster liking of the target. Reciprocity has also been studied online with similar results (Barak & Gluck-Ofri, 2007; Joinson, 2001).

There are three relationships between disclosure and liking: disclosure fosters liking, or people who disclose more tend to be more liked than people who disclose less; liking fosters disclosure, that is, people disclose more to people that they like; and finally, disclosing to someone causes the focal individual to like the target more (Collins & Miller, 1994). Although liking research has often focused on dyads, some work indicates that the relationship between disclosure and liking is a complex process that operates not just on the dyadic level, but on a dynamic interactional level (L. C. Miller, 1990). In fact, although the link between liking and disclosure was found to be insignificant at the individual level for dyads in Miller's (1990) study of women in a sorority, it was significant at the group level for all forms of liking discussed above. More work is necessary to determine how disclosure and liking function among groups; this would be particularly relevant to investigations of disclosure at the workplace, a growing area of health and disclosure research (e.g., Demars, Uluer, & Sawicki, 2011; Gignac & Cao, 2009; Greene et al., 2003; Stewart et al., 2001). It is also relevant to disclosure in online forums and other groups, where multiple people are privy to the shared information.

Characteristics of the target are paramount when people decide whether or not to disclose. The existing relationship between the focal individual and the target is one of the most salient of these characteristics. Interestingly, the convoy model of social support (Kahn & Antonucci, 1980) may be applicable to disclosure: most investigators have found that disclosure follows a similar relational pattern to support. That is, people disclose the most to people with whom they are very close – members of the "inner circle" of the convoy – and to people that they do not know well at all, or people in the outer ring.

Much of the health diagnosis disclosure research focuses on how people disclose to family members. Family members are often in the inner circle of one's social support system; they also share a "family privacy boundary that carries explicit expectations for some level of disclosure within the family on matters significant to the family member" (Greene et al., 2003, p. 99). Disclosing illness to people in the inner circle is often considered as inevitable by the focal individual (Greene et al., 2003), particularly when the disease will likely become more visible over time or will begin to interfere with one's daily life, as discussed above. It is difficult to keep one's diagnosis a secret, for example, as CKD progresses into ESRD and dialysis or a transplant becomes necessary. In other cases, disclosure may be for the benefit of the target – for example, an HIV-positive individual may share their status with potential partners in order to protect their HIV-negative status (Park, Bharadwaj, & Blank, 2011).

People also disclose highly personal information to people that they do not know well at all, members of the outer ring of the convoy. The stranger-on-the-train phenomenon (Thibaut & Kelley, 1959) explains that people will often disclose intimate and detailed personal information to strangers on trains. Other liminal spaces, like airplanes, also foster similar disclosures (Rubin, 1975). This may be because there are very few risks to privacy for the focal individual: since the stranger is unknown, and is likely to never be seen again, there is very little potential for negative consequences (D. A. Taylor, 1979). Furthermore, there is very little risk of contact between the stranger and one's social circle, so it would be difficult for the collective privacy boundary to be violated by the stranger (Derlega & Chaikin, 1977). Interestingly, although online spaces are not transient like trains or airplanes, disclosure to strangers online may follow a similar pattern in some cases. For example, research indicates that individuals who are socially anxious and lonely feel that they can share more personal information with strangers online than they can with people they know well offline (McKenna et al., 2002); the authors liken this to the strangers-on-a-train disclosure phenomenon discussed above. However, this research must be replicated and verified, particularly because perceptions about anonymity on the Internet have changed since 2002.

2.4.3.4 Setting of disclosure. The social environment is an important contextual criterion for disclosure (Petronio, 2002). It is defined as changes in one's situation, such as the diagnosis of kidney failure; and times when the individual's symptoms become more obvious, such as when a dialysis patient has a fistula placed. This has been noted in HIV patients, some of whom have reported waiting to disclose until their symptoms become noticeable (Greene et al., 2003). In this way, the disease trajectory acts as a context that influences disclosure. This is also mirrored in the research on diagnosis disclosure, particularly because diagnosis marks the beginning of the CKD and ESRD trajectory (Jablonski, 2004). Environmental factors surrounding disclosure behavior for health have been most studied in the HIV/AIDS community (Greene et al., 2003).

The physical setting of disclosure is also important and is of particular interest in this study. People may choose to disclose information about their health in particular settings for a variety of reasons; for example, some have reported disclosing their HIV-positive serostatus in public places in order to control the reactions of the target (Greene et al., 2003). This section of the review focuses on the Internet as the location of disclosure. Several researchers have found that people disclose more information more rapidly online, and that the depth of these disclosures is greater when compared with face-to-face disclosures. For example, Tidwell and Walther (2002) found that individuals disclosed more information, and at a faster rate, to strangers that they were instructed to "get to know" in emails than they did in face-to-face conversations, suggesting that they were compensating for the lack of physical cues available online. Joinson (2001) found similar results, although this work measured disclosure in surveys, not to other individuals. A recent systematic review of 15 articles comparing offline and online disclosure found that in interactions between two individuals, disclosure was greater online than offline (Nguyen, Bin, & Campbell, 2012). They posit that this occurs because of the paucity of visible social cues online and because the norms of online communication dictate sharing more personal information when compared with the norms of offline communication. Investigators have also found that people disclose information online that they would not disclose offline (Thon & Jucks, 2014), although the research on the content of online disclosures is extremely limited at this time (Attrill & Jalil, 2011). Instead, work in this area focuses on the general characteristics of online disclosure. There are multiple factors that individuals weigh when they disclose information online, including but not limited to how much control they have over their personal information, how much enjoyment they receive from disclosing, how much they trust others in their network, how much they trust the service provider that houses their disclosures (e.g., Facebook), and other perceived risks and benefits of disclosure (Contena, Loscalzo, & Taddei, 2015).

Privacy attitudes often affect the way that people disclose online (Acquisti & Gross, 2006); however, people are surprisingly inconsistent when applying their attitudes about privacy to their actual disclosure behavior. A study using CPM as a framework for understanding privacy attitudes on Facebook, for example, showed that privacy attitudes do not affect disclosure behavior (Stutzman, Capra, & Thompson, 2011). This privacy paradox, as Barnes (2006) calls it, has been identified in many platforms online, including blogs and social networks; it is often studied in adolescents and young adults sharing personal information online (Viégas, 2005; Viseu, Clement, & Aspinall, 2004). Attitudes about privacy online have changed over time: when Facebook was relatively new, people were very open with their disclosures. Over time, people have restricted their online disclosures in social networking sites, although people still disclose a great deal of what might be considered personal information with selected people in their online networks; de facto, they are sharing that same information with advertisers and other third parties (Stutzman, Gross, & Acquisti, 2013).

As Viseu and his colleagues note, “empirical evidence suggests that there is a significant discrepancy between privacy principles and privacy practices [online]” (2004, p. 2). They offer several reasons for this discrepancy, including the ambiguous nature of the concept itself and varying levels of computer literacy and comfort. People also may not feel that the information they share online is attached to their physical identity (Thon & Jucks, 2014), which is known as practical obscurity. They may manage their online identity using tactics like multiple profiles, varying online usernames, and keeping contextual information about themselves separate from the online content that they do not want attached to their physical selves (Hartzog & Stutzman, 2012). Individuals also may not feel that the risks of sharing personal information online are relevant to them: although most people say they are concerned about having their privacy breached online, the overwhelming majority of individuals have never had anything harmful happen to them on the Internet (Fox et al., 2000).

Privacy policies have been shown to affect whether people share personal information in virtual peer-to-peer communities (Cranor, Reagle, & Ackerman, 1999). On Facebook, people who read privacy policies disclose less information, and people who customize privacy settings are likely to disclose more information (Stutzman et al., 2011). This may be because the explicitness of the rules allows for more freedom to disclose (Petronio, 2002, p. 37). The transparency of privacy policies, or how visible they are on the website and how readable they are, has also been shown to affect disclosure (Cranor et al., 1999; Weitzman et al., 2011). Finally, the composition of the network plays a factor in how people disclose online. People tend to disclose more when the environment is emotionally supportive; they are also more likely to share personal information in online support groups for health as opposed to neutral online discussion forums (Barak & Gluck-Ofri, 2007).

2.4.3.5 Disclosure and CKD. The final section of this review discusses disclosure issues among the CKD and ESRD population. Unfortunately, this researcher is not aware of any work that focuses on disclosure among a CKD or ESRD population. However, some of the psychosocial research on CKD and ESRD hints at disclosure issues. This section reviews relevant research on social support and kidney disease, work that examines whether and how people ask family members to donate a kidney, investigations into uncertainty and CKD, and a questionnaire developed to assess adjustment in post-transplant patients that has a section on disclosure issues.

Some of the social support literature focused on CKD briefly mentions disclosure issues. For example, in a study on social support and kidney disease, Ekelund and Andersson (2010) report that one patient said he did not discuss dialysis or his illness with his family, attempting to hide it from his children. Some of the participants in this study, which aimed to understand the psychosocial problems of dialysis patients with and without significant others, commented that the interview process was cathartic and that they appreciated the chance to talk about their illness. A participant in another qualitative study said she felt alone in her social group as she struggled with kidney failure: “I tried to put on a brave face for everyone, but my spirit was sinking. I felt very alone even though I was surrounded by family and friends” (Molzahn et al., 2008). Other participants in this study experienced similar feelings, noting that they often were unable to discuss their need for support with their friends, who, in the focal individual’s perspective, were already giving as much support as they could.

Asking family members to be tested as potential kidney donors is another area of research where disclosure issues are discussed. This work highlights the fact that focal individuals must disclose their diagnosis in order to ask people to be tested as potential donors. One such study indicated that African Americans with ESRD may be less likely to ask family members and friends if they will consider donating a kidney when compared with non-African Americans (Lunsford et al., 2006). This study found that denial of the severity of one's illness and behavioral disengagement – giving up the effort of dealing with the illness – are common coping strategies used by African Americans with ESRD. These factors directly impact disclosure behaviors. In another interview study with twelve living kidney donors, researchers found that the donors were asked to be tested from a variety of people, most often the ill individual or their spouse, and that this discussion usually took place over the phone (Fellner & Marshall, 1968). Another study of living donors found that donors are often not approached; instead, they offer to be tested after the diagnosis disclosure is made to them (Franklin & Crombie, 2003). Finally, preliminary work by this researcher that investigates whether and how people ask for altruistic kidney donations on the Internet suggests that people may use mediated communication methods in order to bypass the difficulty of disclosing the need for a kidney face-to-face (Costello, 2012; Costello & Murillo, 2014).

Finally, a questionnaire that assesses psychosocial factors related to post-transplant adjustment includes a section on disclosure to others (Ziegelmann et al., 2002). This questionnaire has been used in many transplant populations, including kidney transplant recipients (Calia et al., 2011; Goetzmann et al., 2008 Griva et al., 2002; Scholz et al., 2012; Ziegelmann et al., 2002). Many of these studies focus on only one or two elements of the post-transplant experience, so data on disclosure is limited. However, the results from a few studies suggest that, post-transplant, disclosure is not particularly concerning to most patients. For example, Goetzmann et al. (2008) found that kidney transplant recipients had very little difficulty disclosing their status to others. Griva et al. (2002) found that patients with more comorbid conditions were more comfortable disclosing their transplant status to others, suggesting that people who have greater physical impairment may have less choice about disclosure. Additionally, patients who had strong feelings of guilt associated with their transplant or worry about their transplant were less likely to disclose. In a follow-up study six years later, a subgroup of patients with kidney transplants that still functioned were re-surveyed to see if their attitudes toward disclosure had changed (Griva et al., 2011). The researchers found that increasing age was associated with more disclosure and less worry about the transplant, perhaps because more time had passed since they had the transplant.

2.4.4 Information behavior conclusion. There are three major activities in information behavior: experiencing needs, seeking information, and using information. Information needs arise from the uncertainty or gap discussed in some of the theoretical frameworks. For CKD and ESRD patients, several common information needs have been identified, including but not limited to questions about symptoms, disease progression, the impact of the disease on one's daily life, the meaning of test results, the impact of the disease on one's financial future and career/work opportunities, and how to cope with the disease and its symptoms. These needs are often filled by information seeking, and can be met by multiple information channels.

2.5 Conclusion

This review provided an overview of CKD, social support in chronic illness with a focus on CKD, and information behaviors in health including information seeking and personal health information disclosure. It began with a brief discussion of CKD and the common causes, treatments, and symptoms of the disease. A discussion of the psychosocial effects of CKD, including uncertainty, social isolation, and self-management of the illness was presented. Next, the role of social support in chronic illness was discussed. Social support generally has a positive effect on one's health and well-being; it is often defined as the provision of information, emotional help, or tangible goods or services. There are many places that CKD and ESRD patients may get social support, including healthcare providers, family, friends, and other patients. They may meet other patients in face-to-face or OSGs; exploratory evidence suggests that CKD and ESRD patients experience positive benefits from participating in OSGs. In general, social support has been shown to have a positive effect on the health and well-being of CKD and ESRD patients, although more research on the benefits and drawbacks of OSGs for this patient group is necessary.

Next, an overview of health information behaviors was provided, including information seeking and information use. CKD and ESRD patients have many different information needs: they want to know about symptoms, the progression of the disease, and the impact that CKD will have on their daily life. They are also interested in learning how to cope with CKD and ESRD. They search for information about these and other health-related topics using a variety of information channels, including their healthcare providers, other patients, and the Internet. They use the information they get from these channels in order to make decisions about their treatment, to reduce the uncertainty about their disease, or to help them manage CKD and ESRD more effectively. They may also share this information with their providers or with other patients, although there is currently a paucity of research in this area.

Finally, the review concluded with a discussion of information use with a focus on personal health information disclosure. Most of the research in this area is focused on the disclosure of life-threatening severe illnesses, such as HIV, to other people, usually family members or friends. There is a growing body of literature that investigates online disclosure of personal health information, but it is quite small at this time. There is also a small body of work that mentions disclosure of CKD and ESRD, particularly as it relates to finding a kidney donor; however, there is no known research that focuses specifically on the topic of disclosing one's CKD or ESRD status to others. This is an open question that will be addressed by this study.

CHAPTER 3: METHODS

Although several models and theories were covered the previous literature review that may be applicable to the phenomenon of interest – the relationship between information seeking and personal health information disclosure in online support groups by patients diagnosed with chronic kidney disease – they are insufficient to explain this particular phenomenon. Therefore, grounded theory emerges as a potential avenue for developing a theory that addresses the phenomenon of public disclosure of personal health information to a very large – and potentially infinitely large – audience. Grounded theory is ideally suited for questions about processes and behaviors in situations where no theory exists, or the models and theories at present “do not address potentially valuable variables of interest” (Creswell, 2007, p. 66). As was noted in the previous section, there are many open questions to explore in the arena of health information behavior online. The purpose of this study is to develop a framework of information behaviors in online support groups for chronic kidney disease in order to better understand how and why CKD patients search for health information online, what information they are looking for, what information they are sharing with others, what motivates some of them to share their personal health information on the open web, and what influence these activities have on health outcomes.

3.1 Introduction to Grounded Theory

Grounded theory offers “a set of general principles, guidelines, strategies, and heuristic devices rather than formulaic prescriptions” (Charmaz, 2014, p. 3). In grounded theory, the data drives the researcher to ask analytic questions about the causes, interactions, and consequences of the phenomenon under examination. Through qualitative coding and constant comparison of data and analysis, a theory emerges as a product of interaction between the researcher and the data. Theory is not discovered in the data; instead, it is an outcome of the "dialogue" (Dey, 1999, p. 6) between the researcher and the data. In this study, data comes from two main sources: interviews with patients who use OSGs for CKD, and the posts they have made to OSGs.

3.2 Sensitizing Concepts

Before embarking on this study, I conducted thorough reviews of the literature on topics related to the phenomenon of interest. These topics are presented in the preceding chapter and include CKD; social support in chronic illness; and health information behaviors, including information seeking and personal health information disclosure. While many grounded theorists recommend that researchers refrain from conducting literature reviews prior to embarking on a study (e.g., Suddaby, 2006), the constructivist approach takes the position that it is not possible to actually ignore one's prior knowledge and experiences. Therefore, conducting a preliminary literature review is recommended because it helps provide a rationale for the study, contextualizes the work, and aids the researcher in identifying sensitizing concepts and preconceptions (Dunne, 2011).

Sensitizing concepts provide a jumping off point for shaping initial data collection methods and analysis: "We may begin our studies from these vantage points but need to remain as open as possible to whatever we see and sense in the early stages of the research" (Charmaz, 2006, p. 17). The researcher must be aware of these sensitizing concepts throughout the collection and analysis of data: if she finds evidence that backs up her preconceptions in her data, she must be careful to recognize whether she is importing concepts or whether the evidence truly exists in the data (H. S. Wilson & Hutchinson, 1996).

Several sensitizing concepts were identified in this study and are covered in the literature review in the second chapter, including but not limited to: psychosocial support, privacy, disclosure, stress reduction, identity management, coping with chronic illness, patient empowerment, decision-making, uncertainty reduction, and information-seeking behaviors (e.g., monitoring, information transfer, sense-making, etc.). As I was analyzing the data, I noted in memos when codes emerged that called these sensitizing concepts to mind. This process allowed me to differentiate between what was happening in the data and what I might be importing into my analysis from my previous understanding of the phenomenon. This is because grounded theory is inductive, not deductive – being mindful of sensitizing concepts allowed me to be sure that the analysis was not imposed onto my data, but was a result of things occurring organically within the data itself.

3.3 Research Design

This section describes the research methods used in the study. Again, although all of these processes occur iteratively and nearly simultaneously throughout the research process (for example, there were times when I was transcribing an interview and was compelled to stop in order to work on a memo), this section describes the processes separately for the sake of clarity. There have been two major phases of the study: the initial data collection phase, and theoretical sampling.

First, I discuss how I recruited participants for the initial sample in OSGs for CKD. Next, I discuss how I gathered data from two main sources: semi-structured interviews with each participant, and collection of the comments they made in OSGs. Then, I discuss how I used qualitative analysis to inductively develop codes, categories, and constructs from my data. At this stage in the research, I began theoretical sampling, which is the process of selecting data sources based on the ongoing analysis. I discuss my two theoretical sampling strategies: changing my recruitment techniques, and altering the questions that I asked participants in their interviews. Finally, the section concludes with a description of the activities I underwent to ensure the trustworthiness of the analysis.

3.3.1 Data collection. Because the methods in a grounded theory study occur concurrently – I was recruiting participants, conducting interviews, harvesting data from OSGs, analyzing data using constant comparison, and planning and carrying out theoretical sampling in tandem throughout the research process – it is difficult to describe the process in a linear fashion. However, with each participant I followed a general progression of data collection: first, I recruited individual participants. I then conducted their initial interview, which focused on information seeking online, specifically in OSGs. Then, I harvested all of the comments they posted to the OSG where they were recruited. Several weeks or months later, I conducted the second interview with the participant, which focused on online disclosure of personal health information. I also harvested additional comments they made online after our second interview. Throughout this process, I also analyzed the data as described below.

There are two main sources of data in this study: semi-structured interviews and forum posts made to one of four OSGs for CKD. In grounded theory, an initial sample of data is necessary in order to focus data sampling efforts throughout the study using theoretical sampling strategies, described in more detail below. Intensive interviews are a common data source for grounded theory (Charmaz, 2014). Because I was investigating information seeking and information disclosure in OSGs, I decided to recruit people with CKD who used at least one OSG for kidney disease to participate in the study. I also asked for their permission to harvest and analyze some or all of the comments they had made on the OSG they frequented most often.[4] Using two sources of data strengthens the resulting analysis, as it allows for triangulation both of the sources and of the methods used to obtain data (Lincoln & Guba, 1985, p. 306).

3.3.2 Recruitment of initial sample. To select OSGs for initial recruitment efforts, I conducted a Google search on February 25, 2013 using the search strategy outlined by Weitzman et al. (2011) in their study of diabetes social networking sites. The terms “kidney disease,” “dialysis,” and “kidney transplant” were separately paired with four network terms (“social networking,” “community,” “virtual community,” and “forum”). Ten sites were identified and three were selected for the initial recruitment phase: I Hate Dialysis (IHD), the DaVita forums, and the Home Dialysis Central forums (HDC). These sites were chosen because they were focused solely on CKD, rather than existing as smaller forums embedded in larger pan-health OSGs (e.g., WebMD or DailyStrength); they also had the largest number of active members out of the ten sites considered. For a thorough review of the ten sites, please see Costello (2015). I created accounts on each of the sites in July 2013. I also contacted the moderators of the sites to let them know that I planned to recruit on their sites. None of the sites had policies that addressed research recruiting, but two of the sites responded to my initial email and gave me explicit permission to recruit.

IHD[5] was founded by a CKD patient, Bill “Epoman” Halcomb, in 2005. This patient-centric community is incredibly active and robust; there are currently over 9,000 members on the site. New comments are posted at a steady pace nearly every day, and the site has multiple volunteer moderators – all CKD patients or caregivers – that help keep it running smoothly. There are no static resources available on this site; all of the information is posted on message

---

[4] Only one participant, Sherri, declined to participate in this portion of the study. She told me that she was very protective of her online identity, and she did not want to risk the chance of deductive disclosure.

[5] IHD is accessible at http://ihatedialysis.com/forum.

boards. In contrast, the DaVita forums[6] are embedded in the larger DaVita site, which also provides informational resources for people on dialysis. DaVita is one of the largest dialysis providers in the United States. Their forums are much smaller than the IHD forums, and are staffed by one or more rotating moderators that do not engage in much active policing of content on the site. Their forums have much less of a community "vibe" when compared with the IHD forums, which multiple participants noted. The DaVita forum has over 6,000 active members, and new content is posted sporadically throughout the day. Finally, healthcare professionals moderate the HDC forums: a nephrologist, a CKD social worker, a peritoneal dialysis nurse, a renal dietician, and a cannulation expert. However, this OSG is much less active than IHD or the DaVita site; there are less than 750 members on the site, and very few of them are active. New comments are posted weekly, rather than daily.

Initial recruitment began in early July 2013 on the Home Dialysis Central forums and the I Hate Dialysis forums (July 8, 2013 and July 10, 2013; respectively). Another recruitment message was posted on the DaVita forums on August 30 2013.[7] The text of the initial recruitment message is available in Appendix A. Participants were required to be patients diagnosed with CKD, at any stage of CKD, and to speak English. I also specifically asked for participants that were undergoing a self-defined transition in their health, such as a recent diagnosis or dialysis modality choice. This was done because people with CKD experience uncertainty throughout their illness, particularly during times of transition (Pelletier-Hibbert & Sohi, 2001). Uncertainty is closely linked with information behaviors like the recognition of new information needs, information seeking and avoidance, information use, sharing, and disclosure

---

[6] The Davita forums are accessible at http://forums.davita.com/forum.php.

[7] I refrained from posting on the DaVita forums as I was waiting for a response from them regarding recruiting on their forums. This reply was never received, and was deemed unnecessary by UNC's IRB. Additionally, I opted to offer participants a slightly larger token of appreciation in July, and increased the amount from $25 to $75.

(Case, 2012; Petronio, 2002). Therefore, I believed that participants undergoing a transition in their health would be better equipped to discuss the phenomena in question.

After responding to the recruitment message, potential participants were sent a questionnaire via email about their experience with CKD in order to determine their eligibility for the study (see Appendix B). Only two potential participants did not meet the eligibility requirements; both were caregivers for a patient with CKD. Caregivers were not included in this study because of the focus on personal health information disclosure. I sent all eligible participants a fact sheet (see Appendix C) and scheduled a time for their first interview after receiving their responses to the questionnaire. I had six participants in my initial sample.

3.3.3 Interviews. Interviews were conducted over the telephone using Skype and were recorded using Pamela, a Skype plug-in. I notified participants that each interview would take approximately 60 – 90 minutes; on average, each interview lasted 105 minutes. Twenty-two interviews were conducted with twelve participants between the ages of 25 and 70; most are between the ages of 50 and 59. For information about each participant, please refer to **Error! Reference source not found.**.

The interviews resulted in 42 hours of audio; I transcribed them as soon as possible after the interview was completed (often on the same day). At the time of transcription, a pseudonym was randomly assigned to each participant using random-name-generator.info; I also de-identified other contextual information while transcribing.

Two semi-structured interviews were conducted with each participant. Semi-structured interviews allow for unexpected developments and digressions to take place throughout the discussion. In constructivist research, interviews are essentially conversations about the topic at

Table 3

Participant information, listed by date of first interview.

Pseudonym	Current treatment	No. years on OSG	Posting amount (approximate)
Joan	Transplant (deceased donor)	8	8,500
Nina	Transplant (living donor)	4	200
Brent	Home hemodialysis	3	300
Amy	Fistula placed for in-center dialysis	4.5	Lurker (0)
Steve	Fistula placed for in-center dialysis	5.5	4,500
Travis	In-center dialysis	3.5	80
Gretchen	Peritoneal dialysis	4	1,000 (now a lurker)
Sherri	Recently diagnosed	1	N/A
Candice	Recently diagnosed	<1	5
Jacob	In-center dialysis	4.5	300
Laura	Peritoneal dialysis (began between interviews)	<1	10
Robert	In-center dialysis	4.5	930

hand (Charmaz, 2014). The first interview focused on health information seeking online, although participants also discussed information seeking behavior offline. The second interview focused on disclosure of personal health information online; again, participants also contrasted their online experiences with face-to-face disclosure. Appendix D contains the interview guides for both interviews. I allowed participants to be in any setting of their choice for the interview; at least one participant spoke with me while dialyzing. On average, the second interview took place 10 weeks after the first interview. This allowed for analysis of both the first interview and OSG content to be completed before the second interview took place. The shortest amount of time between interviews was 15 days; the longest amount of time was 120 days.

3.3.4 Harvesting posts. With permission, publically available threads on the OSGs containing one or more comments made by 11 of the 12 participants were harvested from the OSGs. I asked participants who used two or more OSGs to identify the one they visited the most often and only scraped threads from that OSG. The OSGs in question are large discussion boards that contain multiple sub-forums separated by content. Please see Appendix E for a list of sub-forums from the three OSGs where participants in this study were recruited.

In these sub-forums, individuals start threads about a specific topic or question. The threads are arranged chronologically on the sub-forums, with threads containing the most recent comments at the top of the page. Some sub-forums have "stickied" threads that are always visible at the top of the page; these often describe the rules or conventions of the sub-forum. People make comments in threads about the thread topic. Sub-forums are moderated by one or more volunteers or paid staff, depending on the OSG.

Initially, I planned to harvest and analyze all of the content from all participants, but this quickly proved to be problematic for several participants who were incredibly prolific on the sites. The amount of comments over their active participation on the forums varied considerably, from 0 to over 8,000. The number of comments followed an exponential distribution. I harvested all of the comments that participants made from the OSG where they were recruited. To ensure that the prolific commenters were not dominating the dataset, I decided to analyze all of the content from participants with fewer than 250 comments on their chosen OSG and purposefully select threads containing comments from the four participants with over 250 comments to analyze. The number 250 was chosen because it was the median number of comments made by the six participants in the initial sample. For participants with over 250 comments, I analyzed the threads that they had initiated and also took a sample of up to 250 comments from threads that they had commented in from their most-visited sub-forums. I also paid particular attention to threads in sub-forums that were not well-represented by the threads they had initiated, such as comments made in introduction threads on the OSG. Essentially, this sample of threads was done purposefully; I skimmed all of the content and chose threads to analyze that I believed would inform my analysis, rather than aiming for a representative sample of their comments. This initial skim allowed me to develop an understanding of each participant and the type of comments they generally made on the forums, which made purposeful sampling easier. For example, Joan, who is highly prolific, tends to post what she calls "diary entries" on the forums: accounts of her feelings and thoughts each day as she grapples with CKD. I only harvested a few of these types of posts from Joan, after I skimmed them all and was able to get a sense of that theme in her comment history.

To harvest comments, I examined the publicly available profiles for each participant, and manually generated a list of links to on-topic threads containing comments by participants.[8] Using import.io, I created APIs for each of the OSGs and built data extractors for the pages I wanted to harvest. I then ran the crawler to harvest the pages and convert them to .csv files,

---

[8] Some of the OSGs provide one or more "off-topic" discussion boards where members discuss issues that are not focused on health, such as politics or travel plans. Although these boards aided the creation of a sense of community on the OSGs, an initial examination of the posts revealed that they were largely out-of-scope for this project. Furthermore, only two participants commented in them regularly, and both participants were highly prolific in the health-related areas of the OSG.

which I analyzed qualitatively using NVivo 10. Profiles were examined on a monthly basis, and any new posts made by participants with fewer than 250 posts were harvested at that time. I also purposefully harvested posts from prolific participants at this time as necessary – specifically, I looked to see if any of their new content would shed light on the extant data analysis, and only harvested those threads. The final dataset of forum posts contains 1,847 comments from participants from 1,695 unique threads. The majority of participants contributed more than 250 comments total to their OSGs; therefore, most participants have 250 comments in the dataset. I also harvested a list of all of the comments made by every participant in order to analyze their participation quantitatively over time and used R, a statistical analysis software, to create bar and density graphs of participation by sub-forum for each participant over their tenure on the forums.

3.4 Data Analysis

Data were analyzed qualitatively using grounded theory methods (Charmaz, 2014). In grounded theory, data analysis is not linear; it's iterative and constantly evolves as it progresses. There are four distinguishing characteristics of data analysis in grounded theory: inductive analysis, the constant comparative method, memoing, and theoretical sampling.

3.4.1 Inductive analysis. I began by inductively coding the data line-by-line, actively describing the data in the interviews and on the forums. I did not impose an existing theoretical framework on my data; instead, I asked questions of the data like, "What does this data suggest?" I then created simple, precise codes that described the data, often by using the same words or phrases that were present in my data. For example, the concept of *future forecasting* came from a group of codes throughout my data that described how individuals verified information about CKD; Joan compared the process of learning about her future with CKD to reading a weather forecast when she discussed this activity, and I adopted it when I was grouping the codes about the process into thematic categories as a way to describe the entire category. When multiple codes seemed to describe similar or related concepts, I grouped these codes together into categories. This process was aided by memoing, described below. I also wrote codes on index cards and sorted those cards throughout the process in order to identify categories and eventually constructs, which are groups of related categories; this process was also described extensively in my memos. These index cards supplemented my ongoing analysis in NVivo 10, allowing me to easily group codes and categories without manipulating the data structure in the software.

3.4.2 Constant comparative method. As new data were collected, new codes were compared to the existing codes and categories, merging the new analysis with the extant analysis. This is known as the constant comparative method. Here, I would ask questions of my data like, "What are the consequences under which *future forecasting* occurs?" I would then comb through all of my existing data as well as any new data I had collected with this question in mind in order to further flesh out my understanding of the phenomenon. Sometimes, I would be left with more questions than answers; at this point, I knew that I needed to theoretically sample new data in order to better explain the processes occurring in my existing data. I will discuss this in more detail below. Here, I compared data to data, codes to data, codes to codes, codes to categories, and categories to categories. This process resulted in rich constructs containing multiple categories of related codes.

3.4.3 Memoing. Throughout the analysis process, I also wrote memos to track the development of the codes, categories, and constructs over time. I wrote three main types of memos: process memos, persona memos, and analytic memos. Process memos track the research process itself, noting themes to follow and ideas to consider in theoretical sampling. An excerpt from a process memo is available in Appendix F. Persona memos are descriptions of each participant, their health issues, and other things they discussed with me in relation to their experience with CKD. I created these memos for each participant. These memos are not included in the final research product as they may contain enough personal data to be identifiable by readers. An excerpt from a persona memo is available in Appendix G. These memos help to contextualize the data, aiding in answering some of the analytic questions I had about the conditions under which specific behaviors occurred. Finally, the bulk of my memos are analytic memos. In analytic memos, I had multiple objectives. My early analytic memos often focused mainly on the questions I had about what was happening in my data. These memos were often focused on the data and on the codes originating from that data. I frequently flagged things that I wanted to explore further (e.g., "I should ask Brent about this in his second interview" appears in one of my early analytic memos about the difference between curiosity and a gap in knowledge). As I continued to gather data, constantly comparing it to the extant analysis, I also continued writing memos. These later memos were focused more on creating categories of codes, and became increasingly analytic as I aimed to integrate the categories in my data by explicating the relationships between them in these memos. To do this, I asked questions of my data; specifically, I tried to understand under what conditions specific categories of interest occurred (e.g., "Under what conditions do participants attempt to forecast their futures?") and tried to understand the who, what, where, why, when, and how of each category. An example of the start of an advanced memo is available in Appendix H. As my memos became increasingly analytic, they began to coalesce and eventually were shaped into the Results section of this dissertation.

3.4.4 Theoretical sampling. Theoretical sampling is a strategy that is designed to advance the creation of robust categories and constructs: it is about sampling the data, not about sampling the participants. As Glaser and Strauss explain, "Our [sampling] criteria are those of *theoretical purpose and relevance*—not of structural circumstance" (1967, p. 48). Because of this, my sample is not representative in the traditional sense. I used two main strategies for theoretical sampling, which began in early July 2014, in this study. Recruitment techniques were modified, and the interview guides were edited to probe specific issues that had arisen in the data analysis.

At the recruitment level, I made three significant changes. First, I decided not to recruit only participants experiencing a health transition. The data suggested that a health transition was not necessarily a driving factor in the information behaviors that participants described. For example, as Joan said, "[Events in my CKD are] not so much a transition as a push off the precipice." I was unsure if I wanted to remove this requirement from my recruitment materials. However, I received an email from a potential participant that helped me make the decision. In her initial email to me, Gretchen said: "I don't think I'm in a transitional stage at the moment. I'm comfortably doing dialysis and hoping it will continue that way for some time." Later in the email, she offers: "I have gotten a lot of information from the forum. They are amazingly supportive of each other. And I can ask my nephrologist sensible questions after reading other people's questions."

The data I gathered from my initial sample suggested that health transitions were not as important to participants and their information behaviors as I initially believed. Illness transitions did not always impact on their information behaviors. For example, Steve reported searching for and sharing a wide variety of information, none of which was related to his illness transition. He was considering switching from in-center hemodialysis to peritoneal dialysis when we spoke, but the topic only came up once in our interviews, when I asked him about it directly. Because of these factors, I considered adding Gretchen as a participant even though she was not undergoing a health transition. After speaking with two peers as part of the peer-debriefing process, I decided to open my sampling strategy and speak with Gretchen. The data I received from her further reinforced that the concept of a health transition was not as important in my data as I initially believed.

Another significant change I made when beginning theoretical sampling was that I decided to recruit participants in more locations online. I did this because I was finding results in my data that seemed to be site-specific (e.g., the presence of signatures on comments, which were used more heavily on IHD than on DaVita), but I needed data from more sites to fully understand these results. To address this issue, I posted my recruitment message on Twitter, where most of my 584 followers are related to the kidney disease community (many are nephrologists, researchers, or patients). I also returned to the DaVita forums and posted follow-up recruitment messages on July 14, 2014 and August 7, 2014. I posted a final recruitment message on the IHD forums on January 2, 2015. For the text of the recruitment message used during theoretical sampling, see Appendix I. Six more participants from a variety of OSGs were recruited during the theoretical sampling phase.

Finally, in my revised recruitment message I targeted specific demographic categories: individuals on in-center or peritoneal dialysis, lurkers, people who use Facebook in addition to other OSGs for CKD, and people who had consulted multiple nephrologists. I targeted these groups for different reasons. First, I wanted to speak with more people on in-center dialysis because my data suggested that communicating with other patients face-to-face changed the experience of searching for information online, but I did not have enough data to make robust claims about the phenomenon. I also wanted to speak with more lurkers for a similar reason: the one lurker in my sample to date, Amy, described some interesting information behaviors that I needed to explore with other participants. I also targeted Facebook users because several of the forum posts noted that Facebook was where many people with CKD had migrated to in recent years; additionally, as Joan said, "Facebook… there's a completely different vibe, a completely different kind of interaction that goes on the Facebook page than on the website." I wanted to discuss this phenomenon specifically with new participants. Finally, I wanted to speak with more individuals who had consulted multiple nephrologists, as my data suggested that information behaviors were greatly impacted by continuity of care and by receiving second opinions. Information verification was also a strong theme in my data, and I was curious about exploring verification behavior between nephrologists.

In addition to making changes to my recruitment strategies, I also revised my interview guides to specifically probe at some of the themes in my existing data (see Appendix J). For example, I needed more data about how people sought information in order to imagine their own future, and how this imagining process also affected their disclosure behavior (I called this phenomenon *future forecasting* when coding). To that end, I added the question "Is there any information that you look for that you don't need to use right now, but you think you'll need in the future?" to my interview guide. I also added questions about dealing with misinformation on OSGs, the conditions under which people actively seek other seekers (often at an earlier stage of CKD), and about the timing of information seeking and sharing behaviors as participants moved through the illness trajectory.

3.5 Trustworthiness

In naturalistic inquiries, the researcher does not employ the same type of verification techniques common in positivist investigations – internal validity, external validity, reliability, and generalizability (Shadish, Cook, & Campbell, 2001). Instead, there are four generally accepted criteria for trustworthiness in naturalistic, interpretive studies: credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985). The constant comparative method and theoretical sampling help to bolster trustworthiness of theories generated by grounded theory, because the theory is developed incrementally (Schreiber & Stern, 2001). However, employing additional methods for trustworthiness is advisable, particularly because these methods will likely spur the researcher to question the theory more carefully as it is being generated, resulting in a richer, more robust framework. This section discusses the methods for increasing the trustworthiness of the theory generated by this study.

I have used three methods for increasing trustworthiness: member checking, peer debriefing, and negative case analysis. Member checking has taken place using two techniques: asking clarification questions during interviews, and sending each participant a list of their quotes from the interviews and forums for review. An example of a clarifying question from my interview with Nina is: "So you feel – I want to make sure I understand what you're saying, like the nutrition is a general problem and then specifically for people with CKD there are things that could be done to the American diet that might help kidney patients?" Nina gave me a lengthy answer to this question, starting off by saying: "Oh, absolutely. Absolutely. Absolutely. Yeah. But I think as a – I suppose if you were a doctor it must be very frustrating." Here, I checked my understanding of Nina's statements about diet and nutrition in the moment, during our first interview. I also followed up on this topic during our second discussion to make sure that I understood her thoughts about diet and nutrition as they related to communication with healthcare providers.

I also sent all participants an email containing quotes from their interviews and from their OSG comments that I tentatively planned to use in research products. In many cases, I provided some of my analysis of the quotes as context for the participants as well. I asked them to review these quotes and their surrounding analysis, and to contact me within three weeks if they wanted to clarify any of their statements or if they wanted to request that I not use some or all of the statements in publications. An example of a member checking email is available in Appendix K. When replying to an initial member checking email, Brent said to me: "You have my permission to use the quotes noted. I find that those remarks still ring true many months and many forum postings later." The other participants who replied did not note any issues with their posts or their framing.

To improve the trustworthiness of the data collection and analysis processes, I consulted with multiple peers throughout the research process: my doctoral advisor, and other doctoral students in the program familiar with qualitative research methods. This process is known as peer-debriefing. I met with my PhD advisor, Dr. Wildemuth, bi-weekly throughout the research process and discussed issues related to the data collection and analysis with her during our meetings. I also discussed the research process informally on a regular basis with other doctoral students in the program at UNC-SILS. In addition, I underwent peer debriefing and conducted a data audit of two theoretical categories with two doctoral students at UNC-SILS, Leslie Thomson and John Martin III. I supplied both peers with data from four different participants. These sources were chosen purposefully and randomly. For the purposive sample, I wanted each de-briefer to examine an interview focused on information seeking and another interview focused on disclosure; I also needed to make sure that data collected both before and after theoretical sampling was fairly represented. I then chose the data sources – the participants from whom the specific data was generated – randomly using a random number generator. Leslie examined Joan's first interview, Sherri's second interview, Nina's forum posts, and Gretchen's forum posts. John examined Brent's second interview, Laura's first interview, Travis's forum posts, and Robert's forum posts for data related to the theoretical categories I asked them to audit. Leslie, an information behavior researcher, examined my analysis related to information behaviors in online support groups. John, who has experience studying online disclosure, examined my results related to similarity assessment in online support groups. Both of my peer de-briefers spent approximately six hours looking over the data and my analysis; we then met to discuss their thoughts. I specifically asked them to consider if the analysis was grounded in the data, whether there was support for my methodological choices, and whether the analysis accounted for negative evidence. Their full instructions are available in Appendix L. After conducting their de-briefing, I met with my de-briefers independently for two hours each to discuss the results. Both auditors felt that my analysis was well-grounded in the data; they also agreed with my assessment that I had reached theoretical saturation on the categories they examined.

I also engaged in negative case analysis for each of the major themes identified in the data. In negative case analysis, I aimed to find data that contradicted my findings, mainly by asking the question, "Under what conditions does this category *not* occur?" while reviewing each category. This process was documented thoroughly in my memos and discussed at length with Dr. Wildemuth and my peer de-briefers.

I also attended several conferences while working on my dissertation; these conferences offered me the opportunity to discuss my ongoing work with a larger community of peers. The conferences I attended included two annual meetings of the Association for Information Science and Technology in 2013 and 2014, the 2015 annual meeting of the Association for Library and Information Science Education, and the 2015 DIMACS Workshop on Social and Collaborative

Information Seeking. Feedback from reviewers and other attendees at these conferences helped me shape my findings for a wider audience of information scientists. I also had the opportunity to share some of my ongoing analysis with other grounded theorists at a writing workshop with Dr. Kathy Charmaz in August 2014. This experience greatly informed the way I framed my data analysis in my advanced analytic memos as I shaped the following results and discussion section.

Finally, I assessed theoretical saturation as I engaged in data collection and analysis. Theoretical saturation is essentially a process of determining diminishing returns; that is, when new data either does not add new categories or further illuminate existing categories of interest, theoretical saturation has been reached (Bowen, 2008). Saturation is a direct result of memoing, constant comparison, and theoretical sampling. As my memos in this study became increasingly analytic, I identified gaps in my analysis. I then engaged in constant comparison to see if I had data that could help to fill those gaps. When I did not, theoretical sampling helped me to fill those gaps by targeting specific data sources, selected not for their demographic characteristics but for their potential relevance to the analysis. I considered categories to be theoretically saturated if the themes covered by the categories were discussed in the majority of my participants, and if they were confirmed by member checks and by peer de-briefers. I recruited participants until theoretical saturation was reached in the categories of interest for this study.

CHAPTER 4: RESULTS AND DISCUSSION

This chapter begins by framing chronic kidney disease (CKD) as a context that shapes a variety of information practices, including searching for information, disclosing experiential information about one's personal health, sharing other types of illness-related information, handling questions of credibility and relevance, and verifying information. These activities are often contingent upon or even motivated by other people within the patient's network: healthcare providers, family members, friends, and patient peers. They may also be motivated by situations that occur within the context of CKD; these situations may require immediate attention, like needing to make a treatment choice; they might be recurring or routine, like making dietary choices; or they might be overarching emotional concerns, like coming to terms with the illness. They also may be spurred by a general curiosity and a desire to learn more. It is important to note that the participants in this study all engage with information resources as they come to grips with their new life context – the processes and activities described here may never occur, or may occur very differently, for patients who do not engage with any information about their illness outside of their interactions with healthcare providers.

In this chapter, the role that information plays in aiding my participants with coming to terms with their new life context will be addressed. The diagnosis of CKD and the initiation of renal replacement therapy (RRT) are introduced as situations that motivate information behaviors in the context of CKD. Next, the role that interactions with healthcare providers, family members, and friends play in influencing online information seeking and health information disclosure online will be discussed. Emotional motivations for searching and disclosing information online are also presented. Next, the methods that participants use to locate patient peers while searching for information online are discussed.

The following section of this chapter focuses on what type of information people look for when they visit online support groups; participants describe looking for other patients who are similar to them when they go online. The concept of assessing similarity is explored, and the factors that are used to define and determine similarity are addressed. Finally, one of the outcomes of assessing similarity is presented: future forecasting, which is the process of re-orienting one's life context by anticipating future situations that may occur as one's CKD progresses.

4.1 CKD as Context

Participants discuss the overall project of learning about kidney disease as one that begins with coming to terms with the diagnosis of CKD. Coming to terms with the diagnosis is essentially a project that involves understanding an entirely new context. The diagnosis of a chronic illness has been called a "biographical disruption" wherein the "structures of everyday life and the forms of knowledge which underpin them are disrupted" (Bury, 1982, p. 169). It is a profound shift that requires participants to reorient their understanding of their own lives. This shift is especially salient because most of the participants in this study describe little to no exposure to CKD before their diagnosis. For example, Steve says, "I knew nothing about kidney failure, dialysis. I knew none of my options. I didn't even know that high blood pressure could cause kidney failure at the time. And I've been sitting in a chair three days a week ever since!" Travis agrees: "When it first came up, I knew nothing, and most people don't." This period of knowing "nothing" is marked by feeling "in the dark," a phrase that Brent, Nina, and Jacob all use to describe the period directly after diagnosis. Jacob says:

> All I knew [when I joined the forums] was that I had [end-stage renal disease] and that I'd be starting dialysis soon but I had little idea what that meant in reality. All I knew was that I had to face it. It wasn't going to get better and there was no cure. The path that lay before [me] was dark and bumpy looking.

Interestingly, even participants who did have knowledge of CKD and its treatment when diagnosed – both Nina and Joan had mothers who were on dialysis at the end of their lives – characterize themselves as knowing very little about the illness until they themselves were diagnosed with it. Experience is much different than observation, as we will see later when Jacob tells his story of initiating dialysis.

After the diagnosis of CKD, participants often begin searching for information broadly as a way to understand the illness context. As Candice says, "I needed to figure out what this kidney disease is all about." Sherri describes this process as "cast[ing] the widest possible net." At this stage, participants describe conducting general online searches, looking for terms like "kidney," "renal," and "chronic kidney disease." At this stage, participants search generally for information about CKD as a way to manage their uncertainty about the diagnosis. Nina describes:

> I was just looking for general information about it. And I don't, I think it might be almost like, I couldn't tell you how many times I would do those searches, but I'm not sure even what I was looking for. I guess it's just something, almost like a therapeutic kind of thing, that I do, is you want to know more, you want to know more.

Here, Nina latches on to one of the central activities in understanding context: the desire to know more. This can be understood as a desire to come to terms with the "discontinuous, gap-filled, changeable across time-space" (Dervin, 1997, p. 115) nature of reality which participants attempt to address as they engage with information in the form of seeking, sharing, disclosing, and responding to it emotionally. Although context is not simply a *container* in which phenomena occur (Dervin, 1997), the diagnosis of CKD marks a turning point in the lives of participants, where their life context shifts from living without a chronic illness to living with a chronic illness. This turning point is marked by comments like:

- “In my previous life” (Nina).
- “I knew my life was going to change… this disease is going to run its course. And there’s not a damn thing I can do to change that. It’s inevitable; it’s going to happen” (Brent).
- “If anybody would have told me two years down the line that your biggest struggles would be with your kidneys I would have laughed” (Amy).
- “You have a different outlook on life beforehand” (Travis).
- “Before I got sick” (Candice).
- “When I got out of denial” (Sherri).
- “Everything, all the milestones when you’re 28, they all just kind of start circling you, so when someone throws in an illness to the mix, you start thinking, “How long is this going to take? Do I have to stop my life for this? Can I carry on with this? What is it going to affect? What am I going to have to push back?” (Laura).

Therefore, the diagnosis of CKD can be a catalyst for a change in the definition of a “normal life” for participants: “My life as I knew it before kidney failure is over,” says Steve. Throughout their time on the forums and in our interviews, Steve and others describe this adjustment to what Joan and others call a “new normal.” This phrase is also present in the literature on chronic illness, where it typically describes how people develop a reliable pattern of managing their illness uncertainty (Mishel & Braden, 1988). A biographical disruption shakes the “internal coherence of everyday things” (Savolainen, 1995, p. 263); in this study, it often spurs participants to engage with information as a way to regain mastery or control over their new life context. Joan describes the emotions she felt during this time period:

> I became a member [on the forum] when it became obvious that I was headed toward dialysis. I did a lot of reading and a lot of researching on many different sites. The more I learned about dialysis, the more frightened I became…. There was nothing, NOTHING, that terrified me more than the image of me being on [dialysis]. I had years and years of unrelenting anxiety as my renal function deteriorated. The day I had my fistula created was truly the worst day of my life. There are no words to describe the depths of my terror…. Perhaps if I had had to begin dialysis after all, the terror would have abated. It's true that the fear of the unknown can be monumental. But for whatever reason, my fear of dialysis FAR outweighed any fear I had of transplant. I strove for transplantation because I believed it would be better for my family than if I were on dialysis. A healthy life with a [transplant] meant that I could be more help to my husband and could travel to see my son… than if I were on dialysis. Being on [dialysis] meant that I wouldn't be free…. Most of us have to take into account how our decisions may affect our families. But at no time did anyone lobby me. It was entirely my decision.

This turning point is not a one-time occurrence; the shift in context may recur during other situations, such as when participants move from one treatment option to another. Robert describes:

> I was happy and healthy for the first 8.5 years on hemodialysis before beginning to experience continuous access problems. It was then time to get a transplant evaluation and listed on the cadaver donor list. My wait was 4 years before getting the call. Doesn't sound long in the scheme of things, but because of my access difficulties, my physical, and to a degree psychological, health was going downhill from not getting good dialysis. In other words, I was needing the transplant. But sometimes, we have no control over certain situations and must be ready for another treatment option.

Both Joan and Robert describe dealing with difficult emotions as they came to terms with their diagnosis, made treatment decisions, and waited for those treatments to happen. These emotions are commonly associated with illness uncertainty, which is a common feature of most chronic illnesses (Mishel, 1990). Essentially, uncertainty is “the inability to determine the meaning of illness-related events” (Mishel, 1988, p. 225) and it is a process, a “cognitive perpetual state that ranges from a feeling of just less than surety to vagueness; it changes over time and is accompanied by threatening and/or positive emotions” (Hilton, 1994, p. 18). Uncertainty is also closely linked with information behaviors, both in health and in other contexts; in her seminal paper on the information seeking process, Kuhlthau explains that “uncertainty due to a lack of understanding, a gap in meaning, a limited construct initiates the process of information seeking” (Kuhlthau, 1993, p. 347). Other researchers discuss gaps or discontinuities in meaning (Dervin, 1992), anomalous states of knowledge (Belkin, 1980), a perceived wrongness (R. S. Taylor, 1962), information needs (T. D. Wilson, 1981), and changing situations embedded within contexts (Sonnenwald, 1999) as having both cognitive and affective factors that shape and drive information behaviors.

Participants engage with information as a way to understand their new life context as it shifts from “well” to “sick.” This shift is not necessarily a linear process – participants describe their contexts as shifting and changing through time; this is corroborated by other studies on chronic illness that describe this shifting context as one that is ever-changing, waxing and waning over time (e.g., Charmaz, 1993; Paterson, 2001). Information behaviors may occur over a long span of time, or it may be sudden when the diagnosis is a surprise. It is important to note that the learning process does not appear to have an endpoint with this group of participants: although they describe varying levels of interaction with health information throughout their illness, they also stress that, as Joan says, “the education continues.” This may not be the case for all patients with CKD, and may be an artifact of the sampling methods used in this project – that is, individuals who are not actively engaged with health information would not be inclined to participate in a study about health information behavior. However, participants feel like they are, as Jacob says, “still learning huge amounts, even after five years of dialysis…. As long as I’m going to do this for the next 20 years, I might as well – I’ve got time to learn some more things.” This suggests that participants engage with information not just as a way to learn about illness, but they do so in order to gain mastery over their lives – for the rest of their lives.

Many participants say that they use the Internet routinely as they look for information in their daily lives. Steve describes: "I get home from the hospital, at home I'm thinking, you look things up, like WebMD. You look up a cold. I've got kids, you know? So I started looking up kidney failure." Several participants concur, explaining that the Internet is often their first stop for any information need: "I'm online all the time," says Amy. "As far as being online, I'm always looking up stuff. Looking up different recipes, nutrition in different foods…. I could be sitting watching TV and something will come on and it will spur me to look it up on the Internet to learn more." For many participants, the Internet is part of their information routine: "Yeah," says Travis, "If I'm trying to find information I will definitely go on the Internet. When something new comes up I try to learn as much as I can about it, no matter what it is." Jacob, too, says, "I was on the Internet in 1993. So I have a great deal of experience with it." That participants engage with a variety of familiar sources, including the Internet, as they learn about CKD is related to the notion of habitus, wherein mass media use is embedded into everyday life information behaviors (Savolainen, 1995).

Relatedly, the concept of curiosity is a recurring theme: "I've always been curious and asked questions about why, and how, and all the rest of it. I think I'm just… I'm just a curious person, I suppose," Gretchen says. Joan particularly values curiosity, saying: "I don't think ignorance is a bad thing. What's bad is not wanting to alleviate your ignorance. Intellectual incuriosity is not a good thing. But if you're intellectually curious, you don't like your ignorance, and you seek to alleviate that, you seek to learn more." This is also related to something Steve expresses in one of our conversations: "What's very interesting about these forums is the people that stay on these forums are *very* compliant. These are the 1% that live twenty years. They're not part of the 80% who die within five years." While this statement is likely not factual, it drives home an important fact about many of the participants in this study: they believe that searching for information and being present on the forums is a key component of their health and well-being, and that their innate curiosity is one of the things that makes them better patients. As Brent says, the CKD topics he is interested in and curious about at this point in time are “kind of graduate-level type stuff, [while most patients] are still trying to graduate from high school!” In fact, Steve says:

> My chances for survival are exponentially better because I search. I know that for a *fact*. And because I have become a member of a forum…. I’m sure there’s a lot of patients out there who are very good patients who never turn on the Internet…. But one thing I do know is that the people who participate in these forums are generally the good patients. And it benefits them greatly. They actually care enough about their disease and treatment that they went on the Internet to look something up, and like me they stumbled across a forum of other people going through the same thing. Because my kids, my friends, they don’t understand what I’m going through…. It’s nice to talk to other people who understand what you’re going through, it’s – it is so good for me. Like I said, it might not be for other people, but for me…

Like Brent and Joan, Steve separates himself from patients who do not search for information in this quote. He also talks a bit about one of his motivations for using the forums: finding people who understand what he is going through, which will be discussed in more detail below. The fact that many participants label themselves as curious people suggests that personality may play a role in health information behavior online. Curiosity has also been linked with the need for cognition (Olson, Camp, & Fuller, 1984), and is also related to information styles (Bawden & Robinson, 2011). Although “personality does not determine information-seeking behavior… it creates boundaries and possibilities for the way information seeking is executed” (Heinström, 2005, p. 244), curiosity has been found to be a motivator for broad information seeking behaviors (Heinström, 2003), and is an important and common emotion when people begin to learn about something new (Kuhlthau, 1993).

Not all participants begin searching for information about CKD after they are diagnosed. In fact, initiating information seeking is largely contingent on each individual's likely CKD progression. The amount of time that people have to come to terms with their diagnosis varies based on the etiology of their CKD and on the amount of time they have before RRT in the form of dialysis or a transplant is necessary. For example, Jacob and Robert both had untreated strep throat infection when they were young children; this beset them with lifelong kidney issues eventually culminating in end-stage renal disease (ESRD) or Stage V CKD – Jacob initiated dialysis when he was nearly 50, and Robert started dialysis at the age of 22. Similarly, Joan, Laura, and Brent each had about ten years living with their diagnosis before dialysis or a transplant was needed. Nina, Travis, Amy, and Candice were all surprised to receive a diagnosis of CKD for various reasons; they each had less than two years to prepare for the possibility of dialysis or a transplant. In contrast, both Joan and Sherri received a diagnosis of progressive CKD and chose not to focus on that diagnosis – Joan for nearly 10 years, and Sherri for 2 years – before searching for information. As Sherri says:

> I just pushed it to the back of my consciousness, because I had other things going on in my life, and one bright sunny day, the thought crossed my mind, "Oh my god, this is going to KILL YOU! PAY ATTENTION! DO SOMETHING!" You know? And all I did was cry for four days straight, and then I started looking for information. And I went back to my [primary care provider] PCP, and I said, "You know when you wanted to talk to me about (laughs) about my kidneys? (Laughs.) I am ready to listen now!

At the other end of the spectrum, Steve went to the hospital thinking he had pneumonia – he could feel fluid in his lungs and was unable to lie down to sleep – and he was diagnosed with ESRD and put on dialysis while in the emergency room. He says that he had no choice but to learn about it, since he was a hemodialysis patient when he left the hospital nearly 20 days later. In the next section, particular situations within the context of CKD will be addressed.

4.2 Situations

The process of engaging with information about CKD begins after diagnosis or as participants ready for renal replacement therapy and progresses throughout their lifetime in varying intensities that correspond to changes both in the illness – such as the initiation of dialysis, or an episode of acute rejection for transplant recipients – and in the life of the participant. Life events largely unrelated to health status – like retirement (Nina), the onset of other unrelated health issues (Travis), moving to another city (Jacob), or considering having children (Laura) – impact health information behaviors. Generally, these life milestones spur both health information seeking and information sharing. In fact, "health" events and "life" events bleed together for my participants: Jacob's decision to move to a new city was spurred by wanting a better nephrologist, while Nina's decision to retire was impacted by her declining health. It is helpful, therefore, to think of CKD as a *context* as defined by Sonnenwald: "the quintessence of a set (or group) of past, present and future situations" (1999, p. 3). Within the context of CKD, participants encounter multiple situations, "a set of related activities, or a set of related stories, that occur over time" (1999, p. 3). The life events explicated above, for example, are situations. Participants outline a variety of illness-specific situations that occur within the context of CKD, including, but not limited to:

- Advocating for better dialysis care
- Attempting to halt the progression of CKD
- Choosing a dialysis modality
- Coping with anxiety
- Dealing with dismissive or difficult healthcare providers
- Dealing with family members that want to be tested as potential donors
- Experiencing negative emotions about CKD, such as anger, depression, fear, and

loneliness

- Losing health insurance
- Quitting one’s job or retiring
- Receiving “the call” for a deceased donor transplant
- Redefining the self and creating a “new normal”
- Struggling with dietary changes
- Switching dialysis centers
- Trying to figure out what the future will be like
- Understanding the consequences of CKD

It is also helpful to consider Jablonski’s (2004) work on the CKD trajectory, which posits that CKD operates in *phases* – first, a “crisis” phase occurs pre-diagnosis and directly after the diagnosis, when individuals adjust to, i.e., come to terms with, their diagnosis. Then, individuals with CKD experience periods of stability punctuated by phases of decline; these downward phases are characterized by critical events – situations – and often are marked as points of transition wherein “the disruption of reality makes it necessary to reorganize or restructure the existing one” (Jablonski, 2004, p. 58). These critical situations are, as Joan puts it, “Yet another new normal.” However, Jablonski’s conceptualization of the illness trajectory does not take many of the psychosocial dimensions of illness into account. In fact, research shows that patients with CKD experience many shifts that require attention and perhaps restructuring throughout their illness, in the “liminal space” between critical illness events (Molzahn et al., 2008).

Therefore, situations are not just critical events during times of illness transition. In fact, participants frequently discuss periods of time before upcoming transitions when those transitions are foreseeable, like the initiation of dialysis, as situations that necessarily involve engagement with information. Additionally, there are situations that are not critical events but that are still important to participants. For example, Joan's fistula bothered her in a "low-level, annoying way" for years before she was able to address the issue; she periodically sought out information about her fistula and shared information about it on the forums and with her providers, but it never culminated in a "critical event." Participants may be engaged in multiple situations at any given point in time, and the information behaviors that participants engage in for one situation may not be the same as they are for another situation. Participants may also differ from one another in what strategies they use as they engage with information, even when they are grappling with what is essentially the same situation.

Furthermore, situations may be interwoven with one another; they do not necessarily occur in a progressive or linear fashion. As Candice says, "I have a lot going on, all together. A lot of different issues happening all together." She then lists multiple health issues that she needs to address, and ends by saying, "It does get to be overwhelming." Others also say that they feel overwhelmed or overloaded, particularly when there are multiple concurrent situations occurring. Moreover, the seeking process itself can create overload because it brings new situations to the attention of participants: "I wouldn't even thought of that, but I see it [on the forums]. There's been quite a few things that I've seen that I thought, 'Oh, I didn't think of that.' And then it's a new one to go after, and I forget the first thing. I just keep asking and learning then I save the unsolved ones, those I save up for my poor nephrologist and I plop them on her desk every three months," says Gretchen. Nina has a strategy for managing overload when there are multiple concurrent situations: "I divide my attention between them," she says. "My attention gets divided. What I really want to do is just forget about dialysis totally, but on the other hand they made it SO clear that a transplant is just another form of treatment, and it's not a cure. (Laughs.)

I try not to think about it too much." Participants also stop searching for information when they feel overloaded. This finding is not surprising; people often experience overload as a natural part of the search process when they are learning (e.g., Johnson, 1997; Kuhlthau, 1993; Marton & Choo, 2011).

There are many situations that participants classify as immediate or transient issues; the phrase "right now" pops up again and again both in our conversations and on the forums:

- "An issue I'm dealing with right now, which is what to do with the fistula after transplantation" (Joan).
- "I'm doing OK right now" (Amy).
- "Right now I grit my teeth and get by" (Travis).
- "My big thing in life right now is trying to let [people with CKD] know, 'This is where you're headed'" (Jacob).
- "I'm looking for information I need right now because I'm scared that I'm going to end up on dialysis" (Candice).
- "Right now I'm looking for someone of a similar age who's going through this" (Laura).

From these few quotes, it is evident that "right now" situations often have both emotional and technical components, need to be handled as they arise; and are issues that will affect the participant in the present or the immediate future. The language participants use in the above quotes highlights the importance of time in identifying information needs in this context. In fact, these immediate situations often precipitate information seeking or disclosure and act as a catalyst for information behaviors like seeking and disclosure. Moreover, "right now" situations may result in participants identifying other situations about which to learn. For example, in Nina's introductory post, she says, "It seems like the more I read, the more questions I think of."

Joan replies to Nina: “I can assure you that yes, the more you learn, the more questions you will have. And that's not a bad thing.”

During one of our conversations, Nina also says that she thinks this is fairly normal: “All that happens when, I think in the medical world, is you have more questions with everything you learn.” Here, Nina echoes something that many other participants express as well: learning about the context that is CKD opens up more questions about the illness and about specific situations within the context. Joan attempts to explain this phenomenon:

> Well, you know, I don’t know if you’ve ever had this experience, but I find this to be very annoying. When you go to the dictionary, and you look up a word, and you suddenly start finding other words that are really interesting? And after about ten minutes, you’re looking at words that bear no resemblance to the first four that you were looking up? I don’t know if you’ve ever had that experience, but I get intellectually very curious about things, so I might, I might, you know, Google “FSGS” [a genetic form of CKD] and then I would find all different kinds of topics that I would find really interesting. So I would make my way all around the web, and I’d look at, like there’s Renal Fellow Network that I find interesting, The Kidney Doctor, is another really interesting site. Renal Web is another interesting site that has all kinds of research papers and stories about dialysis and just, you know, kidney issues. Start getting kind of political and you end up finding out how Medicare is going to work, and, did you know that there’s only two kinds of people who get, who qualify for getting Medicare, who are not 65 yet? Only those with end-stage renal disease and those with ALS. I didn’t know that! I find that very interesting! So, I would search for an answer to one thing, and then I would find ten other questions.

Amy calls these tangents:

> I usually start with thinking about one thing. Like, like when my potassium got high. I went and tried to figure out all the symptoms and what could go wrong with that. And then after you’ve done that, you kind of get off on tangents. (Laughs). You see something and you say “Oh, that looks interesting!” and there you go. (Laughs). And you’re off. And it spider webs from there. Usually I will say that most times I start with a specific goal, but then it just goes from there.

What Amy calls tangents are anything *but* tangents in many cases; instead, it could be said that the recursive and cyclical nature of information seeking and disclosure embodied by these tangents is a natural part of the process of engaging with information about a new context – in this case, CKD. This can be likened to Dervin's conception of the gap, which is a question, a confusion, or a negative emotion arising from a situation that a person attempts to bridge, to understand, or to solve: "knowledge made today is rarely perfectly suited to application tomorrow, and in some cases [it] becomes tomorrow's gap" (Dervin, 1998, p. 41). This process highlights one of the most interesting characteristics of a "right now" situation: information behaviors within "right now" situations open up other situations – either ones to be handled immediately, or ones that may occur in the future. In this way, it can be argued that these immediate situations act as catalysts for both searching for and sharing information with others – both about the situation at hand, and about other potential issues that may arise. Laura gives an example of how an immediate situation – her diagnosis and her doctor's reaction – spurred and motivated her online information behaviors:

> It happened very quickly for me. I went in for a checkup.... I remember at the end of the conversation, the doctor had said, "We'd best start looking which route we're going to go down in order to prep for your kidney transplant." He said it in a way that was so casual and so normal and nothing that had been said to me prior had pointed in this direction, so I didn't really gauge at the time how serious it was. Coming away from that conversation really panicked me because it had been said so flippantly and so casually that when I got home, and I was talking to my mom and dad about it, they said, "Come on, instead of freaking and stressing and panicking and being all anxious, let's have a little look on the Internet to find some background information and to see if it's very common in people with Alport syndrome to eventually have to go for a kidney transplant." It was a result of me coming away from the doctor's and having all these questions that I perhaps didn't think about when I was in the surgery that I immediately needed answers to because I was quite anxious. When it's 8:00 at night, really the only option for you is to just log online and start doing some digging and some research.

Here, Laura describes several reasons that she went online: first, she was anxious, and her parents suggested that the Internet might have information for her that would quell her anxiety. Second, the Internet was available and convenient. Finally, her doctor's attitude was, as she says, "casual" and "flippant." In fact, many participants say that their doctors acted this way, and that this attitude was an important motivator to look for information online. Laura’s experience encompasses many of the causes, emotions, and consequences that the participants in this study experience as they deal with the diagnosis of CKD and engage with information throughout that process.

There are many emotionally-laden events throughout CKD, but the emotional component of waiting to initiate RRT is a topic that came up with every participant that had to wait for treatment. As Joan says, “Waiting for your health to fail is so difficult.” Nina explains, “You don’t know when you might become disabled, and my quality of life would have been improved if I did not know this was waiting for me.” Participants are also hopeful at this stage: “I’m hoping that I get ten years. That might be my Sherri fantasy land, it might be more like, eight, seven years before I am at that point.” The waiting period is described by participants as “stressful,” “scary,” “a hard, hard road,” and “significantly depressing.” Waiting for treatment exacerbates a tension between two identities experienced by many patients as they come to terms with chronic illness. As explicated in previous research, this process carries a tremendous amount of emotional weight and difficulty (Charmaz, 1987).

Not everyone feels this way, however. For example, Brent does not discuss the emotional component of his experience with CKD or of the waiting period; instead, he says that it gave him time to plan:

> The fact that I was diagnosed over almost 11 years ago now, I had 11 years or 10 years to think about what’s transpired the last year, year and a half, ok? It was getting to the point where kidney function was down to the point where I was going to need dialysis. When I went in for my initial consult 11 years ago I had no idea that it was going to take this long. My, I, I thought I’d be on dialysis in a year. And my nephrologist… no, no. It’s going to be a long while. You’ve got a long time, a long ways to go….. Too many people are diagnosed late in the game. And now they’ve gotta go on dialysis. And my heart goes out to them. They have to assimilate. I’ve had 11 years, 10 years to face this fate. To prepare for it, ok? But, did it take 10 years to prepare for it? No. Six months, to get everything set

> up. But I emphasize or I encourage them to be as planfull [sic] as possible. Grab the bull by the horns. Educate yourself. Take control. One of the reasons why I do what I do is I'm somewhat of a control freak!

Brent later expresses that he feels fortunate that he had time to plan for dialysis, not because of the emotional component of the illness, but because it enabled him to perfect his home dialysis setup. Although he uses emotionally loaded terms – "my heart goes out to them," "facing fate" – he then equates readying for dialysis with preparation, eliding the emotional component of preparation entirely. About six months before he began in-home hemodialysis, he and his wife installed plumbing in a spare bedroom. He describes:

> I've got hard plumbing that I installed myself to provide a water line and a drain line for the equipment in here. And I started that [nine months before dialysis]. And my wife helped me, and I knew exactly what I was going to do. I was going to hook it up in the basement, and bring it up through the floor, and the fittings I was going to go and buy, all that stuff, the connections. I had a heck of a time getting information out of the NxStage people as to what size fittings I needed in order to accommodate the tubes. Most people simply hook this stuff up to their sinks or they put a drain line in their bathtub. I'm not gonna go with a jerryrigged setup like that! I'm going to go right into my own plumbing and get a tap into a cold water line in my basement. This isn't going to be a whatever, a backdoor mechanics job…. And I tell people, I just, with that control… with that control is empowerment, right? I'm not a victim. I'm in control here. This is when I'm going to do my treatment. And I'm proactive about it.

Here, Brent proactively engages with the physical setup of his dialysis equipment as a way to take control of his CKD. Although he rarely discusses emotions online, and does not discuss them at all during his interviews, in one thread he says to another user: "You have no reason to fear dialysis, hemo or PD. It sounds like you have the time to properly educate yourself and then follow through with planning and execution of the steps needed to assure a desirable outcome." This suggests that for Brent, taking control over his treatment helps him to manage any negative emotions that he may experience in relation to his CKD. It is also telling that Brent positions himself as "the answer man" – he does not use the Internet to search for health information, only to share information with others, and this may be one of the reasons that the emotional motivator for engaging with information described by other participants is not present for him. This also relates to Savolainen's work on everyday life information seeking and his typology of the mastery of life (1995). It can be argued that Brent falls in the "optimistic-cognitive mastery of life" orientation, suggesting that he believes that "any problem can be solved by focusing on a detailed analysis, resulting in the selection of the most effective instruments that contribute to the optimal solution of the problem" (Savolainen, 1995, p. 265). Other participants may fall along other dimensions in this typology; for example, Joan could be described as someone who has "pessimistic-cognitive" view on problem-solving, as the earlier example with her fistula illustrates: while she was systematic in seeking out information about how to solve the problem, she felt that the problem was unsolvable, as is common in this viewpoint according to Savolainen (1995, p. 265).

Unfortunately, for some participants, negative emotions may also be overwhelming, leading to a sort of emotional overload that leaves participants unsure of what information might help them in a moment of despair. Jacob describes:

> I can't even form a good question about this because it's all so overwhelming. I'm not even sure what the questions are or might be! I feel like I'm swimming upstream, not making any progress and getting more tired the more I swim! I keep looking for the "silver lining" in my dark cloud but it seems to elude my best efforts. So, perhaps y'all have some insight into this that I'm not seeing. What's the "secret" to your success? How do you deal with this? What's your silver lining? Where do you go in your thoughts to find the inspiration to keep swimming? If I could cry I would.

In fact, some participants report, as Nina puts it, searching for their emotions:

> Sometimes when you're doing a Google search for something and you're just not really getting hits that you want, sometimes if you just type in what you're feeling, just like you'd say to somebody, you get responses that you're really looking for.

These quotes illustrate that the affective component of information behavior is important, specifically when people search for information about their health online. Interestingly, they also problematize Savolainen’s typology of the mastery of life, as they show that the dimensions of the typology may shift on an individual basis due to situational factors. For example, given Jacob’s general information behavior surrounding his CKD, one may cast him as “optimistic-cognitive.” But his efforts to understand CKD and to, as he says above, find the “silver lining,” are highly emotional: “If I could cry I would.” This suggests a defensive-affective point of view for this particular situation. However, it is important to note that none of the participants in this study can be classified as “pessimistic-affective,” as every participant engages with information and at least some problem-solving related to their CKD in the form of going online to search for and, in many cases, disclose health information.

In the next section of this chapter, some of the external motivations for going online are discussed. Namely, these external motivations are interactions with other people: healthcare providers and family members and/or friends. Interactions with these groups of people often spur participants to go online to both search for and to disclose health information.

4.3 Why Participants Go Online for Information and Support

There are many reasons that participants give for going online to both search for and to disclose health information. Participants are often motivated to go online by interactions with other people in their social network at the time of diagnosis, which is largely comprised of healthcare providers, family members, and friends. These interactions with others, although they are both supportive and informational, are often not enough. Participants therefore go online to supplement the support and information they receive from their face-to-face networks. These individuals provide information, tangible support, and emotional care to the participants in this study. These three types of social support are also present in the literature on social support (S. E. Cohen & Wills, 1985). However, most participants focus only on emotional and informational support in our discussions and on the forums. The role of tangible support is less frequently mentioned, although it does come up when participants discuss caregivers – typically family members – who help with things like rides to the doctor or at-home dialysis care.

Each group of supporters – healthcare providers and family/friends – are made up of individuals who may play different roles; for example, healthcare providers include dialysis technicians, emergency technicians, dieticians, social workers, nurses, general practitioners, nephrologists, and other specialists. Family includes family members like spouses, siblings, parents, and children; the category of "friends" is broader, and includes people from church, college friends, and other individuals with whom the participant associates regularly (either face-to-face or virtually via a general social networking site like Facebook). Finally, participants also interact with other patients – but this activity largely happens online, and therefore will be addressed in the section of this chapter that focuses on information behaviors in online support groups. However, some participants do mention seeing other patients with CKD in face-to-face support groups, in dialysis clinics, or as inpatients in the hospital when they are there receiving care.

Joan describes how there are different types of support that come from these different groups of people, and that it is imperative to have multiple sources for support:

> I personally think that you can't just rely on one person or one set of people, really, to create a support net. You need different people to give you a certain part of your net. The people on [the forum], they're great people, and they give a lot of information, but… they don't love you unconditionally. Whereas my husband loves me unconditionally, but it took him several years to get the difference between potassium and phosphorus, you know? But none of [the other forum users] know about my specific physical condition, so that's when your medical team comes in…. So your comfort quilt has to have lots of different patches in it.

Here, Joan offers the underlying metaphor for social support in the life of a patient with CKD: a comfort quilt with "a lot of patches." In this section of the discussion, I will outline how the different patches in the support quilt – the groups of people outlined above – operate within the lives of participants, and how support from these groups impacts information behaviors, with a focus on information behaviors online. Examples of what types of support are offered by which people – and what types of support are lacking – will be given, and a fuller picture of what the support quilt looks like for participants will emerge. The forums make up a central portion of this quilt, which will be discussed in a subsequent section of this chapter. The role that the forum members play in the information behaviors of participants will also be analyzed, and some of the implications of these activities will be offered.

Although all of the patches or groups of people on the support quilt are capable of providing any of the three types of support, the participants in this study describe that they are unlikely to get emotional support from their healthcare providers. Furthermore, their family and friends are unlikely to provide informational support. Finally, other patients – particularly those they meet online – are unlikely to provide tangible support in their interactions. Again, this is not a hard-and-fast rule: there are some cases where participants describe, for example, receiving informational support from family members and friends, particularly when caregivers play an active role in helping participants manage their own health information. However, by-and-large, participants do not get tangible support from other patients, emotional support from providers, or informational support from family and friends. The notion that people get different types of support from a variety of people based on the characteristics of their relationships with those people is well-supported in the literature on social support (e.g., Wellman & Wortley, 1990).

Participants say that healthcare providers primarily provide informational support, and they often characterize their providers as experts. They frequently treat their doctors as the final arbiters of decision-making and of their care. As Travis says, “I’m going to do what my *doctor* tells me to do…. I have all the faith and trust in them. And I've got a nurse practitioner too, and she's given me even more information. I see the nephrologist one time every six months but the nurse I see more often." This is not particularly surprising; the literature in this area demonstrates that, in general, patients do prefer to get health information from their providers (Fox & Duggan, 2013; Gollop, 1997; Johnson & Case, 2012; Lenz, 1984). In fact, many participants bring information from the Internet to their doctors in order to verify what they have read online. I call this *crosschecking*, and it will be discussed in more detail below. On a few occasions, healthcare providers lend an emotionally supportive ear, although this is not very common. There are no examples of participants receiving tangible support from healthcare providers. In fact, in one situation, a participant asked multiple care providers to provide some "holdover" medication when he was having insurance issues, and none of his providers were able to help him obtain trial samples of the needed medication. This led to severe consequences for his health, which he described in detail during one of our conversations. Responses of care providers and their impact on the information behaviors of participants in this study will be discussed below.

Family and friends are the group that largely provides tangible support; for example, rides to the doctor, meal planning, keeping and updating personal health records, and dialysis caregiving are all tangible activities that participants say are carried out by family and friends. Family and friends may also provide emotional support at times; however, participants discuss being very careful of how much emotional support they ask for from this group. In some cases, they may eschew tangible support from family members as a way to protect their loved ones from the emotional aspect of kidney disease. This will be discussed in more detail below on the section on family members and friends.

Finally, participants describe getting emotional support from other patients. Online forums are always on, and can be used at any time a participant feels an emotional need. This is something that many participants mention; Joan frequently uses the example of visiting the site at 3:00 AM when her emotional needs were high; she says that sharing her anxiety when she was unable to sleep was both directly therapeutic for her and also perhaps helps other users of the forum who may be just as anxious in the future:

> That's a constant storyline you'll hear: "I'm glad I'm not alone." So I want people who might be sobbing at 2 am thinking, "I must be the only one who feels this way, everybody else seems to be coping so well, how does everybody else cope, I must be the only one who is whining or who feels bad or who is pitying myself." I don't want people to burden themselves with that kind of feeling. I want people to think at two o clock in the morning, "Well, at least I'm not the only one to feel this way." I think that's important. I don't want people to feel alone emotionally at two o clock in the morning, chastising themselves for having had a bad day emotionally.

Amy also discusses logging on "in the middle of the night" when she is "feeling low." This is related to Laura's decision to go online to look for information after her doctor's appointment, as previously discussed; she says: "When it's 8:00 at night, really the only option for you is to just log online and start doing some digging and some research." The literature corroborates this finding, as the convenience and the "always-on" nature of the Internet are frequently cited as two of the main reasons that people use online support groups (e.g., LaCoursiere, 2001).

4.4 Groups Providing Social Support

In this section, I will discuss how different groups of people – different "patches" in the support quilt – provide different types of support to patients, with a focus on how these supportive activities impact online information behaviors. First, the role of healthcare providers in giving informational support to patients is discussed. The attitude of the healthcare provider, time-pressure, proving compliance with the provider's recommendations, and crosschecking information they have gleaned from other sources all play a large role in the online information behaviors of participants. Next, the impact of support offered by family and friends – and the impact of those relationships in general – on the information behaviors of participants is addressed. Finally, this section closes with a discussion of other patients as providers of emotional support. This sub-section overlaps heavily with the previous discussions on *assessing similarity* and *future forecasting*; therefore, only activities that are *not* included as part of similarity assessment and future forecasting are discussed in this section.

4.4.1 Interactions with providers. Participants describe a variety of interactions with providers. These interactions include, but are not limited to:

- Pre-dialysis check-up appointments with nephrologists
- Meeting with various providers in the dialysis clinic, including technicians, dieticians, social workers, and nephrologists
- Visits to other healthcare specialists for co-morbidities
- Appointments with dieticians to discuss the pre-dialysis or dialysis diet
- Post-transplant annual visits with nephrologists

During these interactions, participants say that they mostly receive information from their doctors and other providers about their CKD. The provider, not the patient, largely guides these interactions, although participants do discuss asking their providers questions and sharing information they find online with their doctors as a way to verify, or *crosscheck*, what they have found. Research has shown that the patient/provider interaction during appointments is very provider-heavy; that is, the relationship is asymmetrical, with the provider receiving more information than patients (McNeilis, 2001). Unfortunately, many participants describe feeling dismissed by their healthcare providers when they do ask questions; it is often this type of negative reaction that spurs further information seeking online. Although negative interactions with providers are a recurring theme in the data, this does not indicate that participants are receiving poor care. In fact, many participants discuss having very positive relationships with their providers, despite having negative *interactions* with them.

Dismissal of a patient's concerns by a health care provider comes in a variety of forms, and participants use words like *nonchalant*, *dismissive*, and *ill-considered* to describe these interactions. Sherri, who is on the cusp of Stage III CKD, describes feeling dismissed during her first nephrology visit – a visit that was recommended by her primary care doctor:

> I went to a renal specialist at the local university hospital, the best people in the area. And it was horribly disappointing. Bottom line, they don't suggest that [you] do anything until Stage IV. "You look fine, you feel fine, continue eating what you feel like! When you start dumping protein in your urine, then you can worry." And this is a respected expert on kidneys – ack!

This advice is the opposite of the advice she received from her primary care doctor, who told her to eat a low-protein diet and to watch her sodium intake. When I ask if she might get a second opinion from another nephrologist, she says:

> I went back to my primary care physician and I said, "You know what? Me and the Johns Hopkins [website], we're fine. I've got so many excellent resources online, and I've got the dietician to help me, and I've got my PCP monitoring me every three months to see whether any of the key indicators are moving in a bad direction, or potentially in a good direction…. I feel comfortable managing things with her as long as things are stable. If they start deteriorating I'll go find another specialist.

In this part of our discussion, Sherri describes a reaction that many participants also have when they feel dismissed by a provider: using other resources, including the Internet, to find information. Sherri does not only go online to look things up, however – she has a dietician, a PCP that she is comfortable with, and trusted online resources. This illustrates that participants do not just turn to the Internet with health questions when they feel dismissed by a provider: the Internet is one of many resources that they use to answer questions about their health. In fact, participants often see the Internet as a helpful resource for enhancing communication with their providers. For example, when I ask Amy what she is looking for when she searches for information about CKD online, she says: “to gain more understanding of what [my doctors] were trying to say, [so] that I have more knowledge to be able to ask more knowledgeable questions in the future.”

Nina also explains that sometimes, it is not that her providers are dismissive – it’s that they don’t know the answers to her questions:

> When I first got my diagnosis, and I said, well, what’s the prognosis, and the nephrologist said, “I have no idea.” [Laughs]…. It was the beginning of my enlightenment. When you actually start using the medical system you realize it’s not what you thought it was. It’s not, here, take this pill; it’s not, here, have this operation; it’s a lot of lab tests and waiting…. Your expectations get – you have to readjust them…. They’re not going to always get it right. And the doctors are trying and they’re working – to a certain extent, they’re working in the dark, like you are at the beginning. They only know so much.

Nina has a rare genetic form of CKD; this, she says, contributes to her doctors knowing less than they might about other forms of the illness. This is one of the reasons that she says that she turns to the Internet to look for information specifically about her particular etiology of CKD.

Interestingly, the data shows that interactions with providers do not greatly influence disclosure of personal health information online. For example, when Laura told her doctors about starting a website for CKD patients, their reaction was mostly positive; however, as she says, “They told me I wasn’t allowed to reference the hospital itself, or any of the staff that works at the hospital. As long as it was all about me and my experience with failing kidneys and on dialysis, and it wasn’t hospital specific, then I was okay to do it.” I ask her if they explained why, and she says, “I guess it’s because of the fear of any bad PR. That’s what I said anyway. I said I wouldn’t. I just said, just so you know, I would never speak badly about the hospital or any of the staff. The website wasn’t as a form of complaining. It was more of a form of positivity and supporting other people and making them feel that they’re not alone, and that there’s someone else that understands." Candice explains that "what I say online is my business, and I'm not sure it's really something the doctor wants to hear about. There's so much else to get through when I'm there in terms of topics that I want to know about and what he needs from me." This also brings up a related issue: time pressure.

4.4.1.1 Time pressure. There are many reasons that participants give for why providers may sometimes be perceived as dismissive. Most participants say that in many cases, it is due to *time pressure*. There is not much time to meet with doctors – on average, visits with specialists or with primary care doctors last about 15 minutes, according to the 2010 National Ambulatory Medical Care Survey – and there is much to discuss during the visit. As Candice says, "There's a lot of stuff to go over when I see my doctor." In fact, Brent attributes most of the questions on the forums to short office visits:

> My participation on the forum tends to be… we'll call it one-way. I, I contribute and answer the questions of others and rarely ever look for any information. I'm the answer man. So that's what I do. I go out there fishing for people who are looking for information… and then I provide it…. And I see it as an indication of mainly, their medical teams are just not giving them the information that they're asking for. Or, they're just afraid to ask these questions of them…. There's a lot of, I get a lot of – a number of people have got kind of what I would consider innocent questions. I mean, maybe they didn't ask their medical team. Or maybe they're just curious and more comfortable with this forum. Right? There are other people who are complaining bitterly that they're not getting the answers from their medical teams. They don't have the access. How do you get that information without making an appointment? They don't want to spend the money or the time to get an appointment. So they're using this [forum] to try to get answers.

In this statement, Brent also mentions something that the other participants do not address: there might be questions that are embarrassing or difficult to ask care providers. For example, questions on the forums about sexual performance, which may be negatively affected by CKD, are often prefaced with phrases like, "I don't know how to ask my doctor this." There are also questions that doctors aren't able to answer; these questions are mostly experiential in nature. Examples of these questions that have been posed in online support groups include: "What does a biopsy feel like?" "How do you keep living your life while you're waiting for the call [for a kidney from the deceased donor list]?" and "Does your spouse eat a renal-friendly diet with you? If not, how do you handle it?" These types of questions and the methods participants use to answer them will be discussed in more detail below, in the section on using the Internet to locate other patients. Finally, there are some issues that providers do not bring up with patients, such as the option of hospice or palliative care. For example, when he met with a social worker to discuss his treatment options, Steve mentioned hospice to her:

> She goes, "Do you know what your treatment options are?" And I was like, "Yeah, in-center hemodialysis, nocturnal in-center dialysis, home hemodialysis, peritoneal cycler, peritoneal manual exchange, transplant, and hospice" - and nobody *ever* says hospice. She was like, "Woah! My gosh!" And I'm like, "That's an absolute choice! That we have!" But that's one they never talk about.

Gretchen, who lives in Australia, relates a similar experience in her dialysis training – the trainer told the group of people in the pre-dialysis seminar "that if we decided not to do dialysis, they would take care of us, and know that there was another way. They didn't have to do dialysis. The woman next to me perked up at this, not realizing that the other way was palliative care." In both cases, the participants had to infer that hospice was an option and they had to approach their providers to discuss it first. This is also the case more generally as evidenced by the literature; for example, a recent meta-analysis reports that providers often do not discuss palliative care with patients before dialysis is initiated (Fassett et al., 2011). As that article notes, and as several of my participants say, this is a serious gap in patient education. However, providers are willing to discuss discontinuing dialysis and palliative care when patients ask about it directly. For example, Jacob decided at one point to discontinue dialysis due to severe depression: "I was just inches away, I had already prepared everything; I was ready to quit dialysis completely. I was *so* unhappy." He describes the conversation with his providers:

> I went to have my last will and testament notarized and the notary happened to be my dialysis social worker. And this girl, this girl saved my life. She, as soon as I called her and said "This is what I want to do and I need to have that done," she said, "Oh yeah, sure, come on in!" What she was thinking was, "Come on in because I'm going to muster the forces here and you're not gonna walk out of here with that same intention." So she talked to me for a little while, not a whole lot of pressure, just talking to me. And then she had the doctor ready to go, I went back in the exam room and he came in a couple minutes later, everything's happening very quickly. But the one that really got me was when Lisa, the doctor's wife and office manager just said, "Jacob, look. You're killing me." That was just – and what that said to me was, "Oh wait, Jacob, this is not just you doing something to yourself. You're not solving anything – you may be solving your problem but you're creating a problem for other people"…. I had the conversation with the social worker, and the doctor, and my nephrologist is just – just, he's got thirty, forty years experience. Just, he's been through this with so many other patients and he knew what to say.

Although some specific topics are either thought of as off-limits or as ones that cannot be addressed by providers, multiple participants say that time pressure is the primary reason that they can't get as much information out of their providers as they would like. This finding is also a popular complaint in general, noted both in the popular media (Varney, 2012) and in the scholarly literature (Gulbrandsen et al., 2012; Sampson et al., 2013). In these situations, participants in this study say that they often turn to the Internet as a source for information. Brent expounds on this:

> It's a time element – you only have so much time to see a doctor. Unless you go in there with a script, and even then they're probably not, they probably don't have that much time for you. It's a 15-minute consultation. You can usually cover, maybe a couple of topics. So they leave it to something like the posts on the DaVita website, to get answers.

As a salient example of this issue, here is what happened to Steve after being released from the hospital – where he had been diagnosed with ESRD and had been placed on emergency dialysis:

> I had, like, a billion questions. And the first month, the doctor would come through [the dialysis clinic] and spend literally five to seven seconds with each patient. And I was like, *woah*. So I called his office, and I said, "I would really like an appointment in-office. I've got a lot of questions." And they're like, "Ok! Here's an appointment in a month and a half." I'm like, "A month and a half! I'm like, I'm really, I don't know what's going on. I-I-I really have a lot of questions,

> this is really, you know, important to me." And they said, "Hold on; let me talk to the doctor." And they said, "Oh, we talked to the doctor, he doesn't need to see you right away." A month and a half.

Steve went online to ask whether or not this was customary, and he quickly switched nephrologists after learning from other patients with CKD that this provider's behavior was not something that he had to live with as he navigated his diagnosis and treatment.

4.4.4.2 Overload during visits with healthcare providers. Because visits with healthcare providers are so short, participants frequently mention feeling overloaded when they see their doctor. Travis explains:

> You go into a doctor's office and you start talking, they give you all kinds of information and it's kind of information overload. So for me I said, well, I'm going to go, I went on the Mayo Clinic website. I want, anything, I put in kidney issues, to see what popped up.

For Travis, the nature of the doctor's visit – it's short, rapid-fire, and does not allow him time to process information – drives him to go online for health information. Joan actually does not use her providers as an information resource due to how much anxiety she has when visiting the office. She explains that "it's not something you want to be reminded of" and that going to the nephrologist's office, or having her blood drawn every month, is "a constant reminder that you're kind of in a fragile condition and it can be very perilous and, it's a scary thing to be constantly reminded of your mortality." Visiting providers is particularly difficult for Joan, because, as she says, "I have never spoken to anyone who deals with CKD patients who has EVER painted a rosy picture. My nephrologist flat-out told me that FSGS is 'a horrible disease.'" When I ask her about discussing dialysis options with her nephrologist, she says:

> Fairly enough, I really have never discussed dialysis with my nephrologist…. A lot of it, I think, to be fair, has to do with the nephrologist. To be honest, I *hated* going to the nephrologist. I *hated*, *hated, hated* the whole process of having to get labs done, and then waiting that horrible, horrible week, until you go get the results, and you have *absolutely* no idea. No idea…. So when I went to get my results, if I saw that my creatinine was still at a certain level, and my [glomerular

> filtration rate] was still above 20, I just wanted to get out of there. I didn't want to discuss dialysis with him. I just *wanted. Out.* And I could breathe a sigh of relief and come home, and in my own time, when my nerves I thought could take it, then I would go online and do my research myself.

Like Travis, Joan goes online so that she can process the information on her own time and at her own pace. Candice, too, discusses how overloaded she feels at her doctor's appointments, largely because she – like many patients – is unable to process medical terminology at a rapid pace:

> They start using terminology that only doctors understand and the general populous don't. That's what I mean. That happens in the doctor's. They'll start to speak and forget that that patient does not understand your lingo…. some of that is still over me and I don't understand what those words mean…. This is beyond me, too much. Then, I go to the Mayo Clinic [website] and back to WebMD where I can understand what they're saying. They put it in a way that takes all of the big words and puts them into people words.

Therefore, some of the participants in this study go online to search for information as a way to manage information overload, and as a method for learning things that their doctors "can't or won't tell them," as Nina says. Amy, too, searches for information online as a way to better understand her interactions with healthcare providers: "First thing I do when I come from any of the doctors I see is sit down and Google and stuff to see, to get more understanding, so that the next time I go I have more understanding to be able to ask better questions." This is an example of crosschecking: checking multiple sources for information as a way to verify the facts, and as a way to gain clarity about what the information means. Crosschecking will be explicated in more detail below.

4.4.4.3 Providing information to providers. Participants are often unhappy about how short their visits are. For example, recall when Steve decided to switch doctors after he was unable to make an appointment with the nephrologist he was assigned in the hospital. He found a new nephrologist who was willing to see him right away – the first day he did not have dialysis after he called, he was meeting with this new nephrologist, who is a sharp contrast to the previous practitioner: “He sits down and he’ll talk to me,” says Steve. “He doesn’t do the 5-second thing. He talks to me for as long as I need.” Gretchen also has a provider that is very attentive: “I’m very lucky to have Margaret, my doctor, to ask questions of,” she says. Like Steve, Gretchen contrasts her experiences with her attentive nephrologist with the dismissive attitude of the nurses she met with during her dialysis training:

> [With peritoneal dialysis], you’re not supposed to let extra fluid in for longer than 16 hours. I thought, “Why? What if I get stuck in a train or something like that on the way home and it goes over 16 hours? Am I in danger?” The first nurse I asked down at the clinic said “Because.” The second one a couple of months later said, “You’ll die.” Then I finally got someone who managed to explain to me exactly why you shouldn’t.

However, Gretchen says that she is careful not to push back with the nurses that do not answer her questions: “I haven’t had any once or twice [or back-and-forth disagreements] with the nurses down at the PD clinic,” she says. “I want to keep them happy!” In fact, maintaining a positive relationship with providers is a concern for many participants. Proving compliance as a way of keeping providers happy provides an incentive to share positive health information with providers. For example, Amy tracks her diet using a website attached to the forum she frequents most often; she describes sharing this information with two providers:

> I’ve been known to copy and paste [my weekly dietary tracker results] into a Word document and I will send it to my dietician to let her look at it to see if there are things that I need to change…. I actually took one to my doctor one time to show him. It was a week I’d been really good (big laugh). I think it helps for them to understand that I am trying my best, I’m following what they ask me to do, and I’m compliant.

Some participants who share detailed personal records with providers, as Amy does, find that this practice is not particularly useful because, as Sherri explains:

> In my experience, doctors only trust tests or data that they do. If you come in with a chart saying “This is what my weight has been like every week or day for the past six months,” they go, “Oh, thanks so much!” and then they ignore it.

This is directly related to the experience detailed by Jacob below: a dismissive response from providers leads to participants deciding not to share information with them in the future. Sherri relates that she's not planning to bring in information about her diet, weight, and other health data she gathers to discuss with her healthcare provider.

These experiences illustrate that participants use information as a tool to prove to providers that they are "good" patients. By giving the right amount of information to illustrate compliance, participants facilitate the work of the provider. Too much information, however, is a burden to be ignored by providers. This is directly related to the way that providers view "problem" patients as shown in the literature – people who take up more time than the provider feels is warranted by their illness during office visits are generally labeled "problem patients" by providers (Lorber, 1975). Some participants also feel that this perception is influenced by the amount of questions that they ask of providers during visits – recall Gretchen, who says that she has "never had any once or twice" with her nurses. When they do not give her adequate information in response to a question, she does not push – she simply waits and asks it of another source at a later time.

A dismissive or negative attitude from a provider can also impact what participants share with that provider, either as a given interaction continues, or in subsequent interactions. For example, Jacob travels frequently to lobby state and national legislators for better kidney care. He is on in-center dialysis, and is "a bit of a hard stick." Technicians unfamiliar with him were taking nearly two hours to successfully insert the needles for dialysis into his arms, causing him great pain and disrupting his schedule. So he talked to his favorite technician at his usual clinic, Tim, and Tim gave him incredibly precise instructions about how to stick his fistula. Another technician, Rita, also jumped in and gave some additional advice about it. Jacob also took several photographs to share with the technicians, but when he got to the center, he decided that felt a bit like "overkill" so he just gave them the verbal instructions: "I'm like, ok, I'm ready for this. So I went to the new site and I gave them that instruction." Unfortunately, Jacob's technicians still had lots of difficulty sticking him:

> I said you needed to use the inch and a quarter needle right here, and they said, "Oh, well we haven't tried that one yet." And I'm like, "You don't even listen to me!" Very often, they're not ready for patients to tell them what, as a technician, they think they already know…. Very often they won't listen to me. They heard me, they listened to me, they heard what I was saying and then totally ignored it.

Jacob never showed them the pictures: "It was a case of where I intellectually detached from it and I just kind of like, 'Ok, fine, when you guys find it, you let me know.' I got kind of tired of that because it *hurts*." In this instance, Jacob decided to stop sharing information with his providers because of their dismissive response, although he plans to do differently in the future: "I'll get better at it. I'll get more involved," he says. This is a particularly telling statement from an individual who lobbies Congress and is a champion of patient empowerment. Like in other situations described by participants, Jacob takes on the responsibility of being dismissed by his providers – he says that he believes that if he were more involved, a "better" patient – one who shares more readily with his providers – he would perhaps not have had a difficult and painful experience dialyzing at this center. This is corroborated in the literature: patients are more willing to disclose information to providers when their providers seem engaged – nodding, using animated facial expressions, and smiling are all things that doctors can do to promote patient disclosure; turning away, breaking eye contact while speaking, and verbally dismissing patient concerns all cause patients to disclose less (Duggan & Parrott, 2001).

4.4.4.4 Healthcare system impacts provider communication. The dismissive attitude that so many participants mention is also directly related to the healthcare system in the United States. This may not be as much of an issue in countries with healthcare systems that are not based on a private health insurance model; both Gretchen and Laura are in countries that use a single-payer healthcare model, and they both remark that their experiences seem very different from the experiences shared by most members on the forums. The forums are mostly visited by people from the United States.

In the United States, providers spend less than 15 minutes on average with patients, and the healthcare system is not focused on preventive care (Farley, Dalal, Mostashari, & Frieden, 2010). As Jacob observes, “They’re just going complaint to diagnosis, or complaint to treatment, and not really sharing the diagnoses or what the issues are going to be.” In fact, there are multiple examples in the data of participants losing access to health insurance and subsequently losing function of their kidneys. For example, when one of the participants lost his health insurance due to his divorce, he was unable to continue paying for his blood pressure medication or for his annual visits to the doctor. He discontinued taking his medication and his blood pressure rose again, and within six months he was diagnosed with ESRD. He tells me that he did not know that high blood pressure caused kidney failure. Another participant lost his kidney transplant because he was unable to pay for his antirejection medications; he is now back on dialysis.

In both of these examples, there were clear communication breakdowns between participants and their respective providers. A larger focus on preventive care – particularly for patients who already have issues like high blood pressure, pre-diabetes, and a history of kidney issues – may be necessary, as illustrated by the stories told by the participants in this study. Unfortunately, there is a dearth of research on information exchange and communication during follow-ups after treatment initiation – not just in CKD, but in other chronic illnesses as well (e.g., Bakker, Fitch, Gray, Reed, & Bennett, 2001). As Jacob says, “All I was told [for 40 years] was, ‘Well, you’ve got suspicious things going on with your kidneys.’ It wasn’t until my kidneys failed that I finally started going backwards and piecing the puzzle together…. Nobody really sat me down and told me what was happening.” Because of this, Jacob became a dialysis patient advocate.

Furthermore, the healthcare system in the United States is highly fragmented. This also influences information behaviors. As Nina says, “the body works together as a whole, but our medical system tries to break us down into some kind of production line or something and that’s not how the body works.” For example, participants may not see the same doctors every time they visit. Amy explains: “Unfortunately because of my insurance I see a lot of residents, and they rotate in and out and so you don’t have much continuum of care with them. Depending on who comes in, sometimes they listen to you, sometimes they don’t.” Research shows building a relationship with a specific provider over time enhances communication between the patient and the provider (e.g., Katz, McCoy, & Sarrazin, 2014; Piette, Schillinger, Potter, & Heisler, 2003), and participants who visit teaching hospitals or who are on Medicaid say that they feel that they are at a disadvantage because they lack continuity with their providers.

When discussing hospice, Steve posits that providers don’t discuss hospice with patients “because then they don’t make money. It’s a business. Dialysis is a business, and hospice terminates that income for that person. That is my true belief.” This is unfortunately substantiated by the medical literature (e.g., Cabin, Himmelstein, & Woolhandler, 2014), and is likely one of the reasons that in-center hemodialysis is the most popular modality in the United States. Steve expands: “I know that in-center hemodialysis is the hardest on your body. But it’s a business. They try to get as many people in and out of the chairs as possible.” In fact, Jacob also mentions feeling like the patients were treated like “cattle” at his first dialysis clinic; he says this feeling greatly contributed to his depression and was a large factor when he considered stopping dialysis. Robert, too, discusses this issue: “unfortunately, in-center dialysis is warehouse dialysis. It is a production line.” Both Robert and Jacob switched dialysis clinics because of their poor treatment; all three men have considered going on home hemodialysis, but none of them have care partners at home and are therefore ineligible for at-home hemodialysis at this time. Robert, however, is on nocturnal dialysis in a clinic, and he finds this experience to be vastly preferable to in-center hemodialysis during the day. The “business” of dialysis is a common thread on the forums and in interviews; it elicits a visceral, emotional response when people discuss it: “Dialysis, it's about the money. It's about following the money and it's a big business. How do you take that out of it? I don't know. What are you going to do, you've got a total of 400,000 now, patients on dialysis. It's only going to get bigger, and they’re only going to profit more,” one participant explains. Another says, “It’s this for-profit type of setup. It’s unbelievable.” Another participant says, with anger in his voice: “In-center dialysis is the patient-centered way of care? Hah. It’s the PROFITABLE way of delivering care!” While there are some non-profit dialysis centers in the United States, they are dwindling in number; for-profit dialysis organizations, both large and small, provide at least 81% of dialysis care in the country (US Renal Data System, 2014).

4.4.2 Crosschecking information. Although participants describe how negative interactions with providers may cause them to search online, they also bring information in from other sources to their providers as a way to verify, or crosscheck, that information. Gretchen calls this *crosschecking*, and all participants engage in this activity in one form or another. In fact, Gretchen is clear that the activity is agnostic as to the source: “After you read a couple of somebody’s posts and you can crosscheck on Google or with your doctor or whatever. Then you can get the gist of, yes, they seem to know what they're talking about and the risk of their post." Here, Gretchen discusses how credibility of a specific person on a forum may build over time after they offer information that is sufficiently checked and verified with a provider; this will be addressed in a subsequent section.

Crosschecking is a routine activity that participants report carrying out with almost all of the information they receive about CKD. It does not only occur with providers; participants also describe crosschecking information from one online source with information from other online sources; they also may check information from the doctor with online sources as well. In this section, the causes of crosschecking will be discussed, examples of the activity will be presented, and the consequences of the behavior will be addressed.

4.4.2.1 Crosschecking online information with providers. Many participants use their doctors as a source for crosschecking information they find online; this activity is, in fact, common for many patients with chronic illnesses (Morahan-Martin, 2004). For example, Steve says, "My doctor knows exactly which forum I get most of my information from. And I print articles – I don't understand a lot of the chemistry, so I will print articles that I found on the forums and have him explain them to me." Sherri, too, brings articles from medical journals to her doctor; she also has read articles with the doctor during her visits:

> In a couple of situations, she pulled up an article right on her computer and we read it together and discussed it. She printed out the reference list so I could go look up some of the, not only that article, so I could have my own copy, but all the major researchers that this author was citing, I could kind of find out what they're doing and look at some of the key terms.

This indicates that Sherri not only crosschecks what she finds online with her provider, but that this activity spurs further searching and learning on her own. In fact, multiple participants say that their providers encourage them to use the Internet to search for health information: Amy's doctor "pushed" her to read the National Kidney Foundation website, and one resident that Nina spoke with encouraged her use of the Internet for health information:

> I said something like "I know you doctors probably hate this, when people come in talking about something they read on the Internet," and he was very surprising. He said, "No, no. That's *fine*," he said, and he was very, like, encouraging. And that kind of surprised me.

In fact, the response from doctors when participants bring online information in to them is typically positive, but cautionary: "They tell me to be careful of what I read, but they're still willing to answer my questions and either validate what I'm saying or giving me the reasons why what I read may not be for me," says Amy. Encouraging patients to crosscheck information found online with the doctor is recommended in the literature (McMullan, 2006). Importantly, participants stress that the information they get from providers has primacy in decision-making and self-care. As Amy says:

> It's not like what I read, I will follow that instead of what my doctors say. It just guides me more into exploring with my doctor, maybe, alternative things. I don't use it as a Bible for, "This is what my healthcare should be doing." It's just, I use it for a basis to examine what's going on in my life.

Travis, too, explains that he does not apply what he reads online to his own care without first consulting with a provider:

> Mayo Clinic, I pretty much trust them. And this Nephrology News and Issues, and the National Kidney Foundation, and other ones like that. To me that's where you're going to go, those are the experts on it, that's where you're going to go find the information you need. And there's some out there, there was something not too long ago and someone had some, "Oh! I cured my kidney problems and all this stuff and I was taking these holistic stuff and all these herbs and everything!" And I'm going, "Eh – (laughs) – I don't think I'll try that." If I did, I'd still want to check with my doctor, because I have all the faith in trust in them.

In addition to explaining that he trusts his doctor more than any other information source, here Travis lists several other locations where he finds trustworthy health information. These sources are repeated throughout the data; the Mayo Clinic, Nephrology News, the National Kidney

Foundation, John’s Hopkins, and WebMD are all sources that participants list as trustworthy. Amy explains: “I don’t go out there and just look at sites that aren’t medically – that don’t have a medical base to them. I don’t go out there and just look – I make sure it’s a university study or medical place, and I try to stay away from the Wikipedias and stuff like that.” Candice, too, says that she only looks for information that she thinks is “reasonable to be looking to and legitimate.” When I ask her what she means when she uses the word “legitimate,” she says: “Well, Mayo Clinic is very highly regarded so I use that as the benchmark. If they don't meet up to Mayo Clinic, then, to me, they're not – you know, Mayo Clinic is respected worldwide.” I then ask her, “Can I ask, how do know that Mayo Clinic is respected worldwide?” She responds:

> Because they are. There are so many people that come to this country to come to Mayo Clinic, that put their life savings in their hands to get treatment there…. If they're respected around the world, then they should be respected here. I've been to Mayo Clinic. It's like the Disney World of medicine. You take a ticket and you stand in line. Then, you get your Upper G.I. Then you stand in line and get your EMD.

Here, Candice describes how her own personal experience with Mayo Clinic leads her to trust them as an information source. She then contrasts legitimate information with naturopathic medicine:

> If I get on to one of these other sites and a lot of them are naturopathic sites and you got to get through there to find that they are. Then, I have no use for that, because I don't want to try any voodoo medicine. Although, there's some use for naturopathic medicine, I wouldn't poo-poo all of it. My daughter uses a lot of it to keep her 7 children healthy and not have to go to the doctor because they're selfpay. For something that's a serious condition, I don't want to talk to somebody who's going to tell me to, like my daughter said, “You can pee on a turnip and hang it on your bedpost.” That was something she read in a folk-medicine thing. “That'll take care of whatever it is that ails you.” I thought that was funny.

This echoes Travis’s sentiment – that information about “holistic stuff and all these herbs” is something he doesn’t generally believe. In fact, many participants mentioned running across this type of information online; the word “herb” is often present in these discussions, used as shorthand for information about holistic, homeopathic, or naturopathic treatments. Amy expands:

> Several nights a week I get a suggested post on Facebook on “37 days to healthy kidneys.” I tried to read it sometime and it was so outrageous. I get a lot of information on Facebook like that. And – yeah, right. I know doctors want to make money, but I can’t believe that if there was a way to [cure CKD] that doctors wouldn’t be jumping on the bandwagon!

It is clear that Amy is inherently skeptical of this type of information because it seems, as Candice puts it, “too good to be true.” Candice isn’t wrong – in fact, many herbs used medicinally are actually toxic to the kidneys (Jha, 2010) and research determining which herbal supplements may actually be helpful for patients with CKD is still in its infancy (Wojcikowski, Wohlmuth, Johnson, Rolfe, & Gobe, 2009). Amy also says: “I have a high regard to the medical people. I don’t necessarily know that they’re always right, but I trust them more than the people that all they want to do is pawn off herbs on you.” In fact, Jacob says outright: “That herb stuff is total, unsubstantiated bullcrap. And I make a point, when I see that kind of stuff, I make a point to make sure that I reply.” Robert replies directly to a user on the forums who asks about herbal supplements to increase function; he says: “I suggest you read the following. No negativity, just a dose of reality. Good luck.” This is followed by a list of six links – three to posts on other forums; one to a page on KidneySchool, a reputable non-profit online kidney education program; and two that lead to static pages on MedScape, a site published by WebMD that is geared towards practitioners. He then ends his comment: “Also suggest you do an extensive SEARCH [here on the] message boards.” Here, Robert gently refutes the medical efficacy of herbal supplements by providing links to reputable sources online rather than confronting the person who asked the question.

Correcting information that is incorrect or misleading in forums is, in fact, something that many participants grapple with. Steve, too, describes a situation where “We had people on the forums saying like, ‘Yeah, I’m going to do *saunas* instead of dialysis!’ and everyone was like, ‘NO! Please! Don’t listen to this guy!’” In this situation, a sort of crowd-sourced, collaborative crosschecking activity takes place; the thread Steve references here contains 90 replies – many of them framed as “hostile” by the original poster. At one point, Steve says:

> I don't know if it is hostility or just a real concern for other people’s health. People can become desperate for a better quality of life. I think that the people who are posting "against" you have a genuine concern for the other people reading these posts. It is a fact that some alternative modes of treatment for various diseases and ailments over the years can have 3 outcomes. Some actually do help, some do absolutely nothing at all and others can be harmful even to the point of being fatal. The others posting are concerned that your sauna treatments could end up hurting others who take your mode of treatment as medical fact. So far the only article I found that discusses sweating and your skin as being a 3rd kidney is an author who is a photographer…who does not have any medical background. If you truly believe that this is "for real," you should be more scientific about it… Please, please, please back up your claims with medical proof. I am not asking this to prove this to others. I am asking this as a genuine concern for your health, period.

Interestingly, Steve says that he wants this user to back things up with medical proof only for his own sake, and not for the sake of other readers. This is likely because there are so many other users who directly refute the claims of the original poster by offering links to the scientific literature and to reputable static web resources as a way to bolster their claims that saunas cannot replace dialyzing.

Gretchen, however, says that she has trouble refuting incorrect information when she sees it in the forums:

> Some of the things on there do horrify me a bit – things that are obviously wrong. Usually somebody else can come in and disagree with them better than I can. I’m not qualified to give medical advice. I have a lot of suggestions on care and things like that. If I do want to contradict something I’ll say, ‘Oh,’ for example, if someone is talking about cheese not having phosphorous or some such, I’ll say, ‘Oh, I’ve been told that there is phosphorus in cheese.’ I won’t say, ‘No, that’s incorrect. You’re wrong.’ I’ll just say, ‘I’ve been told a different story on it.’ I feel like to do otherwise I would be offering medical advice which I’m not qualified to offer.”

Like Gretchen, Sherri is careful about correcting misinformation online as well, particularly when she reads about “fads like herbs and stuff,” and she expands on this when she says:

> Well, what I've been doing from day one, is just ignoring it because what happens if you, even in any kind of a mild way, if you contradict a fanatic, they just get angry. They're not open to any thoughts or ideas…. I don't want to have to fight with people because I want to save my energy for all the things that I'm trying to do for myself. Their doctors can fight with them.

In these instances, Steve, Gretchen, and Sherri all pinpoint the importance of medical advice given by qualified healthcare providers in their discussions on refuting bad information they see online. This is in line with something that Amy says: “A lot of people post on these sites questions that should be answered by doctors, not by me.” This echoes Brent’s sentiment discussed earlier in this chapter: that many people go online with questions that are best answered by providers.

In fact, many participants saw the information they got on the forums as recommendations or as a jumping-off point; nearly all of them talked about how important it was to verify the things they read online with their healthcare providers before making any decisions or changing their care. Travis explains: “I’m not just going to jump into something just because somebody says, ‘Oh, I tried this and it worked.’ Like I said, before I do that, I’d rather – as Reagan used to say – ‘Trust and verify.’” This process is a common thread throughout the data and is a finding that extends our understanding of how the type of information sought online might impact verification behaviors more generally (Flanagin & Metzger, 2000).

4.4.2.2 Crosschecking online information with other online sources. Participants also report crosschecking online information with other online information, as Travis alluded to when discussing the sources he consults for health information. Sherri says:

> I’m just skeptical. I don’t discount, I, when somebody comes up with a suggestion in the online chat group, I go research. What does Johns Hopkins think about this?

> What does the Mayo Clinic think about this? What does some other really reputable source think about this?

However, the ability to crosscheck information online is limited, because, as Amy says, “After you look at four or five different sites you basically get the same information everywhere.” This phenomenon was also discussed in a recent review of websites for patients with CKD (Lutz et al., 2014), which illustrates that the scope and depth of information found on static websites for CKD is limited at best. Most static sites contain only brief overviews of the illness, and very little, if any, practically focused and empirically based information about coping with CKD or lifestyle changes. The limited scope of online information on static sites mentioned by participants (e.g., Mayo Clinic, John’s Hopkins, the National Kidney Foundation site, Nephrology News, and WebMD) may contribute to use of forums, which contain considerably more information about lifestyle changes and practical issues faced by CKD patients.

4.4.2.3 Crosschecking information from providers online. A dismissive response from a provider may cause participants to crosscheck the information they did receive during that interaction with information from other sources. For example, as previously discussed, Joan lived with “discomfort or downright pain” in her arm after her fistula was placed. As she describes on the forum: “There has not been a single day where my arm has not felt like it was being burned, being pricked, being bruised, or being pinched. Even as I type this, FOUR YEARS LATER it aches.” After receiving a pre-emptive transplant, Joan decided to look into fistula ligation – although she may someday still need it if her transplant ceases to function. However, the standard practice in the United States is to keep the fistula without tying it off in case it is needed again in the future (Aitken & Kingsmore, 2014). She inquired about this at an appointment with her GP for an unrelated issue:

> And he said, “You know, you might want to think about tying that off.” And I said, “Yeah, but what if I need it? What if my transplant fails?” And he said,

> "Well, that's a risk you have to take." And I thought, "You know? That's a little bit nonchalant."

Joan then went to her nephrologist, consulted the forums, and met with a vascular surgeon in order to determine what to do. She eventually had the fistula ligated and, as she describes the appointment with the vascular surgeon where she made this decision on the forums: "My arm has been bothering me for four years now, and the very idea that a 15 minute procedure performed as day surgery could 'make this all go away,' as he put it, delights me. Most nights the whole area between my armpit and my elbow just aches. I thought this was all part of it, that it was the nature of this particular beast, but I was mistaken." Had her doctor not initially replied in a nonchalant manner, Joan may have continued to put off asking other providers and the forums about her fistula, which was not only causing her pain but was putting her at risk for cardiac failure.

It is not only that providers have a dismissive attitude towards specific situations brought to them by participants: some participants say that providers also do not generally provide emotional support. Joan describes:

> I don't think there's enough validating people's feelings in general. This whole thing is so medicalized. And your doctors are concerned about your numbers and that's pretty much where their involvement ends. There's a whole other half, and that is your emotional half. And I just, I really don't think that that's stressed enough.

This is a common theme both in my discussions with participants, in the forums, and in the literature about chronic care. Although empathy is a necessary component of effective doctor-patient communication, a distance between patients and providers exists and is propagated as a function of the medical system (Haque & Waytz, 2012). This process may lead people to search for emotional support elsewhere, as they cannot receive it from their care providers. Often, they turn to family and friends for emotional support, but as we will see in the following section, these individuals cannot always provide the support they desire.

4.4.3 Family members and friends. Participants give detailed accounts of the support they receive from family members and friends; this support is largely tangible, particularly when it comes from close family members, who are generally the people who provide tangible support in a crisis according to prior literature on the topic (Antonucci et al., 2011). These individuals attend medical appointments with participants to "lend a second ear" (Nina) and to ask questions and help interpret health information from the doctor; they help participants stay accountable to their renal diet by reading food labels and enforcing dietary decisions, like Amy's daughter and Sherri's husband do for them; and they carry out activities related to at-home hemodialysis like Brent's wife does – she orders supplies, keeps inventory, and occasionally assists in cannulation during Brent's home hemodialysis sessions. Sherri and her husband even have a weekly routine where they track health information together:

> We've got sheets of paper [that we keep in a file folder] and we keep track of what's your blood pressure, exactly how many minutes of exercise did you get this week, and every time I get my GFR or albumin or whatever measures I write it down, and I'm more picture, visual oriented. My husband's more numbers oriented. So what I do is I've got an actual chart that I make, so I was able to see that, is GFR dropping or is it stabilizing around a certain number, and other things.

This is an excellent example of how family members may provide tangible support for information-related activities. However, this example is fairly unusual: Sherri and her husband have always been very health-oriented, and this record-keeping practice is not new – now, it just also includes information about her CKD. Bringing a family member to medical appointments is a more common example of tangible support for information-based activities; for example, Nina brought her husband to her transplant evaluation "so there was a second pair of ears for everything, somebody else to ask questions and stuff." However, most of the burden of illness management falls on participants. For example, Joan says: “In the past, I have been gently admonished by some [forum] members; I have been told that since CKD is MY problem, then the diet is also MY problem and that I shouldn't expect my restrictions to affect others.”

Family members and friends mostly provide tangible support to participants. Although family members and friends attempt to provide emotional support, participants say they often feel like these individuals cannot provide all of the emotional support that they need. In many cases, participants do not feel like their family members or friends truly understand what they are going through. As a result, they often purposefully do not ask for emotional support and may even hide things from their loved ones. This is often described as not wanting to burden their loved ones with emotional needs.

4.4.3.1 Lack of understanding. Sometimes, family members or friends do not really understand the care needs of participants. Dietary needs come up often in these discussions: family members may make dinners that are wholly unsuitable for patients on a renal diet, for example. Not being able to carry out routine activities is another commonly mentioned situation that causes participants to feel unsupported by their family members and friends. For example, multiple participants experience a lack of understanding from family or friends regarding the extreme fatigue CKD can cause; both Amy and Candice use the example of not being able to shower without resting. Candice says:

> [My husband] doesn't understand. To go up the stairs and take a shower and come back down the stairs, I need a nap. I'm exhausted. He doesn't understand it. He thinks, "Come on. Let's go upstairs, you can take a shower and we'll go to the doctors appointment." I say, "No, I'll be exhausted." I'm exhausted just getting out of the car and walking in to the appointment…. He doesn't understand how exhausting it is to walk up the stairs then walk down the stairs and the shower part…. It's not like I like walking around for days without having a shower.

This particular issue is partially due to the “invisible” nature of CKD – because fatigue cannot be seen, it may not be understood by others who do not experience it themselves. After telling a story about having to explain to her friend about how fatigued a shower makes her, Amy says, “Things like that, they’re just things that people don’t *quite* understand.” Her emphasis on the word *quite* here highlights the gulf in context created by actually experiencing CKD. Steve describes this very well:

> My kids don't understand, my friends don't understand. When I say, “I crashed at dialysis today,” it's just words. Where somebody that's gone through this, it's feelings. They know; they've felt it. They know how much it really sucks.

Jacob also talks about how his friends and co-workers don’t understand his fatigue, particularly when he was pre-dialysis:

> Here's another one who's "right there with you"! Like you, I am pre-dialysis too so I can't offer anything about the benefits thereafter but I share your pain and suffering in the BEFORE period. People just don't understand what it's like to be ill and still have to get up in the morning and go to work when it took all your built-up energy just to get out of bed! Then you drive yourself all day to get home in the evening, go to bed early to get enough sleep to do it all over again the next day! It's really a grind! Then, FINALLY, a weekend comes and you spend it exhausted and resting so... yes, we can do it again next week! So... I share your pain.

Joan gives a nuanced view of how understanding is linked with support:

> You don't have to have had a kidney [transplant] to "understand" that that is a rough process… My husband doesn't ‘understand’ much about kidney [transplant] because he's never had one, but he doesn't need that particular sort of “understanding” to listen to what I'm telling him and to accept the truth of my words.

From this, it is evident that there is a particular type of support that participants get from people who understand because they themselves have experienced CKD – something that could be called *experiential understanding*. It is not for lack of trying that Amy, Steve, Joan, and other participants’ family and friends do not understand – it is the lack of experience that makes them unequipped to provide a specific type of emotional support. This desire for experiential understanding is closely related to *future forecasting* and is one of the main motivators for going online to find health information. This will be discussed in more detail in the section on future forecasting, below.

This lack of understanding from family members and friends may spur participants to share health information online. Take Brent:

> [The forum has] been a, it’s proved a great outlet. As I mentioned, the whole need-to-know thing, I’ve got this – during the course of a business day or even with friends and family I can’t (laughs) I can’t go into this, the details. They just really don’t have a desire or a need to know. So it’s quite an outlet to be able to share this stuff in a, through a, through that website, that I can’t and generally wouldn’t. I would be wasting my breath.

Again, Brent does not go online to search for information – and he does not post messages asking for emotional support; he says: “I have my family for that!” Brent further explains that his impulse to share would be a burden on his family members and friends, so he goes online to do this. Nina, too, says that she goes online to help regulate the amount she shares with family and friends:

> You get me on a certain day, you’ll hear all about my kidney disease whether you want to or not, even if you don’t even know me very well. I’m always kind of going back and forth on that. Some days I might talk to somebody and I might not even mention it at all. And I’ll go, isn’t that great, not to bore somebody with this. Because it may mean nothing to somebody. They don’t, they don’t understand it. They can’t understand what that is. Which is what I think sends people to forums like IHD. Because those people are living with it. They really get it. They know what it’s like to live with a serious chronic disease that just gets worse.

For Nina, this is partially born out of a desire not to “bore” people, but it is also about finding people who understand what she is talking about and how she feels. Furthermore, emotional support from family or friends may be downright unhelpful at times. For example, Sherri describes:

> What I've done is, I've shared with neighbors and friends my feelings and my emotions and my fears, and it's just been really, really negative. What I get back is platitudes about, "Oh, I don't worry about dying," or "No, I'm not concerned about that. I just live everyday with joy." I'm going, "Oh bullshit." The reason you're living life, blah, is because you don't have anything on your plate. You're healthy

> and you think you're going to stay healthy and live forever. What we all learn is, share your feelings because people will love you. Well, you know, whatever. The reality is, no, they're not. You know, they're not. What they want me to do is they want me to say all that brave, "I'm going to fight this, and I'm going to win, and I'm going to live forever, and I don't have any negative emotions, and I'm just living every day to the fullest." Bullshit, bullshit, bullshit, you know? I need a *strategy*. I need to find some people that can say things like, when I thought that I was going to have five healthy years, I was really upset…

Here, it is very clear that Sherri feels different from her neighbors and friends because she has been diagnosed with CKD; this difference makes their emotional support less helpful and meaningful to her. This will be discussed in more detail below, in the section on assessing similarity.

4.4.3.2 Protecting family and friends. In some instances, participants actively choose not to share details about their emotional needs with their family and friends in order to protect them. Take Nina, who says, "I don't think [my family] are always comfortable talking about [my CKD]… I try to be pretty matter-of-fact about it. Early on I told myself my family would take the lead from me. If I fall apart, they fall apart. So I can't do that." The desire to protect family members and friends is strong, and it often results in hiding information. Amy explains: "I don't want to burden [my sister, who is a nurse] overly too much with what is going on with me, so it's almost like I have to snap out of it to be able to put on my little happy face back on when she comes in [after working her 12-hour shift]." When asked why she feels this way, Amy says:

> Well she's put in a 12 hour work day and… she needs time to relax before she has to turn around and do it again tomorrow. The last thing she needs to do is worry about me. Which sometimes she gets very upset with me because there's been times where she'll be gone for the weekend and I'll have something and end up in the emergency room and I call her from the ER and she gets mad because she's like, "Why didn't you tell me this before now?"

After a pause, I ask her, "Why didn't you tell her?" and she responds: "Sometimes it's the burden. Sometimes I feel like I am a burden and I feel like I don't want to interfere with her life. I want to be… I, I desperately want to be independent but realize I can't be." This is closely related to coming to terms with chronic illness; feeling like a burden "is rooted in physical dependency and immobilization, [and] ill persons usually recognize that their illnesses have become their major source of social identity" (Charmaz, 1983, p. 188). Protecting family members and friends by hiding information, therefore, may happen as participants come to terms with their diagnosis. It also may be a form of self-protection: when participants do not ask for support, they don't have to grapple with their illness. As Joan says: "It takes a lot of grace and self-confidence to allow someone to help you." Robert expands on this, and says:

> It makes me feel good to hear someone say you don't look sick or you're looking really good despite being on dialysis. It's important to me to know that no matter what all I'm going through, I'm still able to project a positive image while out and about…. Yesterday, I went to lunch with family and friends I haven't seen in awhile. Got compliments on how much better I looked than a couple of months back. Knowing how shitty and despondent I'm feeling, it truly made my day realizing I could still mask my suffering within a social setting. That is important to me. Why bring down others?

Participants may also hide information as an attempt to ration support from their family members in anticipation of needing more of their support in the future. Again, Amy explains that "it makes me sad that somewhere along the line either my sister or my daughter are going to have to take care of me." Candice, too, worries about a time in the future when her husband will have to take a more active role in her care; she tells a story about making him tuna salad and trying to hide her fatigue – particularly because, as she says, her husband is "the one who will stick his head in the sand. But he is going to have to be the one to help me later so I want to be contributing now." Brent discusses how important it is to care for his wife; he has set up his home dialysis room specifically so that he and his wife are able to spend time there together ever night. Many participants discuss making sure that they care for their care partners; as Joan says, "I protect my husband, I care for him and I make the decisions when needed, while at the same time, my husband protects me, he cares for me and he makes the decisions when needed. Since when does it have to be and either/or proposition?" Prior research illustrates that chronic illness often disrupts personal relationships, and can cause what was once a balanced relationship between the patient and the caregiver to become unbalanced (Rolland, 1994). In this study, hiding information is one way that my participants cope with their own changing identities as they attempt to retain or regain the balance in their personal relationships with their caregivers.

4.4.4 Emotional aspects of online interactions. From the themes addressed in the preceding sections on healthcare providers and family members/friends, it is evident that interactions with other people that are not patient peers cause people to go online to both search for and share health information. These interactions have a large emotional component. Therefore, there are many emotional aspects that motivate online information behaviors. This is also evident when discussing what participants mean when they say the word "information." For example, Sherri explains that there are two types of information:

> One is rational and logical, which is after you've got the basics, what is it, what causes it, what can you do about it, then you start drilling down into diets and stuff like that. That's the logical stuff. Then there's another form of drilling down which is related to either things that are of particular interest to me, that I kind of don't want to get into why, and part of that was I realized there were some search terms that I picked because I was particularly terrified.

Jacob, too, makes a distinction between emotional information and technical information. He says that as a man in American culture, he feels like showing any emotion other than anger is difficult; he shares online because, as he says:

> I wanted people to know, hey, you can seriously come to tears too. So part of it comes from when I really had to get down to gut level and share my experience with my own depression. And then there are times when it's like purely technical and it's like, here's what happens. For example, I wrote about dialysis and the procedure. Here's what happens when you sit down in the chair, or before you even get to the chair. Here's what happens when you sit down in the chair, here's what happens 4 hours later.

He then follows that with a recognition that even technical, rational, or logical information has an emotional component: “I didn’t want to scare them, but at the same time I wanted them to understand the entire process so that it wouldn’t be so frightening.” In fact, fear is an emotion that many people mention when they talk about going online both to search for and to share information; Laura says, “The fear of the unknown is what really led me to go onto the forums.” Joan agrees that negative emotions motivate her to take control of her situation via information:

> Fear can be a big motivating force. And I tell people that it’s OK to be afraid, but that you just can’t let your fear paralyze you. What you need to do is you need to take your fear and use it to make yourself, get some education about the disease and about modalities and use the fear to your advantage, because that can be done. So, you know, I often look at new introductions and see if their story is like mine and I can come on and just tell them what I told you, that it’s OK to be frightened.

When I ask Candice, “Has there ever been a time where you avoided information about kidney disease?” she quickly responds, “Out of fear?” I tell her, “For any reason,” and she responds, “No. I'm more inclined to look it up to learn more about it. If I find out that it's something to be feared, then I will dig deeper. I'm not one to put my head in the sand and it'll go away.” This idea of “playing ostrich” is echoed by Amy:

> I… sometimes I play (laughs) ostrich with my head in the sand and don’t really wanna know stuff because dialysis is not something I want to do so I don’t really like to do it but then I come up to reality and decide I better be as knowledgeable when I go into this… I want to be able to have enough information that I can have input into any kind of discussions that come up.

This kind of cyclical engagement with information is common for participants; as Joan says, “I struggle with my desire to be informed about dialysis and my desire to not think about it at all.” Jacob describes a staged process closely linked to his emotions that leads him to share about his CKD with others:

> One of the things that got me into blogging and such, now I’m remembering why I went into blogging. I went through a really, really significant depression…. It was classic Kübler-Ross. Looking back, I’m like, oh yeah, I went through every

> one of these stages. You're probably in depression, and I need to get to acceptance. And I need to embrace my dialysis.

For Jacob, sharing helps him to deal with his negative emotions about CKD; it also helps him come to terms with his illness and with his life context. Robert tells another patient online who wonders if they really need to go to dialysis three times a week:

> It is not uncommon for those new to dialysis to go through the same thought process as yourself. It's kind of like a rationalization stage. While you aren't in denial, you haven't quite reached acceptance of having to be on dialysis either.

Here, Robert links emotionally coming to terms with the illness with getting the best care possible. He follows the statement with: "Think about it...healthy kidneys work 24/7. That is 8700+ hours a year. At 3.5 hours x 3 treatments per week, do you honestly feel getting at best 550 hours a year is adequate to keep you healthy?" The literature actually suggests that coming to terms with illness and relinquishing control by allowing illness and treatments to be integrated into one's life and identity is an important component of empowerment and of patient care (Aujoulat, Marcolongo, Bonadiman, & Deccache, 2008). This is in contrast to the popular understanding of empowerment, which typically focuses on gaining control over one's illness, not on "letting go" or on relinquishing control.

In fact, the notion that disclosure can help people both relinquish control while simultaneously relieving emotional burdens is a common theme in the literature on disclosure (Petronio, 2002; Smyth et al., 2009). Multiple participants say that writing about their experiences with CKD is very helpful emotionally as they come to terms with their illness. Nina says:

> To be able to just talk to somebody. Especially like, someone like yourself who so understands, I mean, is experiencing the same thing. Going through challenges more than I certainly have, anyway. I find it very therapeutic to do that.

Here, Nina calls attention to the importance of sharing her challenges with other people who are similar to her. This is one of the reasons that disclosing in the OSG is therapeutic for Nina and other participants who describe similar feelings: she is disclosing to other people who understand her emotional struggles. This will be discussed in more detail below, in the sections on assessing similarity and future forecasting.

4.5 Information Behaviors in Online Support Groups

In this section, I address how participants find OSGs for CKD and the information-based activities in which they engage throughout their use of the forums. Interestingly, many participants say that they did not set out to look for other patients with CKD when they found online support groups (OSGs). Instead, they encountered OSGs while they were conducting general online searches for information about kidney disease:

- I ran across it by Google, just when I was looking for stuff. (Amy)
- Within three months of kidney failure, I found that forum. I was just searching something. I was Googling something that was happening to me – a symptom. Google came up with a thread from there. (Steve)
- I just Googled "dialysis" and that was one thing that popped up. That was it. (Joan)
- I found it just by doing a straightforward web search… Googling different terms like "kidney" or "renal" or any number of things like that. I just did a bunch of different searches and perused them. (Nina)
- I was just doing a search on the web, and this interesting site came up full of other patients on dialysis. (Travis)
- I'm never good at typing into Google, but somehow I found this fantastic place on the Internet when I was Googling for something about dialysis. (Gretchen)

- I found this forum by accident. (Robert)
- Well, I'm afraid that's a good question that I may not have a good answer to. Uh, I don't know. Yeah, I think possibly out of curiosity I just Googled [the name of my clinic] or something like that, and the website popped up. (Brent)

This is particularly interesting because, although participants at times feel as if they are unsupported – both informationally and emotionally, as described above – they do not necessarily set out to find a support group online. Instead, they report searching for symptoms or looking for general information about dialysis and encountering the forums during those general searches. This is supported by the literature on information seeking, which demonstrates that even when people actively feel a need for information they may wait until it is accidentally encountered rather than seeking it out purposefully, particularly for information that may be stressful to engage with – like health information (Johnson & Case, 2012). Furthermore, most participants don't recall precisely how they found the forums in this study; this leaves open the possibility that some of them were indeed searching for support – for example, Nina says that she thinks that many people find the forums because, as was noted earlier, "sometimes when you're doing a Google search for something and you're just really not getting the hits that you want, sometimes if you just type in what you're feeling, like a thing you'd actually say to somebody, a person? Sometimes then you get what you're really looking for." She goes on to describe the content of the forums as "more relevant to people looking for support, and less sophisticated information probably. That's what makes the forums more real. It's just people talking about what they're going through." Here, Nina stresses the emotionally supportive component of information found and disclosed on OSGs.

Participants describe “lurking,” or reading forums without commenting, for some time before making their first post. Steve says that he looked at the forums for an entire day after he found them; registering and posting his first post that evening. Gretchen says, “I read it day and night for about a month. I read every single post on it and then I joined. It was probably the most useful thing I found [online].” Sherri expands on this; when I ask her if she has asked any questions online, she says, “I'm going to have to cop and say I haven't. I've been feeling like I'm ready to. What you do etiquette wise is you lurk and you find out what are the rules in this social group. I have lurked longer than I needed to. I've been a very enthusiastic contributor in some threads, but I haven't started one.” Here, Sherri sets a high bar for participation: she feels that asking questions is what defines participation, not simply responding to questions posed by other people. Although most participants report lurking first, not everyone does so before making comments on the forums – for example, Robert did not lurk before he registered to make a comment, but he registered specifically after finding a thread that he wanted to reply to directly. This thread, about a specific dialysis center in his area of the United States, was one that he felt he could contribute to because he was also a patient at the center being discussed. He expands on this:

> I never started posting online, or even going online until I found out about [this forum]. The only thing I looked for was information, and I would look specifically for research. Not a specific patient forum, that's not what I was looking for. I just stumbled across it.

Lurking is common in online forums for a variety of reasons, and other studies corroborate the desire to understand community norms first before “de-lurking” and starting to participate (Preece, Nonnecke, & Andrews, 2004). While Preece et al. found that people who lurk are less satisfied with their experiences in forums than people who participate more actively, this is not necessarily always the case in my data. For example, Amy has never commented on the forums but she explains through tears that “reading other people’s stuff is so therapeutic for me…. It just hits me, how lucky I am (tears up)…. It gives me a different perspective on my life. And through that process of seeing someone else’s experience I can see my own experience differently.” In fact, Amy does not post because she finds writing to be overwhelming:

> Writing is not one of my best things, so to me to sit down and write a long post or even a short post, it takes energy and thinking and sometimes my mind is just not there to be able to put coherent words on to paper…. It is just the straw that breaks the camel’s back. Building and building and building all day and you decide that you need to vent, and even that is too hard.

This is a reason for lurking that is not often commented on in the literature – that sharing is emotionally burdensome for the individual who is disclosing, so they instead choose to lurk. However, it is closely related to the finding that some people decide not to share in health communities because they feel too sick to post (Preece et al., 2004). Amy also lacks the energy to write well because she is ill; she also is concerned that she doesn’t have anything to add to the forums: “Sometimes I wonder how much information I have to share and how relevant it is,” she says at a different point in our conversation. Not wanting to share irrelevant information is another example of waiting to understand the rules of the community before posting.

Another “etiquette rule” that many participants discuss is repeating questions. Most participants say that they are concerned about asking questions that have already been asked and answered by other users, particularly when they first start using the forums. For example, Nina, who lurked for years before registering, says in one of her first posts: “I have been trying to get up-to-date with the postings…. It seems like the more I read the more questions I think of. But I want to try to read as much as I can before I ask something that is already answered in all the many posts.” Joan quickly responds:

> Don't be afraid to ask questions! Yes, they've probably been asked before, but we get new members all the time for whom all of this is new, and they have questions, also. Not only that, but there seems to always be new treatment

> options, new dietary advice, new information about all kinds of things, so an answer given 2 years ago to a question might have to be a different answer today.

Later, Nina responds: “On so many web forums people can get a little short-tempered if a question is asked that has already been answered in previous posts. It's a huge relief to know that [this forum] isn't so picky. I think I'm going to like it here. ☺” The issue of repeating posts can pose some frustration when participants want to answer a question that they have already answered in the past on the forums. Brent has two methods for dealing with this issue, which he describes:

> There’s a remarkable amount of redundancy. Pretty much the same thing is asked over and over again. I try to respond multiple different ways. But that’s one of the things that can be a little frustrating, is realizing that I answered that question, or responded to that particular issue, three to four months ago in another post. And I just have to repeat myself. What some of the users do is that they put links. They’ll put a link in there to the other post, rather than repeating themselves. The other thing you can do is you can go back to your post and you can copy and paste the thing in there. There’s another approach.

According to the data, the repetition of content on the forums is due to several factors. As Joan says above, it is related to the fact that new users are registering nearly every day on the most active forums; some of these users do not lurk for very long, which means that they aren’t aware of the community norms, as described by Sherri. Forum users also may not know how to find old posts and may make comments that are redundant because they cannot find related prior comments, as Brent explains:

> Lately, when I go into my profile and I look at what I posted, it doesn’t have what I’ve posted. It’s got some really old stuff in there. So it’s not even easy for me to keep track of things. I have to go in and use my memory as to what I might have responded to and then see if there is any follow-up. It’s not particularly user-friendly either (laughs).

In fact, issues with forum interfaces are a common theme in the data. For example, in a lengthy thread about a recent interface update on one of the forums, Jacob says, “Sorry guys. You still don’t have it together yet. This site is confusing and disorganized.” The other most popular OSG is similarly difficult to navigate. Steve expounds:

> The search sucks. I'll tell you that right now; really, it's horrible. I search stuff that I know is out there, and I'm using the key words, and it's not coming up. I know I've read the thread there, I know it's there. It's not a good search engine. It's a very low budget website. The search is not good.

The search engine on this particular OSG is also something that elicits complaints from multiple participants and other users on the forum. For example, relevance rankings weight text in comments differently than one might expect (“SMF2.0:Search,” 2014). Threads with more comments in them are ranked higher than threads with fewer comments; also, if there is a match in the first comment in a thread, that thread will be weighted more heavily in the relevance rankings. It also only allows users to perform one search every ten seconds, returning an error message (“An Error Has Occurred!”) if the user attempts to conduct several rapid-fire searches, which may happen when users reformulate misspelled queries, or queries that return no results. In fact, Candice tries to find something on the forums during one of our discussions and comes up against this error message, saying: “I don’t understand why it is doing that, what error am I causing? Oh well.” She then stops searching and returns to our conversation, suggesting that this error message may in fact discourage users from using the search function altogether, particularly during sessions where they need to refine queries multiple times. These limited functionalities cause consternation and frustration for participants – and for other users on the forums – and may point to one of the major issues with using out-of-the-box bulletin-board style interfaces for online support groups.

Participants often do not frequent just one forum, and they report going to different forums because, as Amy, who visits two forums regularly, describes, “You might get a little bit of a different perspective on things [from different places] because everybody’s experiences are different." Often, they have one OSG that they visit frequently; this frequency varies for everyone, but some people go to the forums daily, like Robert; others go every few weeks, like Candice; still others visit very sporadically or may stop visiting the forums altogether, particularly when there are problems on the forums. For example, one participant no longer visits his main OSG due to a dispute with another user, but he is still active on other OSGs. Another participant had a dispute with the moderators in the same forum and no longer comments; in her last post, she said that she no longer felt safe posting on the forums. However, she still visits the forum regularly; she just does not make comments there anymore.

The frequency with which participants visit individual forums is closely related to the amount of activity in those spaces. Take Nina, for example. When asked, "Why did you decide to start participating on [this forum]?" she responds:

> There were a few [forums] that I liked. What I liked about [my favorite group] more than anything [was that] they had the most traffic. Every day, there's people posting. Every day. Every day. And I didn't find any other kidney-oriented site that had the kind of traffic that [they] had. And I kind of got stuck on that one, so… I think I visited that site more than, certainly more than any of these other sites.

Robert, too, says that he visits one forum frequently because, as he says, "there's more of a conversation on there." Laura, who uses a more sparsely populated OSG, expands on this: "The forums, they're not so popular, I don't believe." I then tell her about another more heavily populated forum and she says, "Oh good, oh, I will try that one. I'm really interested in all of the different forums that everyone uses because, as I said, I haven't found so many!" Brent, who is also a member on a less heavily-trafficked forum, also says:

> One of the things that I've come to understand in posting is that it's rare to have an individual like myself that's on there pretty regularly. Meaning several times a week. I've had instances where I've posted something and I've gotten a reply three months later. There are posts that are six months old that individuals responded to and then the person who posed the original question comes back eight or nine months later with a response.

The level of activity on different forums is an oft-repeated reason for returning to specific forums more frequently than others – forums with more activity are visited more often. Moreover, the frequency of individual visits by each participant is closely related to illness-related events. For example, Laura had her peritoneal catheter placed in the time between our first and second phone conversation. When speaking with her the second time, she explains:

> I haven't been back to them since I started dialysis. I think the main reason is because I was using those forums to seek information I did not have and I did not know. I wanted to see and hear about people's experiences because I hadn't started it yet, and it was all very new to me. I just didn't know what to expect. Now I've started dialysis and I'm very comfortable. My questions have almost dwindled a little bit because I've now fallen into a routine that I'm comfortable with.

I ask her if she thinks she'll return again at some point, and she says, "Oh, definitely, if and when the transplant comes up, I will probably be there asking the same types of things, only about a transplant and not about dialysis!" The relationship between health events and forum activity is also evident when viewing graphical representations of posting activity of individual participants. Take Nina, for example: as illustrated in Figure 1 on the following page, when she first finds the forums, she posts about three times a week, tapering off to only about one post a month after her first three months on the forums. After her transplant, her use of the forums increases as she shares more about the transplant process. Additionally, she initiates threads only occasionally and during major illness events: one when she joined the forums after her CKD was moved from Stage III to Stage VI, another when she was added to the transplant list, and a final thread announcing her very recent transplant posted the day after she received a kidney.

In contrast, Robert starts threads more readily; these threads are still related to situations that occur in his CKD that might not be classified as "major illness events," but are still things he wants to discuss. For example, he created a document in case he is in an emergency that renders him incapable of communicating his dialysis care needs; he shares this document on the forums,

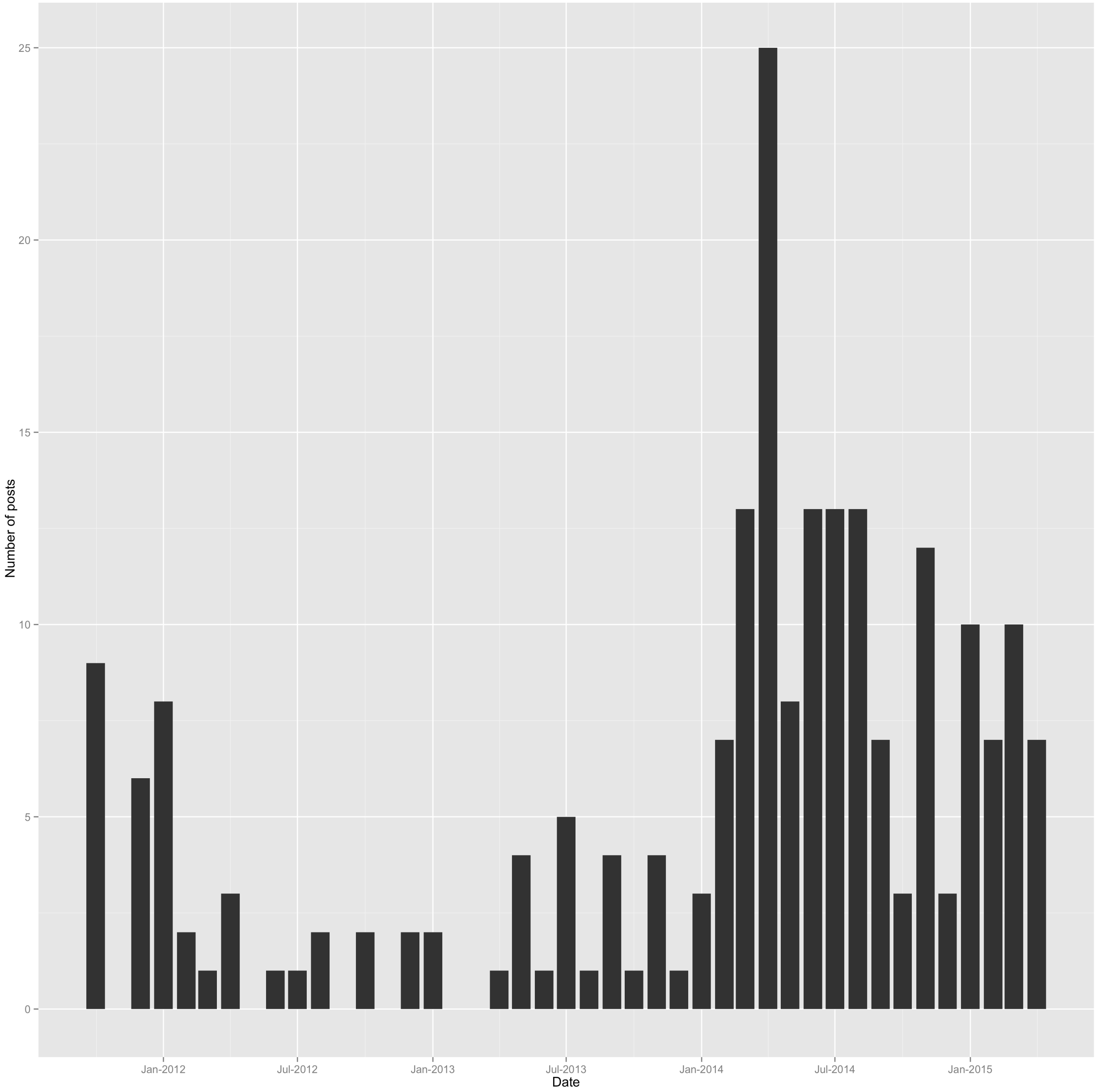

Figure 1. Nina’s comments on the forums over time.

saying, “All you have to do is fill in the blanks, change parameters or what to include/delete then have your nephrologist sign off on it…. Hope some [of you] can find it useful.” In another case, he posted a thread asking whether anyone had heard from a user who had not signed on for some time: “Anyone keep in touch with [her] outside of [the forum]? She hasn’t been active in awhile… I hope she is OK and has been too busy to come around!” The issue of users who are no longer on the forums will be discussed in more detail below.

The number of comments people make and the number of threads they initiate is largely individual, but generally, as Sherri says, “What people seem to do is, they come in when they first get diagnosed, and they're all freaked out, and I'm able to be helpful to them with some resources and stuff. Then they disappear, in some cases forever and some cases for a while, while they're dealing with that.” And, as Brent said earlier, there are few people that visit the forums and make comments on a very routine basis. Nina expands on this as well, linking heavy use with credibility:

> If you read it as I read it, regularly, these people who post all the time? You kind of get an idea of the people that when they’re posting, I pay more attention to. Because I feel they’re better thought out and they are just, they have more credibility, I guess, but also more compassion.

Identifying credible users on the forums will be addressed in more detail below, in the section on assessing similarity. Participants also say that they end up caring very deeply for other users; this emotional bond is fostered by disclosure. Travis expands on this:

> When I first got on there… I said, “Here’s my story. Here we go.” And the concern of other people, again, they’re people that are in the same boat as you’re in, and they came back, “Gee, I’m hoping you’re feeling better,” “I hope nothing ever gets worse.” So stuff like that, where people responded in a friendly way – and that’s the way I try to respond, is, some people they’re really in bad shape and they’re… hang in there, and you know, say a prayer for you, and hope everything turns out. And these are people I wouldn’t know from Adam, if they walked in my front door. But I care about them.

This illustrates that, rather than asking for emotional support outright, Travis instead tells his story and this triggers supportive behavior from other users – which then builds connections and caring. That some participants get emotional support without directly asking for it is also substantiated by several other studies on emotional support in OSGs (Pfeil & Zaphiris, 2007; Wen, McTavish, Kreps, Wise, & Gustafson, 2011).

Jacob uses similar language when he says that his disclosure fosters the feeling of a caring community. He also says that writing allows him to learn about his own experiences and that this learning process is what fosters a true connection with other people who have CKD:

> It's cathartic for me to sit and write about [CKD], because in order to write about it I have to learn, and in order to learn I have to be conscious. So I have to actually look up and see the people in the room and interact with them on a one-to-one level, to use that analogy. And that's what it does. When I write and then I get some comments, I realize I've touched somebody. For example, I do have one person that sent me emails *all* the way through her getting started with dialysis. And I would write her back and let her know and it was very one-on-one. There's even that level, where I've interacted – and I wouldn't know these people from Adam. But I know them through their writing and I still get letters, that sort of thing, emails, rather.

Sharing and disclosure therefore may foster the belief that forums are communities rather than just an assortment of disparate individuals. Forums also operate outside of the traditional boundaries of time, even virtually freezing it in some cases, particularly because new users often report reading many posts from the past as they get acquainted with the forums and as they learn more about CKD. For example, Steve felt so connected to the founder of the forum that he frequents that he didn't even realize that he had passed away:

> These people online, now, four and a half years, there's people that I care, I never met them. And I care *very* deeply about them. I, I, very deeply. And sometimes… sometimes these people just disappear from the forum, and sometimes a family member will come on and say "they passed" and it is. And I'll be si—I remember with [the original creator], who developed this website. I was on this thing for a *while* reading all these posts. I even was like, "Thank you [original member]!" and then all of a sudden I came upon a thread and realized he had died a year earlier. And I was like… I was just sitting in front of the computer just bawling.

In fact, the issue of "disappeared" users is something that worries many participants; one of the forums allows users to give their moderators telephone numbers so that the moderators may call them if they have not been online for more than three weeks. There are two main reasons that participants worry about users who are no longer active: the first is that they are afraid that the user in question has passed away, and the second is that participants are reminded of their own mortality and of the harsh reality of CKD when they begin to think about another forum user potentially passing away. Steve expands:

> That's part of it and that's something, as long as I've been on the forum, is still hard. At first it was hard; I'm like, oh my God, all these people are gone, and then it made me feel like it's part of my own mortality. Now it's people you really care about. It's hard. It's upsetting in both ways. Anytime somebody passes away, you think about yourself. It's like, holy moly, I was just joking with them and now they're gone. A lot of times their loved ones will come on and say they passed, or somebody will come on who's got a more personal relationship with that person and say, "I just found out that they passed away." A lot of people pass away. I know dozens and dozens of people that I've lost through these sites.

The death of users can also contribute to the loss of a sense of community, especially when the users are prominent – like the founder of the forum that Steve frequents. Joan explains:

> I've been on [the forum] for a long time, and you gradually build up relationships and that community kind of feeling, that I might be kind of slipping from there actually, simply because there's just so many new people on there. And in a way, I mean, I'm glad they've all found it because I think [the forum] can be profoundly useful, but there's just no time to get to know everybody. And also it's kind of scary that so many people are facing this terrible disease, and so sometimes that kind of, I've found that recently there doesn't seem to be quite that same feeling of community. And some of the older members have passed away, and that always affects the tenor of a site. So we'll just see what happens. So that's another reason that I stay on there, I try to, with some of the older members, just try to keep that sense of community going.

Relatedly, condolence threads are not uncommon in one of the forums frequented by many of participants; in some cases, users will instruct their caregiver to notify the moderators of their passing, and this will be relayed in a memorial post where users can leave condolences. This is only a feature on the most heavily-populated forums, but all of the participants from those forums have made comments on condolence threads, sharing stories and in some cases offering support to caregivers.

The sense of community and togetherness is not universal, however. Many of the participants from the forums that are less heavily populated do not report feeling like they are part of a community. Brent says that this is partially due to issues with the interface on the forum he frequents:

> One of the features about it I don't like is that you can respond or put a question out there and you have to constantly go back to see if anybody answered it. There's no way to automatically know that somebody followed up on one of your posts…. The stuff on the website can take days, weeks, it can take months, and you just lose the fire. And with the difficulties searching, you might never see it. And if you do find it, it's like, oh yeah, that was three months ago…. Who knows who might come across those and be benefited by them. It's kind of a blessing and a curse. The curse part of it is you really don't know, unless somebody reads something and sends a friend request or a message request as a follow up to something I wrote. But it's more passive, most of it, a lot of the contributions I make are, the feedback I'm going to get, well, I'm not going to get feedback. It's going to be kind of a passive response. So I have no (laughs) it's unknown how much benefit folks are going to get from what I write.

Here, Brent touches upon one of the central issues noted in the literature about online support groups: a sense of community is fostered by member interaction (Maloney-Krichmar & Preece, 2005). If the interface does not promote interaction between and among members, it may be difficult for individuals to feel like they are part of a community.

Candice, who frequents an even less popular forum for CKD, says that she doesn't feel like she is part of a community partially because the forum she uses is less active than she would like, and partially because she isn't able to find people who have her specific issues. When I ask her about whether or not the site she frequents feels like a community, she replies:

> I had some really bad flank pain in my left back the other day. So I went on there but then I can't find anyone there who has the same problems I have. And most people seem to come on once and then never come back, they never come back. So no, there is not a real sense of community for me, and I can't get what information I need from the people that are there because they do not have the same problems that I am having.

Here, Candice discusses one of the important reasons that people use the forums for information seeking and for sharing personal information about their own health: they are looking for people who are similar to them both as information sources and as people to commiserate with and perhaps give useful advice. However, it is helpful when the community has some sort of cohesion – not, as Brent says of the forum he frequents, “so many are onesie, twosie, threesie postings. I have probably close to 120 postings this past year, and there are people that are way beyond me, but I wonder how these folks with one or two or three postings, how do they even find the site? Why are they even? Are they going to become more active, like I am? Or are they just shots in the dark?” Research indicates that identifying cohesive groups or communities often occurs when people define the group as a homogeneous collection of people who are members of the same social category (Ren et al., 2012). Moreover, groups that are perceived to be homogeneous foster assimilation of other similar individuals (Pickett & Brewer, 2001). Therefore, Candice’s feeling that the forum she frequents is not a community – not just because people are not very engaged, but because there are not people there who are similar to her – is not particularly surprising. In fact, the data indicates that similarity is one of the most important features of finding patient peers for the participants in this study.

4.5.1 Assessing Similarity. This section will examine how participants assess similarity in the forums. A section explaining one of the major outcomes of similarity assessment follows it: forecasting the future, a process of using information to try to figure out what will happen as CKD progresses.

One of the most common themes in the data is the notion of finding similar people from whom to get information and with whom to share information. This is not a particularly surprising finding – one of the largest social networks for chronic illness, PatientsLikeMe, is named after this phenomenon, and it’s generally accepted that “people like others who are similar to them in preferences, attitudes, and values, and they are likely to work or interact with similar others” (Ren, Kraut, & Kiesler, 2007).

When participants discuss similarity, they describe facets of similarity that are both structural and experiential, to borrow phrases from Suitor, Keeton, and Pillemer (1995). Structural similarities are typically demographic in nature. For example, *geographic location* and *age* are two types of structural similarities that participants say that they value. Finding other users from the same geographic location is something that multiple participants mention; interestingly, they do not tend to share information about what doctors from their area to visit, or what dialysis centers they prefer, with people with whom they share a geographic location. Instead, geographic similarity is often mentioned when participants greet new users in the Introduction sub-forums, potentially contributing to the sense of community discussed earlier. It is also important to participants who want to meet other patients face-to-face. Multiple participants had met other people from the forums in the flesh; everyone that I spoke with who attended a meet-up used the word "cool" when describing the experience. Joan says that actually meeting other people from her area was a turning point for her, because it gave her tacit information about living on dialysis:

> It was just, it was just seeing people, you know, there was one guy who was there, he was on PD, and he showed me his catheter. And there were other people who had just been through transplant, and there were a few more who had had a transplant for several years, and, um, there was one who was there who had been transplanted but was slowly losing hers. So there were people there in all different phases of CKD, and actually seeing them and seeing them have a good time and just seeing them live their life made me realize that maybe dialysis isn't the black hole that I had imagined it to be. So again, that was a real turning point for me.

Participants also value age as a structural similarity characteristic. Laura describes that age is particularly important to her when she assesses similarity because she is in her 20s, and finding people who are also young and have been diagnosed with CKD is difficult:

> I felt very alone when this whole process started because I never saw anyone my age that was going through this. Never came across anyone at the hospital…. They were an older age group.

Although structural similarity comes up in the data, experiential similarity, or sharing similar experiences with other users, is more important to participants when they assess similarity. When they are searching for information on the forums, participants typically actively seek out users who are at the same stage or a later stage of their trajectory and conversely ignore users who are at earlier stages of kidney disease. For example, as Travis says, "Some of them say, 'Oh my gosh, I'm at Stage II, I'm just going to lie down and wait to die,' and I'm going, 'Stage II? Stage II? You should be thankful you're there!'" Finding users who are farther along to get information from, as Gretchen explains, is important because, "That information was very relevant to me. Because I could see other people's problems, I wasn't having that problem yet, but I was aware of it and could keep an eye open for it." This finding extends the work of Suitor, Keeton, and Pillemer (1995) who show that experiential similarity, or having shared experiences with another person, is more important than structural similarity when people search for social support during stressful times of transition. Interestingly, participants in this current study are not necessarily searching for people who are also going through the transition at the same time as sources for information – instead, as Travis says, they are often looking for people who have already experienced the transition they are currently going through. This will be discussed in more detail below, in the section on *future forecasting.*

Although Travis highlights using people who are further along than he is as sources for information about CKD, many participants say that they look for posts from people who are sicker than they are as a way to put their own illness in perspective. This could be a form of passively gathering social support via assessing similarity and comparison. One participant says:

> I have started following a lot of little kids that have cancer and other medical issues. And reading what they go through on a daily basis goes back to that, "Hey, my life is OK." In comparison I realize life could be worse.

Multiple participants say that what they read on the forums gives them this feeling; this is a comparative activity wherein participants identify their experiences as different than the experiences of others:

- I think I’m very lucky. Some of the people that ask questions [online] are asking questions because they can’t get the answers somewhere else. Their kidney person or support clinic or whatever it is just can’t answer questions or don’t know or whatever. I’m not in that situation (Gretchen).
- I'm lucky in that I don't have diabetes so I'm not dealing with a bunch of those issues like some people (Steve).
- I must have been a lucky person, because I haven’t had any problem at all, and, some people have had to go back and have to do the operation again (Travis).
- I’m lucky enough to say that I’ve never come across [discrimination in the workplace for my CKD] like some people online have (Laura).
- What a wonderful, caring, considerate doctor I have been blessed with! It's wonderful to know I'm not just another body with ESRD. I've heard and experienced many of the horror stories so I'm very thankful to have this doc and the others I have. I am very, very fortunate! (Jacob).

This can be likened to the phenomenon of downward comparison, wherein people under threat compare themselves to people who are less fortunate as a way to increase their own sense of well-being (Wills, 1981). Downward comparison impacts what information participants decide to disclose on the forums. Take Joan, for example, whose posting habits decreased significantly after she received a pre-emptive transplant. She says that this is because she was no longer similar to most of the people on the forums:

> I'm very conscious of the people who either have had a transplant, and are not doing so well or who are waiting for a transplant. So I'm very aware of not wanting to appear prideful or negligent emotionally of all of these other people. Basically, I don't want to brag.

Here, Joan describes how the lack of similarity between her and other forum users results in her disclosing less online. Essentially, Joan avoids downward comparison by sharing little about her transplant. However, Joan is still an active member of the forums; she is heavily involved in the off-topic sub-forums, which she calls her "Internet home" – she has found a group of people with whom to chat about topics unrelated to kidney disease, even on the CKD-based forums, and this is where she goes when she is online. Her activities on the forums decreased after receiving a transplant, as illustrated in Figure 2.

Conversely, as illustrated earlier in Figure 1, Nina's comments increased substantially after she received her transplant; she describes that she refrained from disclosing much

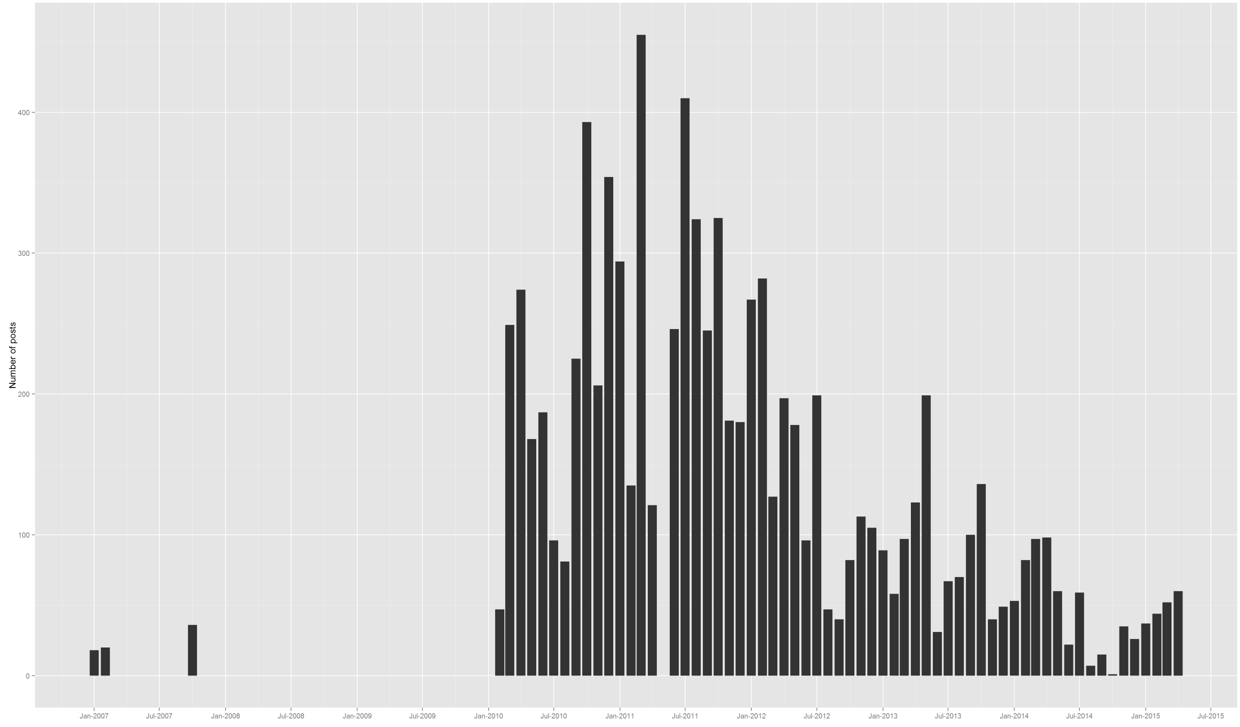

Figure 2. Joan's comments on the forums over time.

information before her transplant because, as she says:

> I don't feel so much like I have that much to give, because… there does seem to be a steady influx of people who do have a lot of experience and there are people who have been on for a long time who know a lot of stuff, what's going on. I feel less of a need, or a willingness, to participate. I don't feel like I necessarily have anything at this point – at this point – that I can share. I guess that's the biggest thing. If I read something and I feel like, I really have something to offer, that then I would post it. But that does not come up too often. More often there are people who have questions having to do with further down the lines with dialysis or transplantation and are in a place that I haven't gone yet. Maybe after that, maybe I would be more likely to post.

Indeed, after her transplant many questions came up that she was able to answer because she had experienced the transition that so many people were asking about on the forums. Her posting activity went up considerably the month of her transplant, and she continues to post more than she did before her transplant. Nina now makes about three comments a week on the forums, as opposed to making comments about once a week before her transplant. The differences between Joan and Nina's online disclosure habits after their transplants illustrates that lacking similarity with other people in the forums – not many people that have transplants stay on the forums, as noted by Robert in our discussions – has different effects for different people.

The process of assessing similarity begins very early in the forum interaction process, both for lurkers and for people who join immediately to make a comment. As previously discussed, the practice of reading the forums before beginning to post was common; many of the participants in this study spent at least a few hours or as long as several years to begin making posts to the forums. One participant, Amy, has yet to make a comment; she feels like she doesn't have enough to share about her kidney disease at this point, particularly because she is not yet on dialysis.

Travis explains how similarity assessment was fostered early in the OSG that he uses. This forum requires that users create an "introduction" post – a short paragraph or two outlining their experiences with CKD thus far, and their reasons for joining the forum. These Introduction posts are quite popular; many of the participants from this forum were very active on the introduction boards throughout their time on the forums. Travis explains that the comments on his introduction post helped him to feel like he belonged to part of a large group of people who shared something in common with him:

> We're all in this together and we can help each other. And so that first post, to have that many people respond to you, I suppose I felt, "Wow, this really is a community type place, and everybody's here with the same issues."

Although an "Introduction" sub-forum is a feature shared by most of the forums frequented by participants, it is not a universal feature. Both Laura and Candice visit forums without a dedicated space for introductions. When I ask Candice specifically about how she identifies people when she visits the forums, she explains, "I don't really see the same people on there. It's always new people, and they post one thing or two things and then you might never see them again. But it's hard to know if the people are the same or not because maybe they just came on under a new name, and no one there really uses the pictures." A convention of introducing one's self likely discourages the behavior Candice suggests – creating a new username for new visits to the forum. When I ask Candice if she's ever done this, she says, "On other sites, yes. On sites where I just can't remember if I was there or not I will create a new name. Sometimes then it says that my email has been used. But sometimes it doesn't. But on this site, no, I have always used this name. I like people to know who I am. That's why I use the picture too, maybe people recognize that it is me." Candice's avatar is not a picture of her face; it's an image of something that is personally meaningful to her that she found online. From this discussion, it's clear that Introduction posts can help build the community Travis describes in his above quote and which was previously discussed – and that some of the features of the interface, like usernames and avatars, are also important components of building a sense of community in these forums. This will be discussed in more detail below.

From Travis's insight, we can see that in some cases the idea of "similarity" is very broad: simply sharing the diagnosis of CKD is enough. This is especially true for newly diagnosed patients, particularly those who have been thrust into CKD without warning. Take Steve, who says that reading about shared experiences was integral for his care from the very start:

> I got hooked, like, immediately, on it. Because I would say, "I have a question," and these people were like, "Oh, yeah, that happened to me! Ask this, and this, and this." And I would go in and I would ask those three questions, and those were exactly the questions that I needed to ask.

In fact, sharing a diagnosis makes Steve trust the information provided by other users more: "I know that I should be asking my doctors these questions," he says in an early post on the forums, "But I believe that I would get a much more straight forward answer from [this] community." This aligns with something that Nina says about similarity: there is information that the doctors "can't or won't tell you," she says, when talking about her first kidney biopsy. "My doctor said, 'Oh, they're not that bad,' and I had to just bite my tongue, because I wanted to say, 'When did you have your last kidney biopsy?' I mean, you know? If you go to a [forum], there's somebody who has actually gone through this." In fact, other research suggests that supplementing information from providers is a major motivator for going online in other patient groups as well (e.g., Rubenstein, 2012). This may be particularly true when participants have questions about emotion. Laura explains that the only people who really know about the emotional aspects of CKD are other patients:

> I think when you are going through something like this, and you're fed so much information from healthcare providers, there's always that little bit, that part of you that thinks, I'm being told this information, but how true is it, especially when healthcare providers are talking about things like feelings. There's no way

> they can actually know. I think that's what I was searching for on the forums I went on.

Participants also discuss finding people who repeat information that they already know, or people who share information that is congruent with their own experiences, as a way to foster trust. Amy explains that she searches for information "that goes along with what I know about. I don't say I know everything, but when I'm reading something, if it's like, yeah, I can go along with that, I can trust that person." She says that the other things they post then seem more trustworthy and accurate because they have shared information that she knows to be true. This could be thought of as confirmation bias in action, wherein people tend to look for information that confirms what they already believe to be true (Nickerson, 1998).

As Robert explains, CKD can be full of what he calls indignities, and sharing this understanding is an important component of similarity to him: "I'm in my dialysis center, and there are 38 chairs, and I think, 'This is humiliating. It's a warehouse.' Dialysis is either prolonging life or prolonging death, depending on how you're being treated. That's the indignity. And you can't understand that – you *can't* – unless you go through it." Here, Robert discusses both the physical and emotional components of the dialysis experience, noting that they are both essential for understanding and for similarity.

Similarity is not just sharing the diagnosis of CKD or having gone through specific treatments or procedures, however. The assessment of similarity becomes narrower and more well-defined over time, as participants begin to have more specific questions about CKD or about their treatments. Laura describes this process:

> I think when you look for someone with similarities to yourself, it's just mainly what you do in a day-to-day life. I'm this age. I work full-time. I like to do a lot of exercise. I like to still socialize. Is there anyone that's the same? If so, how do you deal with it? I think it's just natural that you look for someone that's in the same situation as you to find out if it's possible…. It's very comforting when you find people that have the same questions because you almost feel silly in a way. I

> remember speaking to my renal team and saying, this is December, I said, "I have a Christmas party coming up. What am I going to wear? Am I going to be able to hide this?" The one woman, she was giggling, and she said, "Why on Earth would you ask that question? Is that your biggest concern right now?" I just thought, well, yeah, it is. It may sound silly to her, that she thinks that I worry about physical appearance, but you do when you're 28, and have your Christmas party, and you wanted to wear this dress but you can't, because it's fitted around the stomach. To someone else, it might seem like the most ridiculous concern, but to you, it can be a major thing. Only someone that is similar to you in that situation can really sympathize with that type of concern.

Here, Laura explicates several structural characteristics of similarity: age and gender. She also talks about *lifestyle*: exercising, socializing, working full-time, and taking pride in her appearance. These factors matter because, as she says, the assessment of similarity allows her to make comparisons and to build a hope for a future where she is able to maintain her pre-diagnosis identity. Again, "it's always easier when you see someone that's like you, and they show it has no bearing on them." This is a form of future forecasting, which will be discussed later in this section. This is also an example of how being dismissed by a healthcare provider might motivate online information seeking: doctors and patients may have different ideas about what is important. As in Laura's case above, the literature indicates that patients may be very concerned about their physical appearance while doctors may not think that something that impacts one's appearance is of consequence (Berry, 2006).

Sharing a lifestyle may be more important when participants search for certain types of information. For example, when choosing a dialysis modality, participants may look for people who share their "lifestyle" because, as Joan says, "Choosing your dialysis modality is really a lifestyle choice" – an observation that is corroborated by the literature on dialysis choices (Winterbottom et al., 2012). Different modalities allow for different activities; for example, swimming is difficult on peritoneal dialysis, traveling is more difficult (but not impossible) if one is treated in a center, and someone who lives alone cannot administer home hemodialysis.

These aspects of everyday life, and of lifestyle, impact health choices and also impact how similarity is assessed. For example, Travis, an avid camper and hiker, was concerned about choosing a dialysis modality that allowed him to continue camping. On the forums, he connected with another patient who also enjoyed camping and told him that he was considering hemodialysis:

> He went, “Yeah, you’re probably making the right decision for you. The way you are, and what you like to do, hemodialysis is probably the best,” which kind of made me feel good, too. That was coming from somebody who was removed from my story. He didn’t have, as they say, a horse in the race, but it was coming from somebody I respected and who I thought I could trust. It’s nice to have a second opinion from somebody who knows what they’re talking about, not an amateur!

The idea that “similarity” is related to lifestyle is one that is echoed by many of the participants in this study. Because of this, some participants actively avoid comments that some other users make because their lifestyles don’t align. Robert, for example, talks about another user who he does not understand or agree with; he says that, “there’s a lot on there that she puts that I just have to back away from.” I then ask, “Can you tell me why you back away?” and he responds by relating an issue that she posted about on the forums that he himself grappled with. He gave her advice about what to do, but she did not take that advice – and she continued to post about the problem for many more years. He closes the story:

> She won't do anything about it…. There's a lot of people on there that just want to whine and complain. No matter what you tell them, they're not going to do anything. I've learned now just to stay away from that, because that drives me bonkers. I've got that "guy" personality, that fix-it personality. Okay, let's fix it, and here's what you can do.

Amy, too, says that she tends to ignore specific people for similar reasons:

> I ignore people just because, well, based on what they always post. It doesn’t always seem to be general practice medicine type answers. It’s like almost opinionated more than factual. And I’m more really into the people that can back up what they’re saying by medical stuff. Or seems they’ve done their own research enough to know that it is legitimate.

I then ask her how she is able to differentiate "opinionated" information from "factual" information and she says:

> I guess, the amount of detail they go into it and not going off onto into this, well you can solve that problem by going off and doing this, which is outside the medical. To be honest with you, my daughter's getting married and her husband believes in this holistic stuff and he doesn't believe in a whole lot of stuff that I am doing medically. He kind of thinks I'm overboard medical-wise, and he thinks you can go out and take this herb and it will cure everything. And that's the kind of thing I try to stay away from.

I then ask her, "And you stay away from that because?" and she replies, "It just doesn't go along with my beliefs. I have a high regard to the medical people. I don't necessarily know they're always right, but I trust them." Here, it's clear that Amy's beliefs, specifically about healthcare providers, lead her to "stay away from" information that does not fit with her worldview.

One way that participants assess lifestyle similarity is by using political views as an indicator. One of the forums has an active sub-forum dedicated to political discussion; there, conversations often get heated, and the comments that users make in that sub-forum impact how participants view other information they post on the forums in general. For example, Gretchen describes a vocal user on the forums who has opposing political beliefs to hers:

> When he gets into talking medical stuff, he's really, really useful, helpful, whatever it is but when he's talking politics, he's unbelievable. It's almost as though it's a neighbor or a friend or someone like that. You get to know what their strengths and weaknesses are I suppose.

In fact, the political sub-forums on one of the groups studied are both heavily trafficked and highly emotionally charged. Although they are located in the "Off-topic" sub-forums, multiple participants brought up issues and arguments stemming from political debates on the forum. In fact, several participants say that political arguments influence their participation on other parts of the site; in three cases, participants left the site for long periods of time – some indefinitely – stemming from heated discussions and arguments about politics. Political beliefs – as in, whether one aligns with a typically liberal or conservative viewpoint on a given political issue – on this particular sub-forum seem to play a large role in the construction of community; conversely, they also may make some people feel unwelcome and therefore unwilling to participate on the site as a whole, as evidenced by the reasons some of the participants give for leaving the forums.

Assessing similarity is not just related to searching for information; it also matters when participants disclose information on the forums. For example, Nina says that one of the reasons she discloses information about her health on the forums is that she feels that she owes something to people going through similar issues:

> Well, other people who are going through something similar, some of it has to be giving back. It's not really fair to be on a website, to be reading a website all of the time and not give anything back ever, when there's plenty of people out there who are going through what I went through. It just seems like if there are times when I feel like I have something I can contribute, I should do so. And that may entail having to give details about my own health.

Similarity assessments, therefore, often shape what information people decide to disclose and how that information is relayed. This may be closely related to a strong feeling of group attachment, which is furthered by feelings of belonging and of being similar to other people in the group (Smith, Murphy, & Coats, 1999). This phenomenon also occurs during knowledge sharing interactions in organizations; people are who share interpersonal similarities interact with one another more, which in turn fosters more sharing among like groups (Makela, Kalla, & Piekkari, 2007). For example, in this study Brent identifies himself as an advocate who never uses the forums to search for information: he calls himself a sharer, and his purpose on the forums is to relay information to other people who have questions, using his own experience as a guide. In order to do this, he had to go through experiences of his own first. Like other participants, Brent likens CKD and dialysis to learning how to drive a car:

> At 16 years of age, you've got very little experience, how much confidence are you going to have in wintry weather? Or other circumstances, when you're

> fatigued, and whatnot, or distractions, potential distractions? And so because of that lack of experience you have to (laughs) denote what you can and cannot do until you become experienced and then there you go. Just the familiarity with the rules of the road, the body language of cars, and so on…. However the behavior of the vehicle, the braking, the acceleration, being able to make turns, evasive maneuvers and so on, those are kinds of skills that I needed to develop over time. Experience.

Right after discussing learning how to drive and relating it to dialysis, he says, “Then I had enough repetition if you will, and repeatability, to be able to speak to it. To be able to answer questions.” Furthermore, Brent aims to make his advice as generalizable as possible in order to make it applicable to a wide audience:

> In the forums I try to be more general, try to have a broader focus, rather than a narrower focus. That’s the best way I can explain it. So when I respond in a forum I try to think about more than just the individual who is asking the question. Take into consideration other individuals. And a lot of that is based upon things I’ve read or my own personal experiences.

When I ask him, “You are trying to make answers general because…?” he responds: “To make my answers applicable to more readers. To a broader group.” Brent strives to make the information he discloses about himself and the information he shares about CKD broadly applicable so that it is relevant to many users, not just the person who posed the question that he is answering. In fact, Sherri feels that she can contribute to people that are *dissimilar* to her, but that she can’t get information from them:

> I'm looking for the people who have been eating a typical, horrible American diet and just need basic information about vegetables and stuff like that. Now, they're not giving me anything. I can contribute to them, but they don't have anything to contribute to me. I have a tendency to, you know, I do some contributing and then I skip around looking for people who will say things like, "Oh, I've been a vegetarian for 20 years, and oh, my God, this diet is driving me crazy," because those are my kind of people.

Here, it’s also clear that in addition to looking for people who are dissimilar to her to share with, Sheri also looks for people who are similar to her to get information from – and that these activities occur in rapid succession during one online session. In contrast, sometimes it can be difficult for participants to share information when they feel that they lack similarities with other users. Steve says that, in some situations,

> Sometimes you don't have words. Somebody will lose somebody and it's just so devastating. I'll type, "I'm so sorry. You're in my thoughts and prayers," but sometimes I've even typed, "I don't have words." I really don't have words to tell you how I feel. I've typed a big, long thing and backed up and deleted it and just written that, posted that I don't have the words. Let them know that I'm not just blowing it off, but God; I don't even know what to say. The main thing, like somebody loses a child? I can't even imagine. I haven't been through that…. Sometimes I'll write something and then I'll just delete it. It's not helping anything.

In some cases, participants may offer emotional support when they feel that they do not share enough similarities with another user to give helpful information. For example, when she first joined the forums, Joan says she was concerned that she would be ignored because she was not yet on dialysis; she was pleased to be met with emotional support and warm welcomes:

> Most people on dialysis would have read my post and would have thought, "What's HER problem? She still has 30% and she's not stuck on some machine. She shouldn't be complaining." And frankly, they'd be right, and I know it. But you know how, every once in a while, you think that you really should feel one way, but you just can't? You can't always control your feelings.

In these situations, participants choose instead to offer emotional support rather than information: "I have no experience with this and so have nothing worthwhile to share, but I am so sorry this has happened to you," says Joan to a user online who is experiencing complications due to her comorbidities. Offering emotional support may be related to creating the sense of community discussed earlier; the notion of giving emotional support in response to future forecasting requests will be discussed in more detail in the section on future forecasting.

4.5.1.1 Illness vitae. Although finding users with similar experiences is important to participants, this can often be difficult do to in practice. Steve explains that sifting through comments and trying to understand their context takes a lot of time and effort: "I don't have diabetes. I don't have lupus. I don't have PKD. The reason behind the loss of [those people's] kidney function isn’t pertinent to me. Weeding through all that was... it took a long time.” One way that participants dealt with this problem was to evaluate signature lines. Users on the forums often include signatures that are automatically added to the end of every comment they make. In the two OSGs examined that facilitate this practice, signatures nearly always included bulleted, dated lists of the most important events in the user’s illness trajectory, as defined by the user. Amy describes using these lists as a way to quickly identify posts to read in-depth and posts to ignore: “As I’m reading, I’ll glance down and think, ‘That’s not worth even trying to read in depth.’” I call these signatures *illness vitae* for their structural similarity to a curriculum vitae. Other participants mention that the signature line is helpful for determining what experiences specific users have gone through as they read posts. In this way, the vitae provides important contextual information for every comment a particular user makes.

Therefore, the signature line acts as a similarity badge for users, allowing quick assessments of the potential relevance of the content of specific comments to their own situation. These signatures tend to be dated and are fairly standardized: the date of diagnosis is always included, as are other important events like the date a fistula was placed, the date dialysis was started, and/or the date of any transplants. In this way, signatures function as a heuristic for evaluating credibility in OSGs (Metzger, Flanagin, & Medders, 2010). Other methods for assessing similarity include reading a poster’s comment history, which is available on all of the online support groups, and monitoring the introduction posts for people who have similar stories.

4.5.1.2 Similarity as a cue for relevance and credibility. Sharing a similar illness experience is often seen as a helpful marker of credibility for seekers. For example, Laura says that some of the information she received from her healthcare providers was less trustworthy simply because they had not experienced having a PD catheter:

> My renal team was saying, “You’ll be absolutely fine with a catheter. It’s very easy to hide, and you won’t even feel that it’s there.” These are the types of things they were saying, and I was thinking in my head, “How do you know, though? How do you know if you can fit in? How do you know how well you can hide it? How do you know if other people can see it because you haven’t got one?”I think that’s something that you can only get from other kidney patients, when it’s tried and tested, and people share that information. There’s always that element that you feel like you trust the information more when it comes from someone that has experienced it themselves, rather than someone that’s saying, I know a lot of people, and this is what I think. It’s not as effective from someone that hasn’t been through it.

In fact, some participants say that they use similarity as a heuristic for trust, particularly in online health forums. This is partially because, as the literature suggests, similarity fosters liking; it also fosters empathy and caring (Fan, Lederman, Smith, & Chang, 2014). This finding further suggests that trust is dynamic, not static – since the assessment of similarity changes over time, it follows that trust likely also changes over time as well.

It is also important to note that information found in OSGs was sometimes thought to be more credible simply because patients who provide information online are more likely to be actively involved in their care: “You find that the people who care about their treatment go to these sites,” says Steve. “The people who participate in these forums are generally the good patients. They actually care enough about their disease and treatment that they went on the Internet to look something up, and like me they stumbled across a forum of other people going through the same thing. So I put stock in what they have to say.” However, several participants also discuss being wary of the information provided in OSGs. As Travis says, “I’m kind of still leery, because these are people with kidney problems. They’re not professionals.” This concern is echoed by several of the participants in this study. Therefore, the information participants find in OSGs is often not, as Amy put it, “the Bible for ‘this is what I should be doing.’ I just use it for basis, to examine what’s going on in my life.” This finding is related to research on human information source selection in the workplace. For example, Woudstra and van den Hooff (2008) found four quality-related factors in selecting people as information sources, including topic knowledge and perspective – both factors that are related to, but are not the same as, similarity. It is also closely related to Rogers' (2003) concept of homophily, wherein people tend to communicate with people who are similar to themselves. Similarity may also be a way of assessing cognitive authority (Rieh, 2002; P. Wilson, 1983): if an author has enough in common with the seeker, the seeker is able to assess whether or not the information they share in common is accurate. This may allow seekers to more readily trust information that is shared by the author that the seeker did not yet know.

This finding also highlights the role that time plays in credibility assessments on social websites: users may build up a reputation over time, and this reputation likely impacts whether or not their posts are seen as credible. This may be related to the concept of opinion leaders, trusted individuals who are influential in specific fields and who demonstrate competence in a given topic or profession (Rogers, 2003). It is also similar to the concept of author reputation offered by Savolainen (2011), although the notion of building a reputation over time is not addressed in his work.

4.5.2 Future forecasting. A recurring theme in the data is the notion of *future forecasting,* a process whereby participants grapple with understanding how their experience with CKD will unfold over time and what impact the illness will have on their future. I call this future forecasting because, at the beginning of our second interview, Joan starts talking about her recent vacation and the weather in her area of the United States. As we are chatting about how surprising it is that it's still hot out despite it being October, she laughs and says, "I know that's not why you called, to talk about the autumn summer here—but, you know? Sometimes trying to figure out what's going to happen with my kidney is like reading a weather forecast!" This analogy anchors the concept of future forecasting. Nina gives an excellent definition in our first conversation:

> The really big question is: What is it going to be like when it comes down to actually doing [dialysis]? Or what is a transplant really like? What are these things *really* like? And these are people that post who are living – they are living my future. And that's what brings me back [to this forum].

The term future forecasting describes situations where participants search for information about their own future by reading about what others have experienced or by observing them during their time with CKD, either specifically or generally, as a way to understand what might be to come. It is an excellent example of how participants use information gleaned from other, similar patients as a way to cope with a new life context. Future forecasting can also be done for situations – preparing for medical appointments, for example, is a type of future forecasting that is largely situation-based. This highlights the blurred distinction between *situation* and *context*, an issue with which many theorists in information science have grappled (e.g., Cool, 2001; Sonnenwald, 1999). Future forecasting is a type of illness uncertainty management, as it allows individuals to plan and to gain control over both their new context and the situations that arise within that context (Mishel, 1988). The process of future forecasting is closely related to multiple sources of illness uncertainty as defined in the literature: the complexity of the illness itself, the likely probability of different outcomes, and integrating illness with one's life (Babrow, Hines, Kasch, & Whaley, 2000) all can contribute to the desire to future forecast.

Right after defining the term, Nina stresses the primacy of patient experience in future forecasting: "Rather than being a webpage where – all these companies have an agenda and everything – on [the forum] it's all about real people struggling with real problems." As Travis explains, other CKD patients understand the struggles better than anyone else, even caregivers: "My wife, she went to a kidney class that we took together and learned as much as she could about it, and my family and everything… to them, [I seem] normal. [I] can't ride [my] bicycle anymore and stuff, but I don't think that they really realize." Nina also mentions that providers also don't understand the experience of the illness; recall her story about asking her provider about having a biopsy, discussed in the "assessing similarity" section of this chapter.

As was previously discussed, family members and friends can't provide all of the support that participants need. In particular, they cannot aid participants in future forecasting. Joan explains:

> I think most people on [this forum] who have known me for some years KNOW how much time I have spent educating myself on all things dialysis since that's where I was headed. But the truth is that, since I haven't yet BEEN on dialysis, there is a limit to my true understanding. [Caregivers on the forums] don't really KNOW what it is like to be on dialysis, but they don't NEED to KNOW. There is no limit to their support for their husbands.

From this statement, it is evident that this particular type of understanding – what might be called *experiential support* – is born out of sharing illness similarity. Therefore, assessing illness similarity, as discussed earlier in this chapter, precedes future forecasting, and experiential similarity is an important factor as participants attempt to forecast their own futures or as they aid others in their forecasting endeavors.

Explicit future forecasting occurs when people ask questions about their future, either about events (e.g., preparing for medical appointments) or about coping with the illness more generally over time. Alternatively, implicit future forecasting happens when people seek out information with the goal of learning about what they can expect in their future without asking other patients direct questions. For example, Amy keeps returning to an online support group not to share, but "because I'm trying to find ways to help myself not to [get] further along in my kidney disease…. I don't want to go there. I've told my nephrologist: I do not want to go there. I get a picture of what their life is like. And I don't necessarily want to join that lifestyle."

Future forecasting helps participants develop realistic, concrete expectations about upcoming events related to their CKD. It also helps them come to terms with their illness so that they can begin to create a "new biography" after the biographical disruption that a chronic illness diagnosis causes (Bury, 1982). For example, in our first discussion on the phone, Travis says:

> Getting more information, it sets your mind at ease; it helps you cope with what the issues are. I think if you know more about it, it's not so scary. You've got kidney disease, and ok, they send you home, but to me… to me it's just easier knowing what's going on. Like when I had the fistula put in I read everything I could about fistulas, so I knew what was going to happen before I walked in the office.

Future forecasting gives Travis knowledge about what to expect when he has his fistula placed, reducing his uncertainty about this specific medical procedure. He also alludes to the role that future forecasting plays, more generally, as a coping mechanism. Forecasting upcoming CKD-related events is a common theme in the data; for example, Nina describes preparing for her transplant evaluation using language similar to Travis's quote above. She did not ask an explicit question on the forums about her transplant evaluation, so the process of future forecasting her evaluation was largely implicit. However, she includes the question, "Do I need to just settle down and get more info at the evaluation in July?" in a larger question about preparing to be added to the transplant list. Others use forecasting to prepare for conversations with friends and family about donation, starting dialysis for the first time, and other specific events related to their CKD and treatment.

Some future forecasting inquiries are incredibly specific and situational; in one thread, a user asks if they will be able to shoot a gun if they have a fistula in their arm. Travis responds: "Problem might be easily solved by starting to shoot with your left hand…. I have my fistula in upper right arm and shoot with my left and had no problems about 3 months after the surgery…. The first time I shot my 12 ga. shotgun the recoil from that stung my right arm, but the recoil is quite severe." Brent answers a similarly specific future forecasting question, about how dialysis will impact riding a motorcycle posed by someone's caregiver; after providing a good amount of detail about his own experience, he finishes the comment with: "As a fellow biker and dialysis patient, I'd be more than delighted to share with your old biker the experiences I have had with home hemodialysis." Again, from these situations it is clear that future forecasting relies on similarity assessment – and similarity may not just be illness-related. For both Travis and Brent, these situations illustrate how lifestyle similarity plays a role in information seeking and sharing. This also highlights the role that future forecasting plays in "bridging" the contexts of a life without CKD and a life with CKD. Being able to "do what I used to be able to do," as Candice says, is important to many of the participants; future forecasting can be employed as a method to determine whether or not specific activities that participants enjoy will still be possible.

Travis's posts on the forum are a prime example of implicit future forecasting. He does not initiate threads – he has asked no explicit questions since registering on the forum three and a half years ago – but he still engages in future forecasting in his comments and in his seeking processes. For example, he has knee problems and was considering knee replacement surgery until he encountered information from another patient in a similar situation on the forum. He explains:

> I need two knees replaced and I'm putting that off, because [I read comments from] two guys on [the forum] and they said, for that kind of operation, because your blood pressure drops – even though it's a short amount of time – they said you've got about a 50-50 chance of coming out with no kidney function at all. One guy said, "I don't want to deter you from doing it," but he said he went and did it, got his knee replaced, and he lost all kidney function. He said the worst day of knee pain was far less than being on dialysis.

Asking him for more detail, he says: "[The knee pain] will pass. That will pass. If I can avoid dialysis, I want to avoid that as long as I can." Here, Travis's understanding of dialysis informs his other care choices. In the forums, he thanks one of these men, explaining:

> I need both knees replaced and I am at stage 4 kidney failure and have put off the operation because the doctors say there is a chance I may loose [sic] kidney function. But I have decided to wait, and your situation just reinforces my decision to do so. Hope you are doing well, and have a good holiday.

There are many other examples where participants use future forecasting as a decision-making tool for treatment options. For example, Joan asks on the forums:

> How would you describe your quality of life on dialysis? There are all kinds of numbers that measure this and that, but there's no real measure for quality of life. How would you define it for yourself? I know that life on D isn't as "good" as life without having to have D, but does D enable you to do the things you want to do? Or do you feel that dialysis itself has disabled you more than, well, ENabled you? Does your neph or anyone at your clinic ever ask you about your quality of life? Or is this a side of treatment that you feel goes entirely unnoticed? Thanks for your replies.

At this point in time, Joan was trying to select her dialysis modality; she was also curious about how quality of life factors in to patient care more generally. She chose at-home hemodialysis via NxStage without her nephrologist’s input, using only information she found online, and even remodeled part of her home to accommodate the machine and the treatment supplies. This prepared her for the inevitable conversation with her nephrologist, who recommended peritoneal dialysis to her. She told him she preferred NxStage based on the information she had gathered about the different treatments online. She says that this process was greatly enhanced by future forecasting in the forums.

Future forecasting can also be used to identify knowledge gaps that may then result in other questions. Steve uses future forecasting to this end in his first post on a popular forum. He frames his question as an attempt to learn things that others learned “too late”:

> Hi! This is my first post besides the post I did to introduce myself. I have been reading many of the posts and am finding a wealth of information...things I never had even heard of. It is going to take awhile (I know...I have the time now) to get through all these threads. What I am asking the people who have been through this longer than me is what did you learn to [sic] late? What did you wish someone had told you? I am looking for any tid bits [sic] of knowledge that may help me make decisions in the future.

From Steve's question, it is evident that one of the outcomes of future forecasting is the ability to identify information needs that were previously unknown to the asker – in the literature, this is described as narrowing his anomalous state of knowledge (Belkin, 1980). This example highlights the role that future forecasting can play in the information seeking process itself.

More broadly, future forecasting allows participants to cope with and define a new sense of normal that can only be understood by other people experiencing CKD. It often occurs as participants wait to initiate renal replacement therapy. All of the participants who were aware of their diagnosis well before the need for RRT discuss waiting until they were roughly two years away from needing treatment before they engaged with information about treatments for CKD, aside from dietary interventions. This suggests that the upcoming onset of treatment, and not the diagnosis of CKD itself, prompts participants to begin future forecasting. Nina explains this waiting period when talking about her children being tested for the genetic form of CKD that she was diagnosed with:

> My advice for any younger person in our family is, I mean, my quality of life would not have been improved if I knew this was waiting for me. And I'm glad I didn't know. You know, I'm 50 years old. There's a lot of… if I would have been worrying about this the whole time? I don't think people… I don't see, and with the healthcare system the way it is, with pre-existing conditions? You can lose your life insurance or whatever. I mean… why? Why? Why? Why would you want to know this?

There are no other explicit examples of participants advising against future forecasting in the data, although some participants do discuss the anxiety that future forecasting can cause. This will be discussed in more detail below.

Future forecasting is a time-based information activity; that is, it is specifically about how the future will be experienced and the unfolding of events in the future. This is likely due to the fact that time unfolds differently for different patients: there is not one typical trajectory through CKD, so nephrologists will often not give patients concrete estimates about how long they have until they need RRT. Amy describes this perfectly when she says, “[Dialysis] is maybe in the near future, but I don’t know how near the future is.” In fact, one of the recurrent themes in the data is the desire to, as Jacob calls it, “postpone the inevitable dialysis.” Every participant not yet on dialysis discussed this desire. Jacob bargained with his nephrologist repeatedly to push his initial dialysis treatment back as far as possible:

> I had my appointment with the neph yesterday [August 27th]. In June, we had scheduled tentatively to start dialysis in Mid-August and my most recent labs hinted that perhaps I could push it another month, to mid-September. In spite of my eternal optimism, he said it was time to start dialysis. Like NEXT WEEK. So, like a convict reporting to the jail, I have a week to get my affairs in order and he expects to see me in the hospital next Thursday morning for the first of three treatments.

A few days later, Jacob returns to the forums with a slew of future-forecasting questions, including: “So, what should I expect? What do they do during this hospitalization? What goes on between the treatments? Is the ‘first time’ painful?”

The week after starting dialysis, however, Jacob reverses his thinking. He responds to a user who asks when people knew it was time to start dialysis and says, “For what it's worth, here's my .02 based on my recent experience... I have a similar experience to some of you posting herein. I pushed the envelope as far as it would go…. My best advice is to start dialysis BEFORE you have to. If you push too far, it will be on an emergency basis and that won't be the best circumstances.” Here, Jacob asserts his similarity to others as a way to make his message more credible. In another thread a few minutes later, he says, “I am on my way to being a ‘pro’ now. I got all of one full week in center under my belt.” He follows this with a lengthy description of his dialysis routine, closing the thread with: “I carry my Purple Arm [bruised from infiltrations and issues with his fistula], the new badge of courage I believe, like a pro now. But seriously folks, y'all made it so much easier and better with your sage wisdom and advice.”

Future forecasting also occurs offline, particularly for participants who have family members that also have been diagnosed with CKD. Joan explains: “My mom was on dialysis, and she was in-center. And I saw how that went. You know? Ha! I saw how *that* worked. And that was *not* something I wanted to do.” This experience is echoed by Nina, whose mother was also on in-center dialysis prior to Nina’s diagnosis of CKD. Both women planned to use in-center hemodialysis via NxStage, although they both also received transplants (Joan from a deceased donor, Nina from a friend) before initiating dialysis. Travis, too, talks about his neighbor on peritoneal dialysis. He responds to another user’s inquiry about an upcoming fistula surgery:

> Don't worry about the fistula surgery, had mine done in June 2011 and it wasn't so bad, but then I have had 4 other surgeries in the past 10 years and compaired [sic] to those, the fistula was by far the easiest, no problems at all. I also thought a lot about hemo or PD, and I read everything I could about the good, the bad and the ugly of each and also asked a ton of questions to my nephrologist and nurse practitioner and decided to do hemo. My neighbor did PD and she had quite a few problems, and that was a factor in my decision also, good to have first hand experience from her.

This quote also highlights a necessary precursor to future forecasting: finding people who are willing to share details of their experience. Future forecasting, therefore, is a process that highlights the reciprocal relationship between searching for information and disclosing information. Seeking and disclosure often overlap as information is exchanged between or among similar patients online. As Travis explains, “I’m looking for people with similar problems and people that can give me information, or if I can give them information.” In fact, when participants attempt to future forecast and they can’t find information that helps them to do so, that often prompts them to disclose the details of their experience after they have gone through it. Take Laura, for example:

> Specifically, when I was looking for what a catheter looked like, the images that I found on Google were either someone holding up the catheter, or it was a very old

> person where you just saw a bit of it through a t-shirt. There were no pictures of somebody that's young and there was an actual picture there, what it's like on them. This is what it will look like. I didn't come across anything like that, and that's why I wanted to share mine.

Jacob, too, says that one of the things that leads him to disclose information about his own personal health is that he was unable to find that information when he was looking for it:

> A lot of it is just like helping people deal with the day to day. And especially new people coming in so that they have like, 'Ok, look, let me explain to you. You're *not alone*. And you're not the first person that's going through this. And here's the benefit of everything that I went through so that you can know that.' And a lot of that stuff, a lot of what I share is based on stuff I couldn't find when I wanted it.

An example of how future forecasting fosters disclosure occurs between Joan and Gretchen on the forums. In response to the question Joan posed about quality of life on dialysis that is quoted above, Gretchen shares:

> I would say that my quality of life has improved somewhat since I started PD five months ago. I have four grades of how I am feeling - bloody awful, OK, good, and bloody fantastic. I seem to average one or two BA days per months and 15 to 20 BF days. I deliberately look at a good day and work on turning it into a BF day. I would rather not be on dialysis, but prefer it to the alternative. I do not want a transplant. I am 69, so I've done all my travelling and have a very quiet social life. My pleasures in life now are my cats, gentle gardening and my textile crafts. I can't imagine being young and on dialysis - that would be very frustrating. Since starting dialysis I feel more alive and alert, and I can eat pretty much whatever I want. I'm doing CAPD. I was worried about the time I would be losing each day, but I've settled into a quiet 'exchange' time each time I do an exchange.

Here, Gretchen gives Joan and other readers a window into her life on PD, disclosing a good deal of personal information as she discusses her own quality of life. She gives specific examples of her own activities as a way to describe how the modality she chose fits with her lifestyle and activities. She also presents her own method of gauging her quality of life on a daily basis in this comment. The comment contains no direct advice; it is entirely self-focused. However, the information she gives could be useful for others. In fact, Joan replies: "I love your "BF" day vs

"BA" day...I'm going to remember your post! Working to make a good day into a BF day...I like the way you think…. Thanks for your reply; it's very useful.” This reply illustrates how future forecasting can help users to cope with uncertainty, and highlights the importance of disclosure in future forecasting exchanges.

There are also many cases where participants want to respond to a future forecasting request, but they do not have personal experiences that will be helpful for the seeker’s future forecasting. This is particularly true for more specific questions, like the examples outlined above. In these cases, participants may provide emotional support – a strategy discussed earlier in this chapter in the section on *crosschecking*. They may also give advice on how askers can meet specific information needs as a way to mitigate some of the emotional needs they are experiencing. For example, Jacob offers both emotional support and general advice on the forums, in response to a very specific question about whether or not a child experiencing kidney stones could be a precursor to them being diagnosed with PKD if there is a family history of PKD:

> Welcome to the site! (I'm fairly new here myself) I don't have any answers but I'm also curious about what the more knowledgeable people here will have to say to answer your questions. I'm very sorry you have to go through all this. My understanding of PKD is that it is hereditary and so you and your children are probably going to have problems…. Besides asking here, I would suggest finding a good nephrologist as quickly as possible. There may be lots of nephrologists but finding a "good one" is the trick. Ask nurses or other docs for a start. When you get a name, Google that doc and see what you can find out about him/her. Look for Board Certified docs! That process usually separates the wheat from the chaff.

In this comment, Jacob provides both emotional support and instructions on finding a good doctor. To Jacob, finding a good nephrologist is a process that entails asking other experts, searching Google, and using board certification as a filter. Here, Jacob essentially provides instructions for crosschecking. He also provides emotional support in two ways: he identifies with the person asking the question and stresses a similarity they share ("I'm fairly new here myself") and he offers an apology to the poster: "I'm very sorry you have to go through all this."

Participants may also provide more general answers to future forecasting inquiries when their personal experiences may not match the inquiries. The best example of general advice that many participants give is to self-educate. Candice says, "You have to be your own best advocate. You have to learn everything you can so that you can be your best advocate." Joan likens it to being the "captain of your own ship," something she says in both interviews and repeats on the forums a number of times. And as Brent says on the forums, "The more you educate yourself (this website is an excellent resource) the better prepared you will be for the unknowns that you will face in the future." One of the reasons that Brent gives for answering questions generally is that his experience of CKD is not very common; he has a rare, non-genetic form of PKD, which he says impacts both who he shares with and what he decides to share and disclose:

> I naturally gravitate to… those folks that do reveal that they have PKD, because I've got a lot more in common with them than with people with [other etiologies]. Other than the fact that we both might be on dialysis, the circumstances are very different.

Amy describes a similar issue – the etiology of her CKD is also rare, caused by recurrent infections of unknown origin. Rather than writing general responses, Amy opts not to share in the forums, although she logs in to use their dietary tracker and to read the forums on a daily basis. She explains her reticence to post, linking it to her uncommon experiences and to future forecasting inquires:

> Sometimes I wonder how much information I have to share and how relevant it is…. A lot of the questions, I've not been in their situation. So, talking to people, obviously on dialysis, I don't have that experience. I don't know much more than I'm sorry you're going through this, kind of stuff. And, too, my journey into kidney disease came from a whole atypical background…. I don't know how much my two cents would really make a difference.

Amy feels like emotional support is all she has to offer, but that is not necessarily what people who are trying to future forecast want – so she decides not to share at all. In one of the forums, users discuss lurking on a regular basis; as was previously discussed in the beginning of this section, lurking is often a temporary strategy, as participants become accustomed to the forums and learn community norms. However, Amy has no plans to ever register and post, and she has been lurking for nearly three years, suggesting that she has always intended to lurk. Although the literature indicates that planning to lurk forever is not particularly common, there are still many users of online forums that always plan to lurk (Nonnecke, Andrews, & Preece, 2006).

The final strategy that participants discuss when responding to future forecasting inquires is to stress the individuality of experience. Brent describes:

> I have to qualify my situation all the time so that people aren't mislead and think that they can do what I do. Because generally they can't. But other aspects are more general, for example, the development of more than one set of buttonholes for access with blunt needles.

In practice, Brent does this by saying things like "I'm a testament to the variation of the individual responses to hemodialysis" when he leaves a comment on the forums. Nina, too, explains that one of the benefits of finding people that have already experienced something that she will undergo in the future is learning what to expect, but: "that doesn't mean that your experience is going to be the same. But that is someone who went through it. And you do read, there are people who just go through – and I guess that's the danger of it." Joan concurs; she says "You hear other people's stories, but that's all they are. Stories." Nina also mentions this issue in our first interview:

> You're reading individual experiences. I suppose that is a downside of it. You're reading what happened to all these different people. And the nature of a forum like that… people who where everything is going just swell with no issues, they aren't writing in, for the most part. That is not what you're getting. That's important to remember.

Forum users will often stress that individual experiences are not facts. As Joan says in the quality of life thread quoted above:

> CKD/ESRD/dialysis is such a varied experience. Hell, life is such a varied experience. As such, it is really hard to determine what is needed, who needs and who even wants it. For patient A, being able to do more dialysis at home greatly improves QOL, but for patient B, the idea of polluting his home with the detritus of treatments and sitting in a chair for longer is hell on earth. The key is more "patient centered" care where it is the patient who dictates as much as possible. But that would probably cost too much money.

Qualitative examinations into living with CKD corroborate this finding; for example, a study investigating how patients with CKD experience liminality, or the time that passes between critical situations or events, also stresses that everyone's experience of CKD is unique: "Each person's experience is unique and the experiences are filled with contradictions and challenges, so people with CKD can feel both dependent and independent, restricted or not, normal and nor normal, alone and connected – all at the same time" (Molzahn et al., 2008, p. 19).

Future forecasting may also increase anxiety or concerns, particularly because people share information that might be harrowing or difficult to read. As one individual on the forums explains, some of the stories about starting dialysis on the forums are pleasant and pain-free, while others are "horror stories." These "horror stories" have two effects on the reader: they can cause anxiety, but they may also provide an incentive to stay as healthy as possible. Amy discusses this effect during our first conversation: "Seeing what they're… and actually, those are the people that make me, reading about all their horrible – because most people are the ones that are having horrible experiences with dialysis. But… reading all their stuff makes me that much more willing to work harder to stay out of it." In fact, Joan acknowledges that even engaging with information -- no matter where it is from – can cause negative emotions:

> I cannot count the times I have read something here on [the forums] that has upset me or frightened me, but that is not the fault of this forum. Dialysis is a frightening proposition; it takes real courage to face this on a day to day

> basis. Just as hard is this pre-dialysis waiting game...this process of being able to do so very little while your renal function slowly comes to a halt. I also don't want to contribute to anyone's anxiety, and [another user] is correct; it is hard to know if what you have to say is educating someone or is merely scaring them. But we all take that chance when we either read or post on the internet. We can't know the inner terrors of everyone we communicate with. All we can do is try to be gentle with each other, to show each other some small mercy, to be kind and to refrain from taking offense when possible. We all share a common horror. The least we can do is care for one another as best we can.

Any information about CKD that is posted on the forums has the potential to be profoundly emotionally salient for any given reader. Most of the people that read and post on the forums are patients themselves, all “going through” a very similar experience. The phrase “going through” comes up many times, with most participants, during our discussions and on the forums. The process of “going through” that participants discuss may be analogous to a shift in context, which necessarily highlights the discontinuous, gap-filled nature of reality discussed previously (Dervin, 1997), often causing uncertainty and anxiety. Future forecasting is a technique that participants use as they attempt to make sense of their shifting life contexts, but just as it cannot entirely mitigate uncertainty but instead is used as a strategy for managing uncertainty (Mishel, 1999), it also cannot fully prepare participants for illness events. For example, Jacob actively employs future forecasting on one forum before starting dialysis, which he scheduled well ahead of time with his nephrologist. Two weeks before the first session, he starts a thread on the forums titled, “Looking back.” In it, he says:

> Here's an interesting suggestion... take a look back at your introduction and recall what you were thinking and feeling the first time you came to [this forum]. I just did and whoa! What a long way I've come in a very short time! looking back I was, well, frankly I was scared. I knew only a fraction of what I know now about the predicament I'm in. I recall being overwhelmed by what I was facing and feeling very alone. All I knew was that I had ESRD and that I'd be starting dialysis soon but I had little idea what that meant in reality. All I knew was that I had to face it. It wasn't going to get better and there was no cure. The path that lay before was dark and bumpy looking. Today, I still haven't started dialysis… but if I had to start tomorrow, I'm much more prepared and confident because of the time I spent here and the extremely valuable knowledge gained at [this forum].

> Today, that same path I faced months ago is much brighter and less bumpy. Thanks to all you who post here and share your lives and experience.

Although he says he felt confident, less overwhelmed, and less alone because of his future forecasting activities two weeks before his first in-center dialysis treatment, he still feels lost when he walks into the dialysis center for the first time. He describes the experience:

> I'd had enough notice and I had a mature A/V fistula in my lower right arm, and so that was ready to go. But even then, Kaitlin – here's the thing. I walk into that dialysis unit having *no. clue.* I'm walking into the dialysis unit really having no clue what was going to happen. And they pull out those, at first I thought it was a ballpoint pen, but it – it was actually a needle. And they shoved that in my arm.

Jacob's experience illustrates the importance of tacit knowledge: "There's no substitute for actually just getting in there and doing it," says Brent. "As I have newer experiences, different experiences, I add that. Like, for example, [balancing work with dialysis]. I couldn't speak to that until I experienced it. 'Hey, you can do this, here's how I did it.'" Again, information that relays experience is helpful but also can cause emotional overload; as Joan says, "The idea of dialysis truly terrifies me. That other people do it and can cope with it does little to relieve my fear. I know that it may be in my future." But as she continues reading the forums and participating, this feeling changes: "I started thinking, 'Well, all these other people are doing it. I can, too,'" she says. "But sometimes the quantity of information became so overwhelming that I had to just force myself to just, you know, turn the computer off and walk away." Joan's emotional state is closely linked to the amount and type of information she consumes: "I remember asking, you know, it just seems all so complicated, and I'm not on dialysis yet, but god, I don't know if I can do it, it just seems *overwhelming* and this, that, and the other." Future forecasting, therefore, has multiple outcomes: it can aid patients in coping with CKD and a shifting life context; it can make patients more anxious; and it can also allow patients to learn how to monitor their information intake so that they don’t overload themselves. Here, Joan describes this process:

> The good news is that my condition seems to have stabilized, and my nephrologist says I am doing "very well". I know that the good news may not last forever. So, I struggle with my desire to be informed about dialysis and my desire to not think about it at all. The idea of dialysis truly terrifies me. That other people do it and can cope with it does little to relieve my fear. I know that it may be in my future. I have discovered that the emotional and psychological toll CKD has taken far outweighs any physical discomfort. I have tried counseling, and once I even tried hypnotherapy. The only thing I have not tried is medication. It took me well over a year to be thankful for my so-far successful treatment instead of being just terrified all the time. I am afraid of being too hopeful; optimism scares me because it leaves me open to being sandbagged again. Reading this forum and joining this site takes a lot of courage from me. It is not easy for me to write these things. I would rather avoid the topic altogether, but I realize that anyone with a chronic disease needs to learn as much as possible, and as scary as it is, I need to perhaps find some courage from the rest of you.

Therefore, future forecasting can also be used as an indicator or a tool for monitoring emotions about the information seeking process itself. This quote highlights the tension between reducing uncertainty and increasing anxiety: sometimes, attempting to reduce uncertainty actually *increases* the amount of uncertainty one has about a particular issue related to their CKD. This is corroborated both by existing theoretical frameworks in information science (e.g., Kuhlthau, 1993) and also in theories in other disciplines such as nursing (e.g., Mishel, 1990). This feeling of increased uncertainty is likely amplified when users have more general future forecasting inquiries, because the gap in knowledge is larger with more general questions. As Joan says:

> Knowledge is power, and I think that I avoided dialysis and I got a pre-emptive transplant because of all the research I did, and because of the education that I forced upon myself. But there was a lot of information that I came across, while it proved helpful, it was also *terrifying*…. It’s like driving a car. Before you get in the car, it’s overwhelming, but once you break it down, and once you learn a methodical way about it, and once you learn what you need to learn and nothing more, then it’s not so overwhelming.

This is directly related to what was presented at the beginning of this chapter: participants balance how much information they engage with throughout the process in order to manage the shift to a new life context, especially while they future forecast.

4.6 Conclusion

In this chapter, many of the information behaviors related to CKD that the participants engage in were addressed. Participants begin coming to terms with their illness as part of a contextual shift; at the point of diagnosis, they will engage with information broadly, searching for general information about CKD and treatment options. Throughout the course of their illness, they experience a variety of situations that spur them to engage with information. These situations can be health-related; for example, getting an infection is an example of an acute situation; choosing a dialysis modality may be a more long-term situation, depending on one's personal illness trajectory. However, situations that prompt engagement with health information are not always health-related: life situations, like moving or retiring, are also related to engagement with health information, as life context blends with illness context when one is chronically ill. During these situations, participants experience uncertainty; this uncertainty leads to engagement with information. This is partially due to the fact that participants describe themselves as inherently curious individuals who regularly engage with information seeking – especially on the Internet – for routine information needs. However, participants say that their engagement with health information is largely dependent on their personal illness trajectories and the individual situations that they encounter. As such, their health information behaviors are recursive and wax and wane in concert with these situations.

In many cases, emotions are closely linked with information behaviors, particularly information seeking. Participants often go to the Internet to search for information because they feel a lack of emotional and/or informational support. Healthcare providers are often dismissive of their concerns; family members and friends do not truly understand the concerns either, because they do not have the experience of living with CKD. Participants say that it is difficult to get informational support from healthcare providers due to time pressure, information overload, the fragmented nature of care in the United States, and the emotionally detached nature of the patient/provider relationship. Although participants describe struggles with getting information from their providers, it is important to note that all of the participants in this study say that they trust and respect their doctors; multiple people use the word "love" when describing their feelings for their nephrologist or primary care doctor.

Because participants trust their providers and regard them as experts, they are commonly used as sources for information in two ways. First, participants get original information from their providers during appointments, using doctors as primary sources. Second, participants describe using their providers as a source for crosschecking information that they get online. Participants bring in information from the Internet in the form of questions (e.g., "I read this online; what do you think?") or in some cases will even bring in primary sources found online so that their doctor can explain them in more detail. Providers are generally encouraging about finding information online; they also encourage crosschecking the information found with them or with other healthcare providers. Several participants say that their providers pointed them to credible resources to look at online, like the National Kidney Foundation's website. They also use the Internet to crosscheck information from their providers, particularly when interactions with their providers are less than satisfactory – such as instances where providers dismiss their concerns, particularly when those concerns have an emotional component.

It is often difficult for participants to get the emotional support they desire from their family members and friends as well. There are two reasons for this: first, people who are close to participants often do not have kidney disease themselves. Because of this, participants may not feel like their family members and friends understand them. This points to a specific type of support that participants desire, one that could be labeled “experiential support” – support that stems from people who understand their experiences. The other reason that participants feel like they do not get the support that they desire from their family members and friends is because they are often being self-protective: they choose not to ask for emotional support from these people, even though they want emotional support, because they do not want to burden them. They also may attempt to ration support from these individuals in anticipation of needing more support in the future.

These unmet needs described by participants spur them to go online to look for information about CKD. They are not necessarily actively looking for emotional support or for patient peers when they go online, but discovering online support groups often causes participants to recognize the need for experiential information from patient peers. Most of the participants in this study report encountering the forums while they were searching for general information about CKD; they then join the forums after realizing that forums meet both information and emotional needs that they may not have known they had. This need – one that is difficult to articulate until it is already being met – arises from the lack of patient peers in their existing support quilt.

Most of the participants in this study report lurking, or reading without posting comments of their own, before they begin commenting on the forums. They do this for two reasons: first, they do not want to disrupt the community, and they feel a need to understand the community norms and the tenor of typical discussions before they begin making comments themselves. Second, disclosing information can be emotionally difficult, so some participants wait until they feel emotionally prepared to disclose before they start making comments. As participants become familiar with the forums, they describe specifically seeking out people who are similar to them. Similarity is assessed along two main dimensions: demographic, or structural, similarity –geographic location, age, and disease etiology are all examples of structural similarities. The second dimension along which similarity is assessed is experiential: participants report looking for people who have had experiences that are like their own. Signature lines facilitate similarity assessment, where many users list their own illness events in a kind of illness vitae: a dated list of major CKD-related events experienced by the user. These signatures allow participants to quickly assess the experiences of other users and are often used as cues for both relevance and credibility. In fact, shared experience in general is one of the methods that participants use to evaluate the relevance and credibility of information they find in online support groups.

In addition to looking for people who have shared similar illness experiences, participants also look for people who have had experiences that they anticipate going through themselves in the future. This process, called future forecasting, allows participants to anticipate upcoming issues and events in their own progression of CKD. It is a type of uncertainty management, allowing participants to plan for their own uncertain futures. It allows participants to develop realistic, concrete expectations about CKD; is used as a decision-making tool for choices about treatment, particularly dialysis modality; allows participants to identify gaps in their own information seeking that they can then fill; and helps participants to define their own sense of a new normal. It can also cause anxiety in participants, particularly when the experiential information they acquire is frightening. To manage this anxiety, many participants stress that experiential information that they find online is highly personal and situational and is to be "taken with a grain of salt." What is true for one person in a given situation may not be true for participants if and when they have a similar issue, and they address this by reminding themselves that people are sharing stories when they disclose online. Future forecasting relies on other patients disclosing information about their own health, and is often also a motivating factor when participants decide to disclose information about themselves online. This is largely because they have benefited from the disclosure of others in their own future forecasting endeavors, and they want to provide the same type of help to other people that are in similar situations.

CHAPTER 5: IMPLICATIONS

5.1 Introduction

This chapter begins with a discussion of two contributions that this study makes to our understanding of information behavior: crosschecking and similarity assessment. Next, a model of information behaviors in online support groups for health is introduced. This model is based on the data and analysis presented in the previous chapter. The theoretical implications of the model are discussed, relating it to existing models and theories of information behavior, uncertainty in illness, and disclosure. The implications that the model has for interface design and healthcare are then presented. The limitations of the model and of the study are then discussed, and some suggestions for future research based on the findings from this study are offered.

5.2 Contributions to information behavior research

There are two behaviors from this study that add to our current understanding of information behavior: crosschecking and similarity assessment. In this section, I will describe these findings and discuss how they extend the existing research in this area.

5.2.1 Crosschecking. Crosschecking is the process of verifying information from one source with other sources; in this study, it was most commonly seen when participants brought in information they found online to their healthcare providers, but participants report crosschecking across a variety of sources when they find information that they want to verify. Typically, information that warrants verification with providers is relevant to decision about one’s care, such as the choice of dialysis modality, or questions about supplemental medications.

Participants engage in crosschecking routinely throughout their illness as they learn more over time. Not all of the information that participants find online is crosschecked with a provider; this is closely related to the issue of time pressure during office visits. Participants also are careful about the amount of information they bring in to crosscheck with providers, as they must strike a balance between learning what they want to know with the desire to be classified by providers as an easy or compliant patient. This communication balance impacts how much information participants decide to crosscheck with providers.

This finding furthers our understanding of information verification behavior online. To date, much of the research on information verification has focused on how students use the Internet to verify information they find for class assignments (e.g., Metzger, Flanagin, & Zwarun, 2003; Rieh & Hilligoss, 2008). This study explicates some of the ways that people in a health context verify information found online using sources both online and offline. In fact, most of the research on the verification of information found online does not examine how people use additional sources – like other people – to verify information (e.g., Flanagin & Metzger, 2007). The current study adds to our understanding of verification by describing how people use multiple types of sources to carry out crosschecking activities.

In fact, the present study suggests that the intended use of information impacts information verification, as participants in this study typically crosscheck information from the Internet with providers in cases where it may impact health decisions. Participants also crosscheck information with sources other than providers in some cases. This demonstrates that there may be a hierarchy of verification sources in a health context, and that the use or potential use of information impacts crosschecking. These findings should be explored further as described in the section on future research below.

5.2.2 Similarity assessment. The other main finding in this study is that participants engage in similarity assessment as a way to gauge relevance both when they seek and when they disclose information. Similarity assessments are contextual, change over time, and both impact and are impacted by information behaviors. These dimensions of similarity assessment will be discussed in more detail below on the section explicating the model of information behaviors in online support groups. This finding further illustrates how relevance is dynamic both across individuals and across time, corroborating earlier studies on relevance assessment in a variety of contexts (Saracevic, 2007). Research on relevance assessment is often focused on individual users determining relevance in single search sessions. As is the case with research on verification techniques discussed earlier, most of the studies of relevance examine how college students assess relevance. The current study therefore extends our understanding of how relevance may operate for people who are not college students, adding to a growing body of literature on relevance as it is "related to real users, in real situations, dealing with real issues of relevance" (Saracevic, 2007, p. 2141).

Multiple previous studies show that the identity of the author is an important criterion for relevance in online information seeking sessions (e.g., Maglaughlin & Sonnenwald, 2002). This study extends those findings, showing how author criteria may become increasingly important on the social web, particularly when people are searching for information from people who are similar to them. This study also suggests that the socio-emotional aspects of relevance are particularly important in health information seeking. Socio-emotional relevance criteria include answerer's experience and emotional support (Kim & Oh, 2009). The current study corroborates findings from this earlier work examining relevance on the social web, explicating some of the aspects of relevance that matter in the context of online health information behavior.

Specifically, it is closely related to the notion of patient peers as sources of information and support, particularly in situations where individuals do not have access to other people who share their diagnosis (Veinot, 2010). It also begins to address an understanding of how belief may play a role in assessments of relevance, a topic that has not yet been explored in detail as noted by Saracevic: “The notion of belief has not yet penetrated relevance theorizing in information science…. Beliefs are a murky concept, but they may affect relevance” (2007, p. 1921).

The findings on similarity assessment further illustrate that some information behaviors occur not just when people search for information, but also unfold in similar ways when people use information. This highlights a link between information seeking and disclosure. This link will be discussed in more detail in the following description of the model of information behaviors in online support groups.

5.3 Model of information behaviors in online support groups

Figure 3 is a model of information behaviors in online support groups for CKD as these activities unfold over time. The model is flexible, in that it explains the seeking and disclosure processes both for individual situations over time and for the entire process of learning about the context of CKD. However, it does not include all of the information behaviors described by the participants in this study. Participants use many different online sources for information about CKD; the model only illustrates those activities that take place in online support groups or forums. Because of this, the phenomenon of crosschecking is not illustrated in the model. In this section, the individual constructs in the model are described and the relationships between the constructs are explicated.

5.3.1 Going online for information about CKD. The top box in the model illustrates some of the reasons that participants turn to the Internet for information about CKD. The

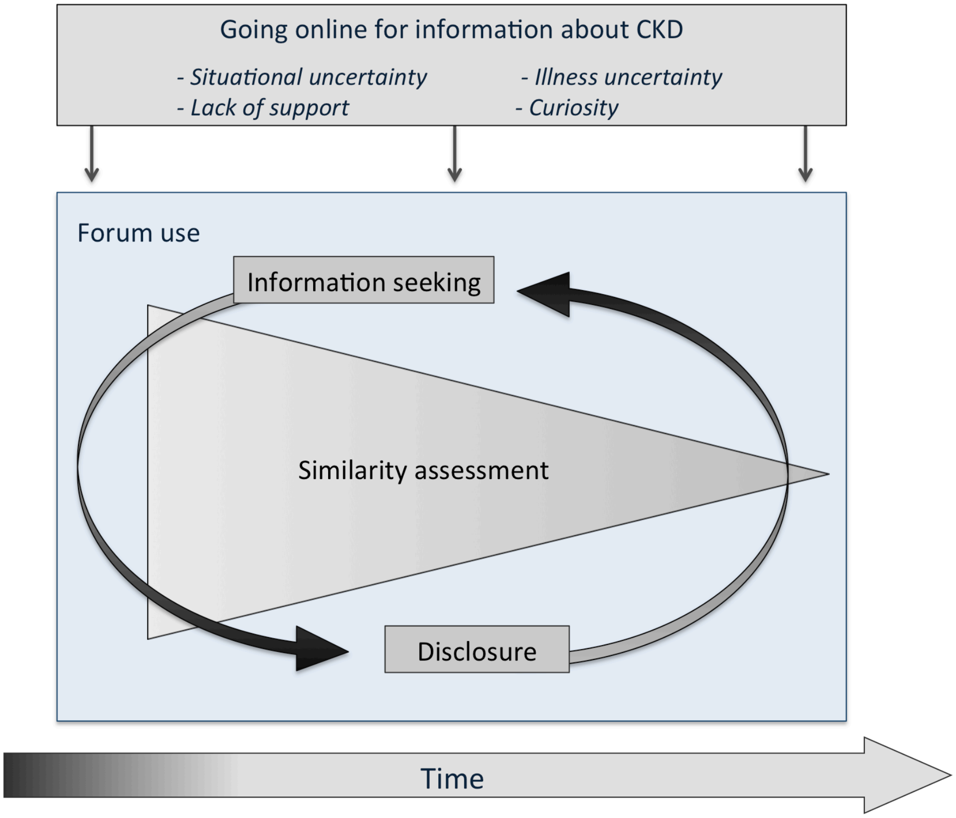

Figure 3. Information seeking, disclosure, and similarity assessment in online support groups over time.

italicized words in this box – illness uncertainty, situational uncertainty, curiosity, and lack of social support – are examples of reasons that people go online that are prevalent in the data. These examples are not intended to be exhaustive.

Participants say that they have a habit of searching the Internet for most of their questions, curiosities, or information needs. It is therefore not particularly surprising that they go online for information about kidney disease, especially when they have an illness or situational uncertainty that is related to their illness. When they initiate their information search on the Internet, they begin by “casting a wide net,” as Sherri says, searching broadly in order to better understand the context of the illness and the potential situations that may arise within that context. At some point in this general search, participants find and begin using online support groups, or forums, for CKD.

The searches that led participants to the forums in this study can be described as directed browsing sessions. These general searches before participants find the forums are not represented in the model, as the model is intended only to illustrate information behaviors on the forums themselves.

5.3.2 Forum use. None of the participants in this study specifically sought out online support groups, although some of them were interested in finding experiential information from other patients while they looked for information about CKD. However, upon encountering an online support group for CKD, participants generally lurked there before creating an account. While lurking, participants learned about two topics simultaneously: CKD and the forum norms. To learn about CKD, they searched and browsed for information related to their situations, uncertainties, and curiosities; they also encountered emotionally supportive information from users, and often reported that the sense of community and activity on the forums drew them in and compelled them to return In this model, information seeking, disclosure, and similarity assessment all occur within the context of forum use.

5.3.3 Information seeking. Searching for information on the forums is illustrated in the leftmost box in the forum use section of the model. In this model, information seeking spans a range of activities on the forums, from directed seeking to undirected exploratory browsing. Participants often switched between these activities during sessions of using the forums, and reported learning new information needs or “tangents,” as Amy called them, during directed searches for information about a specific question, uncertainty, or curiosity.

Information seeking begins early on the timeline of interaction with forums, as illustrated by the right-facing arrow on the bottom of the model. Seeking typically happens before disclosure; in most cases, participants lurk, seek, and learn before they choose to disclose information about themselves and their health. This is represented by the placement of the disclosure box on the bottom right corner of the forum use section of the model.

5.3.4 Disclosure. Disclosure occurs later on the timeline than information seeking, as it often occurs after a period of lurking and searching for information on the forums. Participants start disclosing information about themselves on the forums for a variety of reasons. For example, they may feel like they have something to add to an existing discussion, they may realize that they have learned information via experience that is not on the forums that they think other people should know, or they may have a question or questions about something related to CKD. In many cases, these questions necessarily contain personal disclosures. The story of Steve's first post on the forums, described in the first chapter of this study; Joan's questions on the forums about what to do with her fistula; Jacob's admission of his concerns about dialysis and his discussion of his emotions related to the treatment; and Laura's questions on the forums about the experience of peritoneal dialysis all illustrate the connections between information seeking and personal health information disclosure that are present when people search for health information on the social web. These examples clearly illustrate the relationship between seeking and disclosure that occurs on the forums, as they interweave personal health information disclosures with questions about the illness.

5.3.5 Relationship between seeking and disclosure. In order to receive useful and relevant responses to questions they post online, participants must provide context in the form of disclosing information about themselves. In fact, seeking and disclosure often work in symbiosis, mutually benefiting one another. Seeking frequently begets disclosing, and disclosure frequently begets more seeking on the forums. This often occurs when participants feel that their previous disclosures resulted in positive effects for themselves or for others: when disclosure is helpful, they are likely to return to the forums again as a source of information.

However, asking questions and providing context via disclosure is not the only example of the link between these two activities on the forums. This link also occurs collaboratively. In fact, there are situations where participants do not engage in much seeking or disclosure, yet they still describe a link between the two activities because they occur in a collaborative information space. For example, Brent sought out information on the forums and found that the information he desired was not there. As such, he decided to disclose more about himself and his own experiences on the forums in order to add to the body of knowledge there. This also occurred for users like Laura, who could not find much information about life as a young woman with a peritoneal catheter; after experiencing it herself, she disclosed detailed information about it – including photographs of herself – both on the forums and on her personal blog in order to help others in similar situations.

In contrast, Amy uses the forums only to search for information and as a source of social support. She reported that she did not disclose information about herself on the forums because she did not think she had information that was relevant enough to share. Still, she finds that the forums provide a wealth of information that is useful to her, despite not disclosing there. This is because she observed what information other people share and concluded that she would not be able to aid others in their seeking. Therefore, while seeking and disclosure do not rely on one another to occur in the forums, they are still inherently related processes.

5.3.6 Similarity assessment. Similarity assessment impacts both information seeking and disclosure. This is represented by the triangle in the middle of the forum use box on the model; the triangle comes to a point over time, illustrating how similarity assessment narrows and becomes more specific over time as participants learn about CKD, both by reading the forums and by experiencing more situations as time progresses. The triangle representing similarity assessment overlaps with the arrows connecting information seeking and disclosure, as it impacts and is impacted by those activities. However, it is not a necessary component of either activity: in some cases, participants searched for information or disclosed personal information on the forums without assessing similarity. Similarity assessment also has an emotional component: by relating to someone else, either when searching for or disclosing information, participants say that empathy and understanding is fostered on the forums. This often creates a sense of community, as described in the previous chapter.

5.4 Theoretical implications of the model

Because this model addresses health information behaviors only in online support groups, where similarity assessment is a central activity that occurs over time and that impacts both seeking and disclosure on the forums, it is fairly narrow. It shares several things in common with other models of information behavior, disclosure, and uncertainty in illness. These will be described below.

5.4.1 Sense-making. The current model bears a close resemblance to Dervin's Sense-Making Theory, which describes a user embedded in a context experiencing a situation that is necessarily bound by time and space. This situation highlights a gap for the user, which is analogous to the situational and illness uncertainties that may spur participants to go online to look for information. A gap is essentially the difference between the situation a user is currently experiencing and the situation they desire. According to Dervin, gaps are bridged by “verbings” – activities that aid the user in make sense of a situation or context. Verbings are defined as the “designing of cognitive and emotional elements that serve sense-making and sense-unmaking” (Savolainen, 2006, p. 1117). Examples of verbings related to sense-making in this study include encountering the forums, assessing similarity, forecasting the future, disclosing, and searching. In fact, many of the activities in the current model can be classified as verbings. This may be partially due to the research method used in this study. Constructivist grounded theory encourages the creation of gerunds, or verbs that function as nouns, when coding to describe the causes, interactions, and consequences present in the data (Charmaz, 2014). Furthermore, constructivist grounded theory emphasizes processes; verbings themselves are typically words describing processes. Therefore, a constructivist grounded theory analysis focused on information behavior – such as this present study – is predisposed toward the creation of verbings as defined by Dervin. In fact, one could cast this model as a specific example of sense-making in a given context. However, the addition of similarity assessment and of disclosure in this model extends Dervin’s original model of sense-making theory within this particular context.

5.4.2 Information horizons. The current model is also closely related to Sonnenwald’s concept of information horizons, which sees information behaviors as shaped around and by contexts, situations, and social networks (1999). The presence of information horizons is clear in this current study, which indicates that interactions with other people within one’s social network often cause people to go online to search for information. This is described by the example “lack of support” in the top box in the model, “going online for information about CKD.” While this study did not require participants to draw their own information horizons, it is clear that participants typically referred to the same two general sources when faced with an information need: healthcare providers, including nurses, dialysis technicians, general practitioners, and specialists (including but not limited to nephrologists); and the Internet, including both trusted static websites like government sites and sites published by known and respected groups like the National Kidney Foundation, and online support groups. Depending on the need, the order in which sources were consulted changed, although the Internet was often the first source that participants reported consulting, particularly because it was easier to access than a healthcare provider and was part of their usual information routine. However, participants do crosscheck information found from one source with other sources, a phenomenon that extends our understanding of how information horizons operate in practice.

5.4.3 Information search process. This model is also reminiscent of Kuhlthau's model of the information search process (1991). Kuhlthau's work highlights the emotional and cognitive aspects of information seeking and illustrates how people refine problems and questions over time, managing feelings of uncertainty as they engage with information. This process is echoed in the process of assessing similarity and in how the understanding of similarity narrows and becomes more specific over time as participants search for and disclose information in forums. Similarity assessment is also situational; that is, factors that are used to determine similarity in one situation may have less weight or may not even be relevant in other situations. Finally, as noted earlier, similarity assessment is an emotional activity that fosters empathy, which in turn influences what information people search for and disclose online. This is aligned with Kuhlthau's focus on the emotional aspect of information search as explicated in her model of the process. However, Kuhlthau's work focuses largely on information seeking; the final step in the process is an evaluative activity called "presentation." In contrast, the current model illustrates the links between information seeking and information use in the form of personal health information disclosures online. The current model is also social, whereas Kuhlthau's model is largely focused on individuals.

5.4.4 Disclosure decision-making model. In fact, most models of information behavior are focused on individuals and do not take the collaborative nature of many of these activities into account. Models that do address the role of others in seeking do so largely in a cursory way, such as Wilson's concept of information transfer (1999) or models of information horizons that include other people as information sources (Sonnenwald, 1999). The current model illustrates information behaviors that inherently include other people, as similarity assessment is one of the central activities that participants engage with when they search for and disclose information on the forums. Therefore, the model is perhaps more closely related to some of the theoretical frameworks offered in communications research. For example, the disclosure decision-making model (DD-MM) offers an explanation of several factors that may influence the disclosure of a chronic illness (Checton & Greene, 2012; Greene, 2009). One of the factors related to disclosure in the DD-MM is the relevance of the disclosure to others; this is corroborated by the findings in the current study that suggest that similarity assessment impacts information disclosure on the forums. This finding also suggests that the DD-MM may be applicable to online disclosures; currently, the model is only intended to describe face-to-face disclosures between two individuals at one point in time.

5.4.5 Uncertainty in illness. Both the DD-MM and sense-making theory are closely related to the theory of uncertainty in illness, which posits that uncertainty is essentially a gap in understanding, a "cognitive state created when [a] person cannot adequately structure or categorize an [illness] event" (Mishel, 1988, p. 225). Uncertainty in illness theory shows that multiple factors may help individuals manage or even reduce uncertainty; these factors provide structure and include good relationships with credible healthcare providers, social support, and education about one's chronic illness. However, the current model extends the existing understanding of credible authority as explicated in the theory of uncertainty in illness. In that model, credible authorities are analogous with healthcare providers, while the current model illustrates that in some cases the definition of credible authority can be expanded to include other similar patients.

5.5 Implications for practice

The findings in this study are particularly useful for two groups of practitioners: healthcare providers and interface designers. This section discusses some of the ways in which these professionals can apply these findings to practice in order to address the needs of people with chronic illnesses who search for and disclose health information in online support groups.

5.5.1 Implications for healthcare providers. These results highlight the importance of the relationship and of effective communication between people diagnosed with CKD and their healthcare providers. General strategies for effective communication with patients, particularly taking patient concerns seriously and developing an ongoing dialogue with patients, is advice that is often repeated in the literature (e.g., Berry, 2006) and that corroborates some of the findings from this study.

Providers can teach their patients how to assess the validity of information online by encouraging them to visit sites that are in governmental or organizational domains. Using "people words," as Candice says, to describe how to evaluate online sources can help ensure that the message is received. For example, using Nina's phrase "watch the pages" could be used as a shorthand for evaluating the source of information presented on a website. A provider might instruct patients to evaluate sources by saying something like, “Watch the pages. Sites that end in dot-gov and dot-org may be more reputable sources than sites that end in dot-com.”

Providers can also actively encourage patients to crosscheck information by looking to see if it is repeated across sources. Although participants report crosschecking nearly all of the information they get from any source – stressing in particular that they do not implement anything they have read about online without first discussing it with a trusted provider – this activity may not always occur. Therefore, providers should encourage patients to verify information found online, especially when that information may be used to make treatment decisions. In this study, participants who felt dismissed by providers were less likely to use them as sources for crosschecking in future interactions, highlighting the necessity of a welcome attitude towards information seeking online.

Providers may also want to encourage patients to use OSGs as a source of emotional support and as a place to learn about the psychosocial aspects of CKD, activities that are common among participants. However, encouragements for patients to use OSGs should also be accompanied by the warning to “take everything [they read online] with a grain of salt,” as Steve and multiple other participants say. Reminding patients that information found online posted by other patients in OSGs may not be applicable to their own situation is a necessary component of recommending that patients use OSGs for support and for information. Providers may also want to encourage patients to seek out patient peers that share both demographic and experiential similarity with them, as similarity assessment can be a helpful way to assess the relevance of experiential information found in online support groups.

Finally, many participants feel that interactions with providers regarding the communication of treatment options could be improved. In particular, multiple participants say that they learned about alternative options to in-center dialysis online –not from their healthcare providers. This aligns with the literature in this area, which shows that patients are often unaware that they have options when they initiate dialysis (Mollicone, Pulliam, & Lacson Jr, 2013). More comprehensive patient education is likely warranted with regards to treatment options for CKD.

5.5.2 Implications for designers of online support groups for health. Because the study results indicate that similarity assessment and future forecasting are of great importance to participants, online support groups for health should allow people to easily find other similar users. There are several ways that this activity could be fostered. First, the practice of the illness vitae as described in the results and discussion chapter is currently ad-hoc. The simple addition of drop-down menus in the signature line allowing for users to input dates with a free-text box for a description of illness or other events would allow for the illness vitae to become a source of structured data. This structure could then be built in to search capabilities on the forums, allowing users to find other users who have listed similar experiences or have similar illness trajectories. This could also be employed for other information that is used in the assessment of similarity, such as geographic location and age. Currently, none of the interfaces for the support groups in this study allow users to easily find people who are of a similar age or who are in a similar geographic region. Furthermore, similarity assessment may be improved by the employment of automated health interest profiles through text analysis, a project that is currently under investigation (Hartzler et al., 2014).

As discussed in the results and discussion chapter, the search and browse functions on the most popular online support groups for CKD are lacking. It appears that at least one of the forums is aware of this issue, as it is often changing the interface. In some cases, users are notified of these changes in the “Announcement” sub-forum, but many times there is no accompanying announcement when the interface is re-designed. Unfortunately, users of this forum reported that they have trouble finding the information they are looking for in the forum – even when they themselves posted it. One strategy to improve the navigation issues mentioned by the participants in this study and by other users in comments made to the forums may be to employ usability testing to identify some of the most pressing issues for users of these systems.

Additionally, as discussed in the results chapter, problems with the organization of sub-forums make it difficult for participants to browse them effectively. Online support groups should make an effort to organize sub-forums in a systematic and uniform way. Again, user studies with real users of these forums could prove helpful in determining how to better organize these sites. Browsing could also be enhanced by the implementation of tags. Tags could be either generated manually when users start threads, or they could be assigned automatically using natural language processing and cluster analysis techniques (Chen, 2012). Tags could allow for the creation of browsing interfaces; they could also be used to automatically classify posts that are similar to one another, allowing for the interface to serve a list of related threads to users (Bausch, 2012).

5.6 Limitations

The findings in this study must be considered in light of the limitations of the research methods used. Specifically, there are two major limitations to be addressed: the limitations of conducting telephone interviews, and the limitations of the various sampling strategies employed.

Telephone interviews are often discussed as a less attractive alternative to face-to-face interviews in qualitative research (e.g., Novick, 2008). Typically, researchers are concerned that the lack of both non-verbal and contextual cues results in data distortion or data loss (e.g., Opdenakker, 2006). This may manifest as a reduction or loss of rapport; some researchers also worry that probing questions and in-depth discussions are harder to maintain on the telephone (Novick, 2008). However, there is little evidence to suggest that the quality of the information gleaned from telephone interviews is lower than the information collected in face-to-face encounters (Sturges & Hanrahan, 2004). In the current study, using the telephone allowed me to recruit geographically disparate participants, including individuals who live overseas. Furthermore, in some cases the topics we discussed on the phone were highly sensitive and emotionally difficult. The telephone allowed for participants to discuss these topics in the setting of their choice without as much concern for my reactions to their comments. In fact, multiple participants told me how comfortable they were during our discussions, remarking specifically on how easy it was to speak with me; this indicates that rapport was likely not impacted by the use of the telephone in this study. Finally, the issue of mirroring, wherein participants interact with the researcher as they would in other similar settings related to the interview topic (such as visits with healthcare providers) – was reduced by using the telephone (Holt, 2010).

The sampling strategies used in this study are not representative, nor are they intended to be. This is standard practice for grounded theory research (e.g., Charmaz, 2014). In this study, participants responded to recruitment messages posted online, mostly to online support groups for patients with CKD, and were therefore self-selected. The sample therefore necessarily includes only individuals who were willing and able to talk about their experiences with CKD and with using the Internet for health information. The sample therefore may not include the large portion of individuals diagnosed with CKD who have low health literacy (Devraj et al., 2015; Fraser et al., 2013) and who do not have access to the Internet (Schatell, Wise, Klicko, &

Becker, 2006). In fact, the sample in this study is not representative of the illness population. Demographic data, such as race and exact age, were not collected from participants. This could be seen as problematic, particularly because African-Americans are more than three times as likely to be diagnosed with CKD in the United States (US Renal Data System, 2014). This limitation should be addressed by future research that uses representative sampling strategies to test the model developed in this study.

Additionally, the sampling methods used to select comments made to the online support groups are necessarily purposive and do not include all of the comments made by all participants. This is because some of the participants were highly prolific; the inclusion of all of their comments would have dominated the dataset. This strategy, however, means that the resulting sample of comments is not representative. However, a representative sample is not necessary for grounded theory research, since it is not intended for the results to be generalized to a larger population.

In a naturalistic inquiry such as this study, the transferability of results to other contexts is of concern, rather than generalizability (Lincoln & Guba, 1985). The value of grounded theory research lies not in its generalizability but in the credibility, originality, resonance, and usefulness of the findings (Charmaz, 2014). The findings in this study are credible, as I achieved intimate familiarity with my participants via multiple emails and discussions over two years of research. I also became intimately familiar with the setting of the study by visiting the two most popular forums on a weekly basis over the course of two years, as described in the Methods section. Trustworthiness was enhanced in this study using three methods: member checking, peer de-briefing, and negative case analysis. I conducted multiple member checks throughout my data collection and analysis, allowing my participants to correct and verify my findings and analysis.

This also allowed me to become more familiar with my participants, enhancing credibility. The presence of evidence and thick description throughout the results and discussion chapter also further bolsters the credibility of this study. Peer de-briefers agreed with the claims made in the portions of the analysis that they reviewed after looking at a random sample of some of the data and making their own independent assessments of what the data suggest, enhancing trustworthiness. Finally, negative case analysis was undertaken by engaging in constant comparative analysis with a specific focus on instances where the data problematized or provided conditions for disagreement with my existing analysis.

This study also offers new insights that are both theoretically and practically relevant. The model extends and refines our understanding of information behaviors, offering a unique view on how similarity operates as an assessment of relevance on the social web. It also illustrates how online health information behaviors change over time, becoming more refined and narrow as experience and information become assimilated as part of a new normal for individuals diagnosed with CKD. The findings also have several implications for doctor/patient communication and interface design, demonstrating practical applicability of the analysis. The findings from this study provide a basis for future substantive research both in information science and health communications.

5.7 Future research

As intended with grounded theory research, this study has opened multiple fruitful avenues for future research, including studies examining crosschecking, similarity assessment, and the transferability of the findings to other contexts and settings. Some of the possibilities for future studies in these areas are discussed in this section.

First, the constructs explicated in this study – most notably crosschecking and similarity assessment – are worthy of exploration in more detail. As explained above, this study adds to our understanding of information verification activities. Further research should be conducted to better understand how and why individuals crosscheck health information found on the Internet with healthcare providers. Observational studies, including shadowing visits with care providers and health information search transaction logs from participants, may be an effective way of developing a better understanding of crosschecking. This would also respond to the call for studies that observe verification techniques directly, as prior research suggests that people who self-report verifying online information are actually less likely to do so in practice (Flanagin & Metzger, 2007).

While participants described many different factors of similarity, the relationship between and among these factors has not been addressed by this research. Furthermore, there may be other factors of similarity that were not mentioned by participants in this study. This is especially true given that similarity assessment is contextual and changes over time. Future exploratory studies examining the different factors of similarity assessment that are evaluated when people search the social web are necessary in order to determine what factors matter in what contexts. Another grounded theory study could aid in the operationalization of the concept, providing a useful set of constructs to be tested quantitatively in future work. Furthermore, an examination of personal beliefs and the role they play in similarity assessment is warranted, particularly given the dearth of studies examining how beliefs impact relevance judgments noted above.

Finally, this study presents a model of information behaviors in online support groups that should be tested for its transferability to other contexts and domains. Because the model as developed is fairly general, it may be applicable to forum behaviors for other chronic illnesses. It may also be transferrable to contexts outside of health where people search for and disclose information to other people. For example, it may be transferrable to forums and online social networks dedicated to hobbies (e.g., Ravelry for knitting or Flickr for photography) or to more general social networks like Twitter and Facebook. Future work should assess the transferability of this model and the relationship between and among its constructs.

APPENDIX A: INITIAL RECRUITMENT MESSAGE

My name is Kaitlin, and I am a PhD student investigating how kidney patients and their caregivers look for information online and what health information they share with other people in online support groups. I am particularly interested in kidney-specific groups because I have had CKD for 15 years, and I believe that this research will help other patients like us searching for and sharing health information online.

This research study investigates how people search for and share information about their health in online support groups for kidney disease. If you choose to participate in this study, I will interview you over the telephone at your convenience. The whole project will take between 2 and 3 hours of your time, and will consist of two interviews on the telephone. Each interview will take between 60 and 90 minutes. You will be sent a $25 gift card at the conclusion of the second interview as a token of appreciation for your time. Approximately 20-25 people will be participating in the study, overall.

I have received permission from the site administrator to conduct this research, which includes gathering some of the forum posts for analysis. If you would prefer that I do not collect and analyze your posts, please contact me at kaitcost@email.unc.edu.

For more information or to take part in this research study please contact me by e-mail at kaitcost@email.unc.edu.

Participants must speak English and be a CKD patient or a caregiver for a CKD patient. In addition, you or the patient you care for must fit one of these criteria:

- Diagnosed with CKD within the past four months
- Begun dialysis in the last four months
- Had a kidney transplant in the last four months

- Have been on dialysis for at least a year and a half (18 months)
- Have had a kidney transplant for at least a year and a half (18 months)

In addition, you should have been a member of this online support group for at least four months in order to be eligible to participate.

Because this research is not connected with services provided by physicians or hospitals, there is no risk that you will lose access to care by participating in the study.

This study has been approved by the UNC Chapel Hill Institutional Review Board for Social and Behavioral Research. If you have questions or concerns about this study please contact the IRB at 919-966-3113 or by email at irb_questions@unc.edu. You can also contact my faculty advisor, Dr. Barbara Wildemuth, at wildemuth@unc.edu, with any questions or concerns about this study.

APPENDIX B: EMAIL QUESTIONNAIRE

Thank you very much for your interest in my research study! I have a few questions to aid me in selecting participants. Please do not answer any questions that you do not wish to answer.

1. Where did you hear about this study? Please give the full name of the support group where you saw the recruitment message. If you heard about it through other means (like through a friend), please indicate that here, and list the support group or groups where you participate.
2. Are you a CKD patient or caregiver?
3. If you are a patient, how long have you had CKD? If you are a caregiver, how long have you been a caregiver for a CKD patient?
4. Have you been diagnosed with CKD within the last four months?
5. Have you started dialysis in the last four months?
6. Have you received a kidney transplant in the last four months?
7. Have you been on dialysis for at least 18 months?
8. Have you had a kidney transplant for at least 18 months?
9. How long have you participated in the online support group?
10. How often do you post?
11. What is your username on the online support group, if you have one?
12. Why are you interested in participating in this study?
13. Is there anything else that you would like to share with me?

I will be in touch shortly to let you know if you are eligible to participate. At that time, I will send you a fact sheet about the study and we will set up a time for your first and second interviews.

APPENDIX C: FACT SHEET

University of North Carolina at Chapel Hill

Information about a Research Study

Adult Participants

Consent Form Version Date: March 11, 2013

IRB Study # 13-1952

Title of Study: Online information seeking and disclosure of personal health information in CKD patients

Principal Investigator: Kaitlin Costello

Principal Investigator Department: School of Information and Library Science

Principal Investigator Phone number: 919-627-1741

Principal Investigator Email Address: kaitcost@email.unc.edu

Faculty Advisor: Barbara Wildemuth

Faculty Advisor Contact Information: (919) 962-8072, wildemuth@unc.edu

What are some general things you should know about research studies?

You are being asked to take part in a research study. To join the study is voluntary.

You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

Please keep a copy of this information sheet. You should ask the researchers named above, any questions you have about this study at any time.

What is the purpose of this study?

The purpose of this research study is to understand how and why chronic kidney disease patients look for and post personal health information in online support groups. The main aim of this study is exploratory. No one has done research in this area yet, and the aim of this research is to determine the major themes and issues that arise when kidney patients conduct information searches and share health information in online support groups. You are being asked to participate in this study because you are a member or reader of at least one online support group for kidney disease.

Are there any reasons you should not be in this study?

You should not be in this study if talking about kidney disease, information seeking, or information sharing will cause you undue stress or emotional disturbance. If you decide to participate and the study is too stressful, you can quit the study at any time.

How many people will take part in this study?

There will be approximately 20-25 people in this research study.

How long will your part in this study last?

Your participation will include two 60- to 90-minute telephone interviews. In some cases, the researcher may contact you for a third follow-up interview; this would take between 30 and 45 minutes. You will also be contacted by email to verify your interview responses in a process called "member checking" which will allow you to correct misinterpretations and to clarify your responses. Finally, you will be sent a list of all quotations to be published from your interviews and your online forum posts for verification.

What will happen if you take part in the study?

- Overall design:
    - Interviews
        - You will participate in two 60- to 90-minute telephone interviews, at least two weeks apart.
        - The first interview will be about searching for health information online; the second interview will be about sharing personal health information online.
        - With your permission, these interviews will be recorded for transcription. The recordings will be deleted after the transcriptions are created.
        - A one- to two-page bulleted list of the main findings from each interview will be sent to you for verification. If you feel that your statements have been misinterpreted in these notes, another interview will take place for

clarification. This interview will take between 30 and 45 minutes.

    - Your name will not appear in any published results of this study; pseudonyms will be used.

- Online content
    - With your permission, posts that you have made to online support groups for kidney disease will be collected and analyzed by the researcher.
    - Content that you have posted online may be quoted directly; however, your online username will not be reported. There is a small chance that someone could search for your quote and find other content you have posted in the online support groups. These quotes could then be tied to your interview quotes, because the same pseudonym will be used for your forum posts and interview quotations. To combat this, a list of all quotes that the researcher may publish from both your interviews and your online content will be sent to you for verification before publication. You will be able to request that any of these quotes be removed from publications for any reason.

<u>What are the possible benefits from being in this study?</u>

Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being in this research study.

<u>What are the possible risks or discomforts involved from being in this study?</u>

The first risk to you as a participant is that some of the questions may be difficult for you to answer, causing emotional discomfort. This is not expected to occur; however, if you are uncomfortable for any reason you may skip questions or withdraw from the study at any time. The second risk is that full quotes from your online content will be used, although your online username will not be reported or published. This means that someone may be able to locate your online account by searching for your quotes online. They would also be able to identify your published interview quotes from your pseudonym as belonging to you. However, there are minimal risks associated with finding your online information, given that it is already available on the public Web. There may also be uncommon or previously unknown risks. You should report any problems to the researcher.

What if we learn about new findings or information during the study?

Your responses will not affect your care in any way. This study is not connected to your healthcare providers, so new findings or information will not affect your care. You will be given any new information gained during the course of the study that might affect your willingness to continue your participation.

How will your privacy be protected?

All the information I receive from you will be strictly confidential and will be kept on a password-protected computer. I will not identify you by name or username in any presentation or written reports about this study. You will be able to choose where you are located during the telephone interviews in order to maximize your privacy at that time.

If it is okay with you, I might want to use direct quotes from this interview, but these would only be quoted as coming from “a person” or a person of a certain label or title, like “one dialysis patient said." With your permission, I would also like to ask for the ability to collect all of the posts you have made to online support groups for analysis. You are not obligated to take part in this part of the study.

Kaitlin Costello, the primary researcher, will be the only person with access to individually identifiable data. Any emails from you to the primary researcher will be deleted after the interview has taken place. Your name and address will be stored only for the purpose of sending you a gift card after the interview has taken place. This information will be stored on paper in a location that is separate from the data. It will be destroyed after you confirm that you have received the gift card or three months after the gift card was sent, whichever occurs first.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

- You can decline to have your interview recorded as long as the researcher is allowed to take notes throughout the interview
- Recordings of your interviews will be destroyed after transcription
- The audio recorder may be requested to be turned off at any time

Check the line that best matches your choice:

_____ OK to record me during the study

_____ Not OK to record me during the study

<u>What if you want to stop before your part in the study is complete?</u>

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

<u>Will you receive anything for being in this study?</u> You will be receiving a $75 VISA gift card for taking part in this study. It will be sent to you after the last interview has been completed.

<u>Will it cost you anything to be in this study?</u>

No. The only cost to you is your time.

<u>What if you have questions about this study?</u>

You have the right to ask, and have answered, any questions you may have about this research. If you have questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

<u>What if you have questions about your rights as a research participant?</u>

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

APPENDIX D: INITIAL INTERVIEW GUIDES

Information-seeking interview guide

This is a semi-structured interview. Not all questions will be asked of all participants. The indented questions are just avenues that the interviewer might explore; they are not essential questions, but are mostly extra questions as defined by Berg (2008).

1. Tell me a little bit about yourself.
2. Can you tell me a little about <the health transition you are in right now>?
    a. *Participants will explain their health transition in their reply to the email questionnaire. The interviewer will ask specifically about the transition noted in the email.*
3. Tell me a bit about how you use the Internet.
    a. *How long have you been going online?*
    b. *Do you have Internet access at home?*
    c. *What do you usually use to go online? A computer, an iPad, your phone?*
    d. *What is the purpose of your Internet use?*
4. When you started experiencing <the health transition>, what things did your doctor, nurse, or other healthcare providers tell you about CKD?
    a. *Did you ask them questions about it?*
    b. *Did you feel like you had unanswered questions?*
    c. *Did your doctor say anything about using the Internet to find out more about your kidney disease?*
5. Tell me about how you use the Internet in relation to your kidney disease.
    a. *Did you decide to go online to learn about your kidney disease?*

   b. *What other health information do you look for online?*

6. Tell me a little bit about a time you found something about kidney disease you were looking for online.
   a. *What were you looking for?*
   b. *Did the thing you were looking for stand alone, or was it related to other questions?*
   c. *How was it related to other questions?*
   d. *Did you get an answer?*
   e. *Was the answer complete or partial?*
   f. *How did you get the answer?*
   g. *How important was it for you to get an answer?*
   h. *Did the importance ever change? How?*
   i. *Did you expect the answer to help you? Did it? How?*
   j. *Did you expect the answer to hurt you? Did it? How?*
7. Has there ever been a time when you wanted to find something out about your kidney disease and you were unable to?
   a. *What were you looking for?*
   b. *Did you see yourself as blocked or hindered when you asked this question? How?*
   c. *Why did you ask this question?*
   d. *How important was getting an answer?*
   e. *Did you get a partial answer, or no answer at all?*
   f. *Why do you think you weren't able to find anything about it?*
8. How did you find <online support group(s) name>?

    a. *For registered users: Why did you decide to create an account there? Why do you continue to use the site? How often do you post?*
    b. *For lurkers: What makes you continue to come back without creating an account or posting?*
9. Do you have a favorite post, or something that was very helpful for you to read?
10. Can you tell me about a time that you posted something about yourself on an online support group for kidney disease?
11. Did you have any other comments to share?

Thank you very much for your time. I really appreciate your participation. I will speak to you again soon!

Disclosure interview guide

This is a semi-structured interview. Not all questions will be asked of all participants.

1. We talked a bit last time about how you found <online support group where they were recruited>. Can you tell me a bit more about why you keep using this or other OSGs?
2. Tell me a little bit more about your activities in <online support groups>
    a. *How often do you visit OSGs?*
    b. *Do you visit multiple OSGs?*
        i. *Why do you use multiple OSGs?*
        ii. *Which site is your favorite? Why?*
        iii. *If they do visit multiple sites, ask them to tell you which site they are discussing in their answers. Additionally, the interviewer will want to probe about the differences between sites when appropriate.*

3. I’d like to hear about a time that you posted something about your health in an online support group and you had something specific that you wanted other people to comment on in their responses.
    a. *Tell me a bit about the content of the responses.*
    b. *Were the responses helpful?*
    c. *What was the most helpful response?*
    d. *Did this experience affect your willingness to post other things about your health in OSGs?*
4. Tell me about a time that you decided not to share something about your health in <online support group>
    a. *Did you share something else instead, or did you just not comment on the post at all?*
    b. *What are some concerns you have about sharing things about your health online generally?*
5. Have you ever regretted sharing things about your health online?
    a. *Tell me a bit about this experience.*
    b. *What did you do about it?*
    c. *Did this affect your willingness to post other things about your health?*
6. Has the process of talking about your health online changed over time for you?
    a. *If so: How has the process changed?*
        i. *What are some of the factors that contributed to this change?*
    b. *If not: Why do you think the process hasn’t changed?*

7. Tell me a bit about your Internet use. Do you connect with people in other places online, aside from <online support groups>?
    a. *Do you have a Facebook account? How often do you use it? How often do you post?*
        i. *Twitter?*
        ii. *A personal blog?*
    b. *Have you ever shared anything about your health in these places?*
    c. *Do you post different things about your health in different places?*
8. Can you tell me a bit about what you get from sharing things about your health online?
    a. *Have you ever shared information about your health because you wanted to learn more about other people's experiences with CKD?*
9. Do you have any other comments that you would like to share?

Thank you very much for your time. I really appreciate your participation.

APPENDIX E: SUBFORUMS

Sub-forums on DaVita

This is a comprehensive list of all of the sub-forums on the DaVita online support group. They are organized in the order in which they appear on the front page of the forum.

- Welcome/Introductions
    - New Member? Introduce yourself here!
- General dialysis
    - Share your experiences – General dialysis
        - New to dialysis
        - Living on dialysis
        - What helps me cope
        - My care partner and me
        - Other experiences
        - Treatment options & vascular access
        - Nocturnal dialysis (in-center)
    - Health conditions – General dialysis
        - After dialyzing, I feel…
        - Diabetes, hypertension, PKD, etc.
        - Depression
        - Hospitalization
    - Employment & Insurance – General dialysis
    - Medication – General dialysis
        - Prescriptions

        - Over-the-counter medications
- Kidney disease, not on dialysis
    - Share your experiences – Kidney disease
        - Just diagnosed with kidney disease
        - Living with kidney disease
        - Preparing for dialysis
        - Treatment options and vascular access
    - Health conditions – Kidney disease
        - Diabetes
        - High blood pressure, PKD, etc.
        - Depression
    - Employment & Insurance – Kidney disease
    - Medications – Kidney disease
        - Prescriptions
        - Over-the-counter medications
- Home dialysis
    - Share your home dialysis experiences
        - New to home dialysis
        - Living on home dialysis
        - Living well on home dialysis – Q&A’s
    - Home dialysis caregiver support
- Diet & Nutrition
    - The kidney diet

    - Kidney diet tips – Q&A's
    - Dialysis diet
    - Recipe exchange
    - Fav recipes
    - Fav foods
    - Kidney cooking tips
    - Kidney friendly cookbooks
    - The CKD diet
    - Dining out
    - DaVita Diet Helper
  - Nutrition reports & lab values
    - Understanding my lab values
    - Albumin
    - Hemoglobin
    - Calcium
    - Phosphorus
    - Phosphorus challenge questions
    - PTH intact
    - Potassium
    - URR
    - Cholesterol
    - Glucose
    - HGB A1c

    - Exercise & weight loss
        - Exercise
        - Weight loss
- Education, inspiration, and lifestyle
    - Resources & education
        - Best resources
        - Helpful books
        - Other education topics
    - Support
        - Online support group
    - Advice & inspiration
        - Jokes, funny stories
        - Helping others cope
        - Who helps me deal with my kidney disease
        - Best advice I ever got
        - Best words of inspiration
        - In Memory Of
        - Other inspiration
    - Lifestyle
        - Lifestyle issues
- Travel
    - US travel
    - International travel

  - Traveling on PD/HHD
- Transplant
  - Transplant recipient
  - Waiting for a transplant
  - Donors
- Caregivers
  - Coping
  - Caring for someone with kidney disease
  - What I do for my caregiver
- DaVita Online
  - Announcements from the DaVita Online team
  - How can we improve the DaVita community?
  - Troubleshooting and bug reports

Sub-forums on Home Dialysis Central

This is a comprehensive list of the sub-forums that appear on the Home Dialysis Central online support group. They are organized in the order in which they appear on the front page of the forum. The names of the experts listed have been removed from the sub-forum titles.

- Welcome
  - Message board rules
  - Guest involvement
- Ask our expert
  - Nephrologist
  - Social worker

    - PD nurse
    - Renal dietician
    - Cannulation expert
- Discussions for patients, family, and friends
    - PD for patients
    - HD for patients
    - HD and PD care partners (all home dialysis)
- Discussions for dialysis professionals
    - PD for professionals
    - HD for professionals

Sub-forums on I Hate Dialysis

This is a comprehensive list of the sub-forums that appear on the I Hate Dialysis online support group. They are organized in the order in which they appear on the front page of the forum. None of the 6 forums or 35 sub-forums under the "Remembrance for past members" sub-forum are named, as their titles include the full names and usernames of deceased members.

- Guest Board
    - The "IHD Lobby/Front Desk" - Guests & Non Members - ANY LOG-IN PROBLEMS - Please Read
- Introduction
    - Introduction – PLEASE READ THIS SECTION FIRST
    - Introduce yourself
    - The IHD Family – Our Members
    - Las Vegas a Vision Come True

  - I Hate Dialysis ONLINE STORE
  - I Hate Dialysis GAMES
- Dialysis Discussion
  - Dialysis: General discussion
    - Premium member information
    - IHD chat room
  - Dialysis: Pre-dialysis
  - Dialysis: FAQ (Frequently Asked Questions)
  - Dialysis: News articles
  - Dialysis: Diet and recipes
    - Dialysis: Thanksgiving Recipes
    - Dialysis: Christmas Recipes
    - Dialysis: Easter Recipes
    - Dialysis: Recipes Section for Specific Holidays
  - Dialysis: Home dialysis
  - Dialysis: Home dialysis – NxStage users
  - Dialysis: Nocturnal
  - Dialysis: Transplant discussion
    - Potential donors
    - Transplant stories
  - Dialysis: Medicare/Insurance
  - Dialysis: Traveling tips and stories
  - Dialysis: Working while on dialysis

  - Dialysis: Centers
    - Dialysis: Workers
    - Dialysis: Doctors
  - Dialysis: Internet links
  - Dialysis: Medical breakthroughs
  - Dialysis: Humor, pictures, stories, and poems
  - Dialysis: Spouses and caregivers
  - Advocacy
- Introducción (Spanish Section)
  - BIENVENIDOS A ihatedialysis.com
  - INTRODÚZCASE
- DIALISIS: Discusión general
  - DIALISIS: Discusión general
- FUERA DE TÓPICO
  - FUERA DE TÓPICO
- Off-Topic
  - Off-topic: Talk about anything you want
  - Political debates – Thick skin required for entry
  - Diabetes
  - Wheelchair discussions
  - Other severe medical conditions
  - Site requests, comments, technical help
- Tributes for members lost

APPENDIX F: PROCESS MEMO (EXCERPT)

I've been thinking a lot about the emotional reactions that participants discuss in the interviews. It might be helpful to pull some of those emotions out and to focus on them specifically as potential antecedents or outcomes (for lack of a better term) of activities like using the forums or for searching and also for situations like being diagnosed with CKD. The reason I started thinking about this is that I was looking at the node where I've been sort of collecting all the codes about the emotional reactions to their diagnosis or to symptoms and treatments - looking specifically at negative reactions like fear, anxiety, hatred, being overwhelmed... etc. Being able to pull out specific emotional reactions is a good way to really get at what is happening in the data, so I might start thinking about re-structuring some things, particularly in the "Process of seeking" node (which I still really, really do not like; I don't really think that's what is always happening... encountering isn't really seeking, for example). For that matter, I don't think that the node really captures what is going on in when people choose not to seek, for example. It might be more beneficial to think about the "process of seeking" in terms of "how people deal with information generally as they move through CKD" - so, I think I might be using "seeking" much too broadly. Perhaps pulling out the emotions that I am seeing in the data thus far will help to make this more clear.

So, with Joan, we see that her negative reaction to her illness experience itself strongly influenced the type of information she sought (just enough and nothing more; dialysis is like driving a car), where she sought it (at home, not at the doctor's office), and when she sought it (when she felt safe and comfortable). This is something that should be addressed with future participants - is there a connection between the emotional reaction one has to illness and how they search for or share information?

I see it in Brent, too, thinking of it - he had the opposite reaction to Joan: he was surprised by his diagnosis, but he approaches his CKD with an overwhelmingly positive attitude: Adapt, improvise, and overcome is his "motto" (he said it in one of our interviews, and has also repeated it multiple times on the forums). This might be part of the reason that he is so gung-ho about sharing about his illness experience online. He seeks CKD as a challenge to overcome, a hurdle over which to jump - while people like Joan and Steve see it as something that causes them a lot of anxiety, pain, and worry. I really think that I am "on to" something with this idea of emotions and how they are showing up in my data, and I am going to keep following that thread. I think there are some interesting clues that are showing up when I think about emotions rather than thinking specifically about searching for or sharing information - something tells me that the focus on those concepts was too much, too soon, and I may not have properly paid attention to my bias when I initially started coding based on "outcomes" and "processes" (which are intertwined anyhow).

I have also been thinking about how the term "implications" might be a much better word than "outcomes" for the impact that activities have - "outcomes" feels so... final. So I think that emotions may have different influences (implications, impacts) on information behaviors. I think that this might get at some of the issues I have been having with the "After searching" node. Sometimes things aren't really happening "after" searches…

APPENDIX G: PERSONA MEMO (EXCERPT)

Jacob has struggled with kidney issues for his whole life, most likely due to a delayed treatment for a case of strep throat when he was young. Unfortunately, Jacob did not have continuity of care; moreover, he explains that his providers did not give him information about what was happening with him or his body: “No one had said to me things like, ‘Be careful of these kinds of things. Here’s things you need to think about. Here’s things you need to watch for.’ They’re just going basically, complaint to diagnosis, or, complaint to treatment. And not really sharing the diagnosis or what the issues are going to be.” Eleven years ago, the damage sustained over a lifetime of infections caught up to him, and he was referred to a nephrologist. Unfortunately, this nephrologist did not give him much information about CKD – he was unaware, for example, that his extreme fatigue and circulation issues were due to the illness: “I couldn’t understand – the unconscious side of me is saying, ‘Gee, what’s going on here,’ but not piecing it together with, OK, this is CKD. Because I was being told, ‘OK, you have CKD or renal failure, CRF,’ all the acronyms, but nobody really sat down and told me what was happening.” He was, as he puts it, “*clueless* about what is going on other than the fact that I have some kind of kidney problem.” Seven years ago, Jacob’s brother, a doctor and a specialist in another medical field (not nephrology), set him up with a second opinion with a doctor in his city and also told him that he believed that his current doctor was mistreating him. Shortly thereafter, Jacob moved to the city where his brother practices; a year later, he began dialysis.

…

APPENDIX H: ADVANCED ANALYTIC MEMO (EXCERPT)

Downsides to future forecasting

Brent does not find future forecasting to be particularly useful to him; this is directly related to his experience of being diagnosed with PKD very early on, giving him over 10 years to prepare for his eventual kidney failure: “There’s a lot of folks that are in stage II and Stage II who certainly are curious to see what the future’s going to hold. See if they can get some things to, uh, uh… lengthen their kidney function, so they don’t have to go on dialysis. But just, it’s a strange dichotomy to me. I just don’t understand it. I honestly don’t understand it. What’s the point? I mean, like, I point out the fact that, I was diagnosed 11 or 12 years ago. And once I got within about 2 years of impending dialysis, then I started to do the research. Because I knew my life was going to change. Up until then, I followed my nephrologists’ orders, and I took my medications, and I did all that stuff. The disease is going to run its course. There’s not a damn thing I can do to change that. It’s going to run its course.” Brent simply didn’t think it was necessary to information-seek far ahead of time: “Once it got to the point where I’m monitoring my values and all that stuff, it’s inevitable, it’s going to happen, I was ready.”

Future forecasting is, obviously, imperfect: it’s like trying to predict the weather. One can predict based on patterns, but every individual is different. Participants can use future forecasting to try to make decisions (it’s not always used for decision-making, but is a central factor in decision-making; that is, one is using future forecasting as a method of predicting the success of a particular option for a future decision-making process; e.g., dialysis modality choice or whether or not to accept an EDC kidney). As Joan put it: “That's the kind of decision you make based on the best info you have at the moment, never knowing if it is really the right decision in the long run.”

Under what conditions does future forecasting occur?

Future forecasting is directly related to the concept that I have been working on of *intermediate information needs*, when people ask questions directly related to what things might be like or how things might play out as the disease progresses. It is also related to *immediate information needs* like questions about diet, medications, etc. Essentially, future forecasting *bridges* immediate needs with intermediate needs: “Immediately, my immediate focus is: What can I do to slow the process?” Sherri asks.

Joan gets a bit “meta” with future forecasting, asking other people on the forums how *they* view their own future: “My husband sees a more carefree future, [but] I see a very bleak time ahead, and I just have not been able to share his enthusiasm. And to be brutally honest, it hurts a bit to see him forget that his happy future is not one in which I will get to share. He seems to forget that my future is so full of fear and uncertainty and that there is a lot of pain and sickness ahead of me that I won’t be able to escape. How do you view your future?” After getting a few responses where people tell her essentially not to worry about the future, she comes back and more clearly defines what she means by the idea of future – she’s thinking specifically about her immediate future, which is one that she is almost certain will include dialysis. The rest of the replies in this thread are very supportive, and focus on giving Joan virtual hugs and encouraging her to use the forums as a place to discuss her worries and concerns. Another user reminds Joan that what is unknown now will soon become routine, and Joan returns to say that her experience with the renal diet was similar. It is evident that the unknown becomes known through experience – and it doesn’t only become known, it becomes routine, a part of life. This is a helpful framework for thinking about coming to terms with CKD in general as well.

APPENDIX I: THEORETICAL SAMPLING RECRUITMENT MESSAGE

My name is Kaitlin. I am a doctoral student studying how people look for information online and what they share about their health in online support groups. I have had chronic kidney disease (CKD) for 17 years, and I believe that this research will help other patients like us find and use health information.

I would like to ask you to join my research study. If you choose to join, I will interview you over the phone twice to ask you about how you use the Internet to look for and share information about kidney disease. With your consent, the interviews will be recorded. Each phone call will take between 60 and 90 minutes. To thank you for your time, you will receive a $75 gift card after the second interview is finished. About 20 to 25 people will be in this study.

I will also collect some of the posts on this forum for my research, starting with this site's creation date and ending no later than June 2015. If you would prefer that I do not collect and analyze your posts, even if you are not speaking with me on the phone, please contact me at kaitcost@email.unc.edu.

If you do not take part in the study, your posts may be collected and analyzed if they appear in threads where participants have posted. However, nothing you have posted on this site will be quoted in any research products, and you will not be individually identifiable in any way.

To take part in this study or to request that your posts not be used please contact me by e-mail at kaitcost@email.unc.edu.

You must speak English and be a CKD patient to join the study. I am particularly interested in speaking with people who are being treated for CKD with in-center or peritoneal dialysis, individuals who do not post to the forums but visit and read the information posted here, people with multiple nephrologists, and people who visit multiple online support groups for

CKD (including Facebook). However, any English-speaking individuals who have been diagnosed with CKD are eligible.

Because this research is not affiliated with a healthcare provider or hospital, there is no risk that you will lose access to care by joining this study.

The UNC Chapel Hill Institutional Review Board approved this study. If you have questions or concerns please contact them at 919-966-3113 or by e-mail at irb_questions@unc.edu. You can also e-mail my advisor, Dr. Barbara Wildemuth, at wildemuth@unc.edu.

APPENDIX J: REVISED INTERVIEW GUIDES

These guides have been revised for the purposes of theoretical sampling. Two versions of the guides are available in this appendix. The first is an unmarked version of the revised interview guide. The second is a version with editing marks to facilitate easier comparison with the original interview guides located in Appendix D. Changes are noted as follows: questions and phrases that were removed use the strikethrough mark to indicate that they are no longer in the new interview guide. New questions or phrases are underlined.

Information seeking interview questions (revised)

1. Can you tell me a bit about yourself?
2. Can you tell me what prompted you to start looking for information about kidney disease?
3. What role does information that you've found online play in your discussions with doctors or other healthcare providers?
    a. Do you bring information from the Internet to your doctor or other providers?
    b. What about information from the doctor – do you use the Internet to learn more about what you've heard from your doctors?
4. Has your search for information about kidney disease changed over time?
5. Have you ever felt like you learned something you didn't want to know about CKD?
6. Has there ever been a time that you have purposefully avoided information about CKD?

7. What makes you search for information about a new topic related to CKD? That is, at what point do you decide “I need more information about this particular aspect of kidney disease”?
8. Is there any information that you look for that you don’t need to use right now, but you anticipate needing in the future?
9. Can you tell me a bit about how you compare your experience to the experiences other people are having with CKD online?
10. Can you tell me about a time that you posted something about yourself on an online support group for kidney disease?
11. Did you have any other comments to share?

Thank you very much for your time. I really appreciate your participation. I will speak to you in a few weeks.

Information seeking interview questions (revisions marked)

~~1. Tell~~ Can you tell me a ~~little~~ bit about yourself~~.~~?

~~2.~~ Can you tell me ~~a little about <the health transition you are in right now>?~~

  ~~*a. Participants will explain their health transition in their reply to the email questionnaire. The interviewer will ask specifically about the transition noted in the email.*~~

~~3. Tell me a bit about how you use the Internet.~~

  ~~*a. How long have you been going online?*~~
  ~~*b. Do you have Internet access at home?*~~
  ~~*c. What do you usually use to go online? A computer, an iPad, your phone?*~~
  ~~*d. What is the purpose of your Internet use?*~~

2. ~~When you started experiencing <the health transition>,~~ what prompted you to start looking for information about kidney disease?

~~4.~~ 3. What ~~things did your doctor, nurse~~, role does information that you've found online play in your discussions with doctors or other healthcare providers ~~tell you about CKD~~?

~~a. Did~~ Do you ~~ask them questions~~ bring information from the Internet to your doctor or other providers?

b. What about ~~it~~?

~~c. Did you feel like you had unanswered questions?~~

~~d. Did your~~ information from the ~~doctor say anything about using~~ do you use the Internet to ~~find out~~learn more about what you've heard from your ~~kidney disease~~ doctors?

~~5~~.4. ~~Tell me about how you use the Internet in relation to your kidney disease.~~ Has your search for information about kidney disease changed over time?

~~a. Did you decide to go online to learn about your kidney disease~~

~~b. What other health information do you look for online~~?

~~6~~.5. ~~Tell me a little bit about a time you found something about kidney disease you were looking for online.~~ Have you ever felt like you learned something you didn't want to know about CKD?

~~a. What were you looking for?~~

~~b. Did the thing you were looking for stand alone, or was it related to other questions?~~

~~c. How was it related to other questions?~~

~~d. Did you get an answer?~~

~~e. Was the answer complete or partial?~~

~~f. How did you get the answer?~~

~~g. How important was it for you to get an answer?~~

~~h. Did the importance ever change? How?~~

~~i. Did you expect the answer to help you? Did it? How?~~

~~j. Did you expect the answer to hurt you? Did it? How?~~

~~7.~~ 6. Has there ever been a time ~~when~~ that you ~~wanted to find something out~~ have purposefully avoided information about ~~your kidney disease and you were unable to~~ CKD?

a. ~~What were you looking for?~~

~~b. Did you see yourself as blocked or hindered when you asked this question? How?~~

~~c. Why did you ask this question?~~

~~d. How important was getting an answer?~~

~~e. Did you get a partial answer, or no answer at all?~~

~~f. Why do you think you weren't able to find anything about it?~~

~~8. How did you find <online support group(s) name>?~~

~~a. For registered users: Why did you decide to create an account there? Why do you continue to use the site? How often do you post?~~

~~b. For lurkers: What makes you continue to come back without creating an account or posting?~~

~~9. Do you have a favorite post, or something that was very helpful for you to read?~~

7. What makes you search for information about a new topic related to CKD? That is, at what point do you decide “I need more information about this particular aspect of kidney disease”?
8. Is there any information that you look for that you don’t need to use right now, but you anticipate needing in the future?
9. Can you tell me a bit about how you compare your experience to the experiences other people are having with CKD online?
10. Can you tell me about a time that you posted something about yourself on an online support group for kidney disease?
11. Did you have any other comments to share?

Thank you very much for your time. I really appreciate your participation. I will speak to you in a few weeks.

Disclosure interview questions (revised)

1. We talked a bit last time about the online forums that you use for kidney disease. Can you tell me a bit more about why you keep using going back to those forums for information?
2. Are there things that you purposefully do not share in these forums?
3. Has there ever been a time that you wanted to share something but decided not to? Tell me more about that.
    - *a. Did you share something else instead, or did you just not comment on the post at all?*
    - *b. What are some concerns you have about sharing things about your health online generally?*

4. Has the process of talking about your health online changed over time for you?
    - *a. If so: How has the process changed?*
        - *i. What are some of the factors that contributed to this change?*
    - *b. If not: Why do you think the process hasn't changed?*
5. What type of posts do you generally comment on in the forums? Are there specific places types of questions that you prefer to answer?
6. Do you ever go to the forums specifically to find people to share information with?
    - *a. If so, how do you select those people?*
7. Do you share different information about your health in different places online?
8. I'm wondering what you do if you encounter information that you know is wrong in one of these forums online. Can you tell me a bit about what you would do or what you did do in this situation?
9. Do you have any other comments that you would like to share with me?

Thank you very much for your time. I really appreciate your participation.

Disclosure interview questions (revisions marked)

1. We talked a bit last time about ~~how you found <~~the online ~~support group where they were recruited>.~~forums that you use for kidney disease. Can you tell me a bit more about why you keep ~~using~~ ~~this or other OSGs?~~ going back to these forums for information?

~~2. Tell me a little bit more about your activities in <online support groups>~~
- ~~a. How often do you visit OSGs?~~
- ~~*b. Why do you use multiple OSGs?*~~

~~*c. Which site is your favorite? Why?*~~

~~*d. If they do visit multiple sites, ask them to tell you which site they are discussing in their answers. Additionally, the interviewer will want to probe about the differences between sites when appropriate.*~~

~~3. I'd like to hear about a time that you posted something about your health in an online support group and you had something specific that you wanted other people to comment on in their responses.~~

~~*a. Tell me a bit about the content of the responses.*~~

~~*b. Were the responses helpful?*~~

~~*c. What was the most helpful response?*~~

~~*d. Did this experience affect your willingness to post other things about your health in OSGs?*~~

2. Are there things that you purposefully do not share in these forums?

~~4.~~ 3. Has there ever been a time that you wanted to share something but decided not to ~~share something about your health in <online support group>~~? Tell me more about that.

a. Did you share something else instead, or did you just not comment on the post at all?

b. What are some concerns you have about sharing things about your health online generally?

~~5. Have you ever regretted sharing things about your health online?~~

~~*a. Tell me a bit about this experience.*~~

~~*b. What did you do about it?*~~

~~c. Did this affect your willingness to post other things about your health?~~

~~6.~~ 4. Has the process of talking about your health online changed over time for you?

a. If so: How has the process changed?

i. What are some of the factors that contributed to this change?

b. If not: Why do you think the process hasn't changed?

5. What type of posts do you generally comment on in the forums? Are there specific places types of questions that you prefer to answer?

~~6. Tell me a bit about your Internet use. Do you connect with people in other places online, aside from <online support groups>~~?

~~a. Do you have a Facebook account? How often do you use it? How often do you post~~?

~~b. Twitter?~~

~~c. A personal blog~~?

~~d. Have you ever shared anything about your health in these places~~?

~~e. Do you post different things about your health in different places~~?

6. Do you ever go to the forums specifically to find people to share information with?

a. If so, how do you select those people?

7. Do you share different information about your health in different places online?

8. I'm wondering what you do if you encounter information that you know is wrong in one of these forums online. Can you tell me a bit about what you ~~get from sharing things about your health online?~~ would do or what you did do in this situation?

~~*a. Have you ever shared information about your health because you wanted to learn more about other people's experiences with CKD?*~~

9. Do you have any other comments that you would like to share with me?

Thank you very much for your time. I really appreciate your participation.

APPENDIX K: MEMBER CHECKING EXAMPLE

Dear Nina,

I hope this email finds you well. I am writing because you participated in the research study “Online information seeking and disclosure of personal health information in CKD patients, UNC IRB #13-1952,” and I am currently writing up the results of that research for publication.

As part of the research project, I am required to send you a list of quotes from you that I plan to use in any upcoming publications. I am currently planning to defend my dissertation, titled “Social information behaviors in the context of chronic kidney disease: Information seeking, disclosure, and future forecasting in online support groups,” and I would like your permission to use the following quotes from our two telephone conversations and from the [name redacted] forums in my dissertation and in any publications that result from the dissertation.

If you would prefer that I do not use any of these quotes, please let me know within three weeks of receiving this email and I will remove them from my dissertation and any subsequent research products arising from my dissertation. If my interpretation of your quotes is incorrect, please let me know so that I can edit the paper to clearly reflect what you meant.

Please contact me if you have any questions or concerns, or if you would like any additional information.

Best,

Kaitlin

Quotes

“I was just looking for general information about it. And I don’t, I think it might be almost like, I couldn’t tell you how many times I would do those searches, but I’m not sure even what I was looking for. I guess it's just something, almost like a therapeutic kind of thing, that I do, is you want to know more, you want to know more."

[Your pseudonym] has a strategy for managing overload when there are multiple concurrent situations: "I divide my attention between them," she says. "My attention gets divided. What I really want to do is just forget about dialysis totally, but on the other hand they made it SO clear that a transplant is just another form of treatment, and it's not a cure. (Laughs.) I try not to think about it too much."

For example, in [your] introductory post, she says, "It seems like the more I read, the more questions I think of." During one of our conversations, she also says to me that she thinks this is fairly normal: "All that happens when, I think in the medical world, is you have more questions with everything you learn."

"You don't know when you might become disabled, and my quality of life would have been improved if I did not know this was waiting for me."

"Sometimes when you're doing a Google search for something and you're just not really getting hits that you want, sometimes if you just type in what you're feeling, just like you'd say to somebody, you get responses that you're really looking for."

"When I first got my diagnosis, and I said, well, what's the prognosis, and the nephrologist said, "I have no idea." [Laughs]…. It was the beginning of my enlightenment. When you actually start using the medical system you realize it's not what you thought it was. It's not, here, take this pill; it's not, here, have this operation; it's a lot of lab tests and waiting…. Your expectations get – you have to readjust them…. They're not going to always get it right. And the doctors are trying and they're working – to a certain extent, they're working in the dark, like you are at the beginning. They only know so much."

As [your pseudonym] says, "the body works together as a whole, but our medical system tries to break us down into some kind of production line or something and that's not how the body works."

One resident that [your pseudonym] spoke with encouraged her use of the Internet for health information: "I said something like "I know you doctors probably hate this, when people come in talking about something they read on the Internet," and he was very surprising. He said, "No, no. That's *fine*," he said, and he was very, like, encouraging. And that kind of surprised me."

[Your pseudonym] brought her husband to her transplant evaluation "so there was a second pair of ears for everything, somebody else to ask questions and stuff."

[Your pseudonym], too, tells me that she goes online to help regulate the amount she shares with family and friends: "You get me on a certain day, you'll hear all about my kidney disease whether you want to or not, even if you don't even know me very well. I'm always kind of going back and forth on that. Some days I might talk to somebody and I might not even mention it at all. And I'll go, isn't that great, not to bore somebody with this. Because it may mean nothing to somebody. They don’t, they don’t understand it. They can’t understand what that is. Which is what I think sends people to forums like IHD. Because those people are living with it. They really get it. They know what it’s like to live with a serious chronic disease that just gets worse.”

Take [your pseudonym], who says, “I don’t think [my family] are always comfortable talking about [my CKD]… I try to be pretty matter-of-fact about it. Early on I told myself my family would take the lead from me. If I fall apart, they fall apart. So I can’t do that.”

“To be able to just talk to somebody. Especially like, someone like yourself who so understands, I mean, is experiencing the same thing. Going through challenges more than I certainly have, anyway. I find it very therapeutic to do that.”

“I found [the forum] just by doing a straightforward web search… Googling different terms like “kidney” or “renal” or any number of things like that. I just did a bunch of different searches and perused them.”

Furthermore, most participants don’t recall precisely how they found the forums; this leaves open the possibility that some of them were indeed searching for support – for example, [your pseudonym] tells me that she thinks that many people find the forums because “sometimes when you’re doing a Google search for something and you’re just really not getting the hits that you want, sometimes if you just type in what you’re feeling, like a thing you’d actually say to somebody, a person? Sometimes then you get what you’re really looking for.” She goes on to describe the content of the forums as “more relevant to people looking for support, and less sophisticated information probably. That's what makes the forums more real. It's just people talking about what they're going through."

For example, [your pseudonym], who lurked for years before registering, says, "I have been trying to get up-to-date with the postings…. It seems like the more I read the more questions I think of. But I want to try to read as much as I can before I ask something that is already answered in all the many posts."

Later, [your pseudonym] responds: "On so many web forums people can get a little short-tempered if a question is asked that has already been answered in previous posts. It's a huge relief to know that [this forum] isn't so picky. I think I'm going to like it here. ☺"

When asked, "Why did you decide to start participating on [this forum]?" [your pseudonym] responds: "There were a few [forums] that I liked. What I liked about [my favorite group] more than anything [was that] they had the most traffic. Every day, there's people posting. Every day. Every day. And I didn't find any other kidney-oriented site that had the kind of traffic that [they] had. And I kind of got stuck on that one, so… I think I visited that site more than, certainly more than any of these other sites."

[Your pseudonym] expands on this as well, linking heavy use with credibility: "If you read it as I read it, regularly, these people who post all the time? You kind of get an idea of the people that when they're posting, I pay more attention to. Because I feel they're better thought out and they are just, they have more credibility, I guess, but also more compassion."

For example, [your pseudonym] says that one of the reasons she discloses information about her health on the forums is that she feels that she owes something to people going through similar issues: “Well, other people who are going through something similar, some of it has to be giving back. It’s not really fair to be on a website, to be reading a website all of the time and not give anything back ever, when there’s plenty of people out there who are going through what I went through. It just seems like if there are times when I feel like I have something I can contribute, I should do so. And that may entail having to give details about my own health.”

[Your pseudonym] gives an excellent definition in our first conversation: “The really big question is: What is it going to be like when it comes down to actually doing [dialysis]? Or what is a transplant really like? What are these things *really* like? And these are people that post who are living – they are living my future. And that’s what brings me back [to this forum].”

[Your pseudonym] stresses the primacy of patient experience in future forecasting: “Rather than being a webpage where – all these companies have an agenda and everything – on [the forum] it’s all about real people struggling with real problems.”

She did not ask an explicit question on the forums about her transplant evaluation, so the process of future forecasting her evaluation was largely implicit. However, she includes the question, “Do I need to just settle down and get more info at the evaluation in July?” in a larger question about preparing to be added to the transplant list.

[Your pseudonym] explains this waiting period when talking about her children being tested for the genetic form of CKD that she was diagnosed with: “My advice for any younger person in our family is, I mean, my quality of life would not have been improved if I knew this was waiting for me. And I’m glad I didn’t know. You know, I’m 50 years old. There’s a lot of… if I would have been worrying about this the whole time? I don’t think people… I don’t see, and with the healthcare system the way it is, with pre-existing conditions? You can lose your life insurance or whatever. I mean… why? Why? Why? Why would you want to know this?”

[Your pseudonym], too, explains to me that one of the benefits of finding people that have already experienced something that she will undergo in the future is learning what to expect, but: “that doesn’t mean that your experience is going to be the same. But that is someone who went through it. And you do read, there are people who just go through – and I guess that’s the danger of it.” [Your pseudonym] also mentions this issue in our first interview: “You’re reading individual experiences. I suppose that is a downside of it. You’re reading what happened to all these different people. And the nature of a forum like that… people who where everything is going just swell with no issues, they aren’t writing in, for the most part. That is not what you’re getting. That’s important to remember.”

APPENDIX L: PEER DEBRIEFING INSTRUCTIONS

Unfortunately, there is no one accepted way to conduct a peer debriefing. Lincoln and Guba (1985, p. 308) note:

> The process keeps the inquirer 'honest,' exposing him or her to searching questions by an experienced protagonist doing his or her best to play the devil's advocate. The inquirer's biases are probed, meanings explored, the basis for interpretations clarified. All questions are in order during a debriefing, whether they pertain to substantive, methodological, legal, ethical, or any other relevant matters. The task of the de-briefer is to be sure that the investigator is as fully aware of his or her posture and process as possible.

I have provided you with several documents: interviews from two different participants conducted both before and after theoretical sampling, forum posts from two more participants harvested both before and after theoretical sampling, and a section from the discussion/results of my dissertation that you are qualified to review based on your research experience and areas of expertise. You can ask yourself these guiding questions as you move through the data and the analysis if you find them helpful. Essentially, the main questions I would like you to ask yourself is: "Where are the gaps in this analysis? Where are there problems? How could the analysis be improved?" These questions may be helpful as you work through that question.

- Are there concepts that are missing from the analysis?
- Is the analysis grounded in the data?
- Are the inferences made in the results/discussion logical?
    - Does the analysis accurately reflect the concepts from the data?
    - Are alternative inferences possible?
- Is there unused or conflicting evidence in the data that is not supported?
- Does my analysis reflect my preliminary questions too closely?
- Is there sufficient support to substantiate the methodological choices I have made?

- Is the description in the results and discussion section sufficiently detailed?
- Does the account allow for or present negative evidence?

We will then meet to discuss this at a time that is convenient to you. This meeting will take approximately 2 to 4 hours. If you feel that you need more data, memos, or other information that will help you as you peer debrief, please let me know.

REFERENCES

Acquisti, A., & Gross, R. (2006). Imagined Communities: Awareness, Information Sharing, and Privacy on the Facebook. In G. Danezis & P. Golle (Eds.), *Privacy Enhancing Technologies* (pp. 36–58). Berlin, Germany: Springer Berlin Heidelberg.

Afifi, T. D., & Olson, L. (2005). The chilling effect in families and the pressure to conceal secrets. *Communication Monographs*, *72*(2), 192–216. http://doi.org/10.1080/03637750500111906

Afifi, T. D., Olson, L. N., & Armstrong, C. (2005). The chilling effect and family secrets. *Human Communication Research*, *31*(4), 564–598. http://doi.org/10.1111/j.1468-2958.2005.tb00883.x

Aitken, E., & Kingsmore, D. (2014). The fate of the fistula following renal transplantation. *Transplant International*, *27*(9), 90–91. http://doi.org/10.1111/tri.12326

Allam, A., Kostova, Z., Nakamoto, K., & Schulz, P. J. (2015). The effect of social support features and gamification on a web-based intervention for rheumatoid arthritis patients: Randomized controlled trial. *Journal of Medical Internet Research*, *17*(1). http://doi.org/10.2196/jmir.3510

Anderson, K., Devitt, J., Cunningham, J., Preece, C., & Cass, A. (2008). “ All they said was my kidneys were dead”: Indigenous Australian patients’ understanding of their chronic kidney disease. *Medical Journal of Australia*, *189*(9), 499-503.

Antheunis, M. L., Tates, K., & Nieboer, T. E. (2013). Patients’ and health professionals’ use of social media in health care: Motives, barriers and expectations. *Patient Education and Counseling*, *92*(3), 426–431. http://doi.org/10.1016/j.pec.2013.06.020

Antonucci, T. C., & Akiyama, H. (1987). Social networks in adult life and a preliminary examination of the convoy model. *Journal of Gerontology*, *42*(5), 519–527. http://doi.org/10.1093/geronj/42.5.519

Antonucci, T. C., Birditt, K. S., Sherman, C. W., & Trinh, S. (2011). Stability and change in the intergenerational family: A convoy approach. *Ageing & Society*, *31*(07), 1084–1106. http://doi.org/10.1017/S0144686X1000098X

Antonucci, T. C., & Jackson, J. S. (1990). The role of reciprocity in social support. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 173–198). New York, NY: John Wiley & Sons.

Attrill, A., & Jalil, R. (2011). Revealing only the superficial me: Exploring categorical self-disclosure online. *Computers in Human Behavior*, *27*(5), 1634–1642. http://doi.org/10.1016/j.chb.2011.02.001

Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control.

Social Science & Medicine, *66*(5), 1228–1239. http://doi.org/10.1016/j.socscimed.2007.11.034

Babrow, A. S., Hines, S. C., Kasch, C. R., & Whaley, B. (2000). Managing uncertainty in illness explanation: An application of problematic integration theory. In Whaley, B. B. (Ed.), *Explaining Illness: Research, Theory, and Strategies* (pp. 41–67). New York, NY: Routledge.

Bakker, D. A., Fitch, M. I., Gray, R., Reed, E., & Bennett, J. (2001). Patient–health care provider communication during chemotherapy treatment: The perspectives of women with breast cancer. *Patient Education and Counseling*, *43*(1), 61–71. http://doi.org/10.1016/S0738-3991(00)00147-6

Barak, A., & Gluck-Ofri, O. (2007). Degree and reciprocity of self-disclosure in online forums. *Cyberpsychology & Behavior, 10*(3), 407–417. http://doi.org/10.1089/cpb.2006.9938

Barak, A., Hen, L., Boniel-Nissim, M., & Shapira, N. (2008). A comprehensive review and a meta-analysis of the effectiveness of internet-based psychotherapeutic interventions. *Journal of Technology in Human Services*, *26*(2-4), 109–160. http://doi.org/10.1080/15228830802094429

Barnes, S. B. (2006). A privacy paradox: Social networking in the United States. *First Monday*, *11*(9), 11–15. Retrieved from http://firstmonday.org/article/view/1394/1312

Barnieh, L., King-Shier, K., Hemmelgarn, B., Laupacis, A., Manns, L., & Manns, B. (2014). Views of Canadian patients on or nearing dialysis and their caregivers: A thematic analysis. *Canadian Journal of Kidney Health and Disease*, *1*(4), 1-10. http://doi.org/10.1186/2054-3581-1-4

Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American Journal of Community Psychology*, *14*(4), 413–445. http://doi.org/10.1007/BF00922627

Bausch, P. (2012, July 30). How does the “Related Posts” widget work? Retrieved April 12, 2015, from http://metatalk.metafilter.com/21924/How-does-the-Related-Posts-widget-work#1012355

Bawden, D. & Robinson, L. (2011). Individual differences in information-related behaviour: What do we know about information styles? In A. Spink & J. Heinstrom (Eds.), *New Directions in Information Behaviour* (pp. 127-158). London, UK: Emerald.

Bayoumi, M. M. (2014). Subjective burden on family carers of hemodialysis patients. *Open Journal of Nephrology*, *4*(2), 79-85. http://doi.org/10.4236/ojneph.2014.42011

Beder, J. (2008). Evaluation research on social work interventions: A study on the impact of social worker staffing. *Social Work in Health Care*, *47*(1), 1–13. http://doi.org/10.1080/00981380801970590

Belkin, N. J. (1980). Anomalous states of knowledge as a basis for information retrieval. *Canadian Journal of Information Science*, *5*(1), 133–143.

Berg, J. H., & Archer, R. L. (1980). Disclosure or concern: A second look at liking for the norm breaker. *Journal of Personality*, *48*(2), 245–257. http://doi.org/10.1111/j.1467-6494.1980.tb00831.x

Berger, A., Edelsberg, J., Inglese, G. W., Bhattacharyya, S. K., & Oster, G. (2009). Cost comparison of peritoneal dialysis versus hemodialysis in end-stage renal disease. *American Journal of Managed Care*, *15*(8), 509–518.

Berns, J. S. (2012). Patient information: Chronic kidney disease (Beyond the basics). (G. C. Curhan & A. M. Sheridan, Eds.). *UpToDate*, Wolters Kluwer Health. Retrieved from http://www.uptodate.com/contents/chronic-kidney-disease-beyond-the-basics

Berry, D. (2006). *Health communication: Theory and practice*. Berkshire, Great Britain: McGraw-Hill International.

Bers, M. U., Gonzalez-Heydrich, J., & Demaso, D. R. (2003). Use of a computer-based application in a pediatric hemodialysis unit: a pilot study. *Journal of the American Academy of Child and Adolescent Psychiatry*, *42*(4), 493–496. http://doi.org/10.1097/01.CHI.0000046810.95464.68

Bers, M. U., Gonzalez-Heydrich, J., Raches, D., & DeMaso, D. R. (2001). Zora: A pilot virtual community in the pediatric dialysis unit. *Studies in Health Technology and Informatics*, *84*(Pt 1), 800–804.

Bhavnani, S. K., & Peck, F. A. (2010). Scatter matters: Regularities and implications for the scatter of healthcare information on the web. *Journal of the American Society for Information Science and Technology*, *61*(4), 659–676. http://doi.org/10.1002/asi.v61:4

Binik, Y. M., Devins, G. M., Barre, P. E., Guttmann, R. D., Hollomby, D. J., Mandin, H., … Burgess, E. D. (1993). Live and learn: Patient education delays the need to initiate renal replacement therapy in end-stage renal disease. *The Journal of Nervous and Mental Disease*, *181*, 371–376. http://doi.org/10.1097/00005053-199306000-00006

Bircher, G., & Woodrow, G. (2014). Gastroenterology and nutrition in chronic kidney disease. In *Comprehensive Clinical Nephrology* (5th ed., pp. 1005–1014). Elsevier Health Sciences.

Bowen, G. A. (2008). Naturalistic inquiry and the saturation concept: A research note. *Qualitative Research, 8*(1), 137–152. http://doi.org/10.1177/1468794107085301

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication*, *11*(2), 123–151. http://doi.org/10.1207/s15327027hc1102_2

Brashers, D. E., Goldsmith, D. J., & Hsieh, E. (2002). Information seeking and avoiding in health contexts. *Human Communication Research*, *28*(2), 258–271. http://doi.org/10.1111/j.1468-2958.2002.tb00807.x

Brunier, G., Graydon, J., Rothman, B., Sherman, C., & Liadsky, R. (2002). The psychological well-being of renal peer support volunteers. *Journal of Advanced Nursing*, *38*(1), 40–49. http://doi.org/10.1046/j.1365-2648.2002.02144.x

Buettner, K., & Fadem, S. Z. (2008). The internet as a tool for the renal community. *Advances in Chronic Kidney Disease*, *15*(1), 73–82. http://doi.org/10.1053/j.ackd.2007.10.002

Burleson, B. R., Albrecht, T. L., & Sarason, I. G. (1994). *The communication of social support: Messages, interactions, relationships, and community*. Thousand Oaks, CA: SAGE Publications, Inc.

Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, *4*(2), 167–182. http://doi.org/10.1111/1467-9566.ep11339939

Cabin, W., Himmelstein, D. U., & Woolhandler, S. (2014). For-profit dialysis: The authors reply. *Health Affairs*, *33*(11), 2083–2083. http://doi.org/10.1377/hlthaff.2014.1101

Cacioppo, J. T., & Cacioppo, S. (2014). Social relationships and health: The toxic effects of perceived social isolation. *Social and Personality Psychology Compass*, *8*(2), 58–72. http://doi.org/10.1111/spc3.12087

Calia, R., Lai, C., Aceto, P., Luciani, M., Romagnoli, J., Lai, S., … Citterio, F. (2011). Effects of switching from twice-daily to once-daily tacrolimus formulation on quality of life, anxiety, and transplant benefit perception after kidney transplantation. *Transplantation Proceedings*, *43*(4), 1020–1023. http://doi.org/10.1016/j.transproceed.2011.03.048

Cameron, J. S. (1985). The continued care of pediatric patients with renal disease into adult life. *American Journal of Kidney Diseases*, *6*(2), 91–95.

Cameron, J. S. (2001). The continued care of children with renal disease into adult life. *Pediatric Nephrology*, *16*(8), 680–685.

Cantrell, K., Fischer, A., Bouzaher, A., & Bers, M. (2010). The role of E-mentorship in a virtual world for youth transplant recipients. *Journal of Pediatric Oncology Nursing, 27*(6), 344–355. http://doi.org/10.1177/1043454210372617

Caplan, G. (1974). *Support systems and community mental health: Lectures on concept development.* Pasadena, CA: Behavioral Publications.

Case, D. O. (2012). *Looking for information: A survey of research on information seeking, needs and behavior* (3rd ed.). Bradford, UK: Emerald Group Publishing.

Cetingok, M., Hathaway, D., & Winsett, R. (2007). Contribution of post-transplant social support to the quality of life of transplant recipients. *Social Work in Health Care*, *45*(3), 39–56. http://doi.org/10.1300/J010v45n03_03

Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness*, *5*(2), 168–195.

Charmaz, K. (1987). Struggling for a self: Identity levels of the chronically ill. *Research in the Sociology of Health Care*, *6*(283-321).

Charmaz, K. (1993). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis* (1st ed.). Thousand Oaks, CA: Sage Publications Ltd.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage Publications Ltd.

Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision making and postdisclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*, *136*(2), 236–256. http://doi.org/10.1037/a0018193

Checton, M. G., & Greene, K. (2012). Beyond initial disclosure: The role of prognosis and symptom uncertainty in patterns of disclosure in relationships. *Health Communication*, *27*(2), 145–157. http://doi.org/10.1080/10410236.2011.571755

Checton, M. G., & Greene, K. (2014). “I tell my partner everything . . . (or not)”: Patients’ perceptions of sharing heart-related information with their partner. *Journal of Family Nursing*, *20*(2), 164–184. http://doi.org/10.1177/1074840714521320

Chelune, G. J. (1979). Measuring openness in interpersonal communication. In Chelune, G. J. (Ed.), *Self-disclosure: Origins, patterns, and implications of openness in interpersonal relationships*. San Francisco, CA: Jossey-Bass.

Chen, A. T. (2012). Exploring online support spaces: Using cluster analysis to examine breast cancer, diabetes and fibromyalgia support groups. *Patient Education and Counseling*, *87*(2), 250–257. http://doi.org/10.1016/j.pec.2011.08.017

Chen, S., Tsai, Y., Sun, C., Wu, I, Lee, C., & Wu, M. (2011). The impact of self-management support on the progression of chronic kidney disease—a prospective randomized controlled trial. *Nephrology Dialysis Transplantation*, *26*(11), 3560–3566. http://doi.org/10.1093/ndt/gfr047

Chiu, Y.-W., Jiwakanon, S., Lukowsky, L., Duong, U., Kalantar-Zadeh, K., & Mehrotra, R. (2011). An update on the comparisons of mortality outcomes of hemodialysis and peritoneal dialysis patients. *Seminars in Nephrology*, *31*(2), 152–158. http://doi.org/10.1016/j.semnephrol.2011.01.004

Chou, W. Y. S., Hunt, Y. M., Beckjord, E. B., Moser, R. P., & Hesse, B. W. (2009). Social media use in the United States: Implications for health communication. *Journal of Medical Internet Research*, *11*(4). http://doi.org/10.2196/jmir.1249

Christensen, A. J., & Ehlers, S. L. (2002). Psychological factors in end-stage renal disease: An emerging context for behavioral medicine research. *Journal of Consulting and Clinical Psychology*, *70*(3), 712–724. http://doi.org/10.1037/0022-006X.70.3.712

Christensen, A. J., Smith, T. W., Turner, C. W., Holman, J. M., Gregory, M. C., & Rich, M. A. (1992). Family support, physical impairment, and adherence in hemodialysis: An investigation of main and buffering effects. *Journal of Behavioral Medicine*, *15*(4), 313–325. http://doi.org/10.1007/BF00844725

Christensen, A. J., Turner, C. W., Slaughter, J. R., & Holman, J. M. (1989). Perceived family support as a moderator psychological well-being in end-stage renal disease. *Journal of Behavioral Medicine*, *12*, 249–265. http://doi.org/10.1007/BF00844870

Chuang, K. Y., & Yang, C. C. (2012). Interaction patterns of nurturant support exchanged in online health social networking. *Journal of Medical Internet Research*, *14*(3), e54. http://doi.org/10.2196/jmir.1824

Chung, J. E. (2013a). Patient–provider discussion of online health information: Results from the 2007 Health Information National Trends Survey (HINTS). *Journal of Health Communication*, *18*(6), 627–648. http://doi.org/10.1080/10810730.2012.743628

Chung, J. E. (2013b). Social networking in online support groups for health: How online social networking benefits patients. *Journal of Health Communication*. http://doi.org/10.1080/10810730.2012.757396

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine*, *38*(5), 300–314.

Cohen, S. D. (2013). Social support interventions will improve the quality of life of ESRD patients. *Seminars in Dialysis*, *26*(3), 262–265. http://doi.org/10.1111/sdi.12064

Cohen, S. D., Sharma, T., Acquaviva, K., Peterson, R. A., Patel, S. S., & Kimmel, P. L. (2007). social support and chronic kidney disease: An update. *Advances in Chronic Kidney Disease*, *14*(4), 335–344. http://doi.org/10.1053/j.ackd.2007.04.007

Cohen, S. E., & Syme, S. L. (1985). Issues in the study and application of social support. In S. E. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 3–22). Orlando, FL: Academic Press.

Cohen, S. E., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*(2), 310–357. http://doi.org/10.1037/0033-2909.98.2.310

Collins, N. L., & Miller, L. C. (1994). Self-disclosure and liking: A meta-analytic review. *Psychological Bulletin, 116*(3), 457–475. http://doi.org/10.1037/0033-2909.116.3.457

Colman, D. (2011, May 6). Challenging the second "A" in A.A. *The New York Times*. Retrieved from http://www.nytimes.com/2011/05/08/fashion/08anon.html

Contena, B., Loscalzo, Y., & Taddei, S. (2015). Surfing on social network sites: A comprehensive instrument to evaluate online self-disclosure and related attitudes. *Computers in Human Behavior*, *49*, 30–37. http://doi.org/10.1016/j.chb.2015.02.042

Cool, C. (2001). The concept of situation in information science. *Annual Review of Information Science and Technology*, *35*, 5–42.

Coresh, J., Selvin, E., Stevens, L. A., Manzi, J., Kusek, J. W., Eggers, P., … Levey, A. S. (2007). Prevalence of chronic kidney disease in the United States. *JAMA: The Journal of the American Medical Association*, *298*(17), 2038.

Coresh, J., Stevens, L. A., & Levey, A. S. (2008). Chronic kidney disease is common: What do we do next? *Nephrology, Dialysis, Transplantation: Official Publication of the European Dialysis and Transplant Association - European Renal Association*, *23*(4), 1122–1125. http://doi.org/10.1093/ndt/gfn117

Cormier-Daigle, M., & Stewart, M. (1997). Support and coping of male hemodialysis-dependent patients. *International Journal of Nursing Studies*, *34*(6), 420–430. http://doi.org/10.1016/S0020-7489(97)00035-7

Correa-Rotter, R., Cueto-Manzano, A., & Khanna, R. (2011). Peritoneal dialysis. In M. W. Taal, G. M. Chertow, P. A. Marsden, K. Skorecki, A. S. L. Yu, & B. M. Brenner, *Brenner and Rector's the kidney: Expert consult* (9th ed., pp. 2347–2370). Philadelphia, PA: Saunders.

Costello, K. L. (2012). Online organ solicitation: Finding a kidney donor using the Internet. Presented at the Medicine 2.0, Boston, MA. Retrieved from http://www.medicine20congress.com/ocs/index.php/med/med2012/paper/view/962

Costello, K. L. (2015). Information quality, privacy policies, and data safety practices in online social networks for health: A longitudinal analysis. In *Proceedings of the 78th ASIS&T Annual Meeting, St. Louis, MO.*

Costello, K. L., & Murillo, A. P. (2014). "I want your kidney!" Information seeking, sharing, and disclosure when soliciting a kidney donor online. *Patient Education and Counseling*, *94*(3), 423–426. http://doi.org/10.1016/j.pec.2013.11.009

Coulson, N. S. (2005). Receiving social support online: An analysis of a computer-mediated support group for individuals living with irritable bowel syndrome. *Cyberpsychology & Behavior*, *8*(6), 580–584. http://doi.org/10.1089/cpb.2005.8.580

Coulson, N. S., & Shaw, R. L. (2013). Nurturing health-related online support groups: Exploring the experiences of patient moderators. *Computers in Human Behavior*, *29*(4), 1695–1701. http://doi.org/10.1016/j.chb.2013.02.003

Cozby, P. C. (1973). Self-disclosure: A literature review. *Psychological Bulletin*, *79*(2), 73–91.

Cranor, L. F., Reagle, J., & Ackerman, M. S. (1999). *Beyond Concern: Understanding Net Users' Attitudes About Online Privacy* (Technical Report No. TR 99.4.3). Florham Park, NJ: AT&T Labs. Retrieved from http://arxiv.org/abs/cs/9904010

Creswell, J. W. (2007). *Qualitative inquiry & research design: Choosing among five approaches*. Thousand Oaks, CA: Sage Publications, Inc.

Crews, D. C., Liu, Y., & Boulware, L. E. (2014). Disparities in the burden, outcomes, and care of chronic kidney disease. *Current Opinion in Nephrology and Hypertension*, *23*(3), 298–305. http://doi.org/10.1097/01.mnh.0000444822.25991.f6

Cummings, K. M., Becker, M. H., Kirscht, J. P., & Levin, N. W. (1982). Psychosocial factors affecting adherence to medical regimens in a group of hemodialysis patients. *Medical Care*, *20*(6), 567–580.

Curtin, R. B., Mapes, D., Schatell, D., & Burrows-Hudson, S. (2005). Self-management in patients with end stage renal disease: Exploring domains and dimensions. *Nephrology Nursing Journal*, *32*(4), 389–398.

Curtin, R. B., Walters, B. A. J., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Advances in Chronic Kidney Disease*, *15*(2), 191–205.

Cutrona, C. E., & Russell, D. W. (1990). Type of social support and specific stress: Toward a theory of optimal matching. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 319–367). New York, NY: John Wiley & Sons.

Daneker, B., Kimmel, P. L., Ranich, T., & Peterson, R. A. (2001). Depression and marital dissatisfaction in patients with end-stage renal disease and in their spouses. *American Journal of Kidney Diseases*, *38*(4), 839–846.

Danovitch, G. M. (2012, August 20). The kidney transplant waiting list. (D. C. Brennan & A. M. Sheridan, Eds.). UpToDate, Wolters Kluwer Health. Retrieved from http://www.uptodate.com/contents/the-kidney-transplant-waiting-list

Darby, C. R., Cranston, D., Raine, A. E. G., & Morris, P. J. (1991). Bilateral nephrectomy before transplantation: Indications, surgical approach, morbidity and mortality. *British Journal of Surgery*, *78*(3), 305–307. http://doi.org/10.1002/bjs.1800780313

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology of illness support groups. *American Psychologist*, *55*(2), 205.

De Choudhury, M., Morris, M. R., & White, R. W. (2014). Seeking and sharing health information online: Comparing search engines and social media. In *Proceedings of the 32nd annual ACM conference on human factors in computing systems* (pp. 1365–1376). New York, NY: Association for Computing Machinery. Retrieved from http://dl.acm.org/citation.cfm?id=2557214

Demars, N., Uluer, A., & Sawicki, G. S. (2011). Employment experiences among adolescents and young adults with cystic fibrosis. *Disability & Rehabilitation, 33*(11), 922–926.

Dennen, P., Douglas, I. S., & Anderson, R. (2010). Acute kidney injury in the intensive care unit: An update and primer for the intensivist. *Critical Care Medicine*, *38*(1), 261.

Dennis, C. (2003). Peer support within a health care context: A concept analysis. *International Journal of Nursing Studies*, *40*(3), 321–332. http://doi.org/10.1016/S0020-7489(02)00092-5

DePasquale, N., Ephraim, P. L., Ameling, J., Lewis-Boyér, L., Crews, D. C., Greer, R. C., … Boulware, L. E. (2013). Selecting renal replacement therapies: What do African American and non-African American patients and their families think others should know? A mixed methods study. *BMC Nephrology*, *14*(1), 9. http://doi.org/10.1186/1471-2369-14-9

Derlega, V. J., & Chaikin, A. L. (1977). Privacy and self-disclosure in social relationships. *Journal of Social Issues*, *33*(3), 102–115. http://doi.org/10.1111/j.1540-4560.1977.tb01885.x

Derlega, V. J., Winstead, B. A., Greene, K., Serovich, J., & Elwood, W. N. (2004). Reasons for HIV disclosure/nondisclosure in close relationships: Testing a model of HIV–disclosure decision making. *Journal of Social and Clinical Psychology*, *23*(6), 747–767.

Dervin, B. (1992). From the mind's eye of the user: The sense-making qualitative-quantitative methodology. In J. D. Glazier & R. R. Powell (Eds.), *Qualitative research in information management* (pp. 61–84). Englewood, CO: Libraries Unlimited.

Dervin, B. (1997). Given a context by any other name: Methodological tools for taming the unruly beast. In *Proceedings of an international conference on information seeking in context* (pp. 13-38). London, UK: Taylor Graham Publishing.

Dervin, B. (1998). Sense-making theory and practice: An overview of user interests in knowledge seeking and use. *Journal of Knowledge Management*, *2*(2), 36–46. http://doi.org/10.1108/13673279810249369

Dervin, B., Foreman-Wernet, L., & Lauterbach, E. (Eds.). (2003). *Sense-making methodology reader: Selected writings of Brenda Dervin*. Cresskill, N.J.: Hampton Press.

Devraj, R., Borrego, M., Vilay, A. M., Gordon, E. J., Pailden, J., & Horowitz, B. (2015). Relationship between health literacy and kidney function. *Nephrology*, epub in advance of print. http://doi.org/10.1111/nep.12425

Dey, I. (1999). *Grounding grounded theory*. San Diego, CA: Emerald Group Publishing, Ltd.

Diaz, J. A., Griffith, R. A., Ng, J. J., Reinert, S. E., Friedmann, P. D., & Moulton, A. W. (2002). Patients' use of the internet for medical information. *Journal of General Internal Medicine*, *17*(3), 180–185. http://doi.org/10.1046/j.1525-1497.2002.10603.x

Dindia, K. (2000). Sex differences in self-disclosure, reciprocity of self-disclosure, and self-disclosure and liking: Three meta-analyses reviewed. In S. S. Petronio (Ed.), *Balancing the secrets of private disclosures*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Doulton, T. W. R., Farmer, C. K. T., & Stevens, P. E. (2015). Self-management in chronic disease: Clear benefits for blood pressure control in CKD. *American Journal of Kidney Diseases*. http://doi.org/10.1053/j.ajkd.2015.01.006

Duggan, P., & Parrott, L. (2001). Physicians' nonverbal rapport building and patients' talk about the subjective component of illness. *Human Communication Research*, *27*(2), 299–311. http://doi.org/10.1111/j.1468-2958.2001.tb00783.x

Dunkel-Schetter, C., & Bennett, T. L. (1990). Differentiating the cognitive and behavioral aspects of social support. In B. R. Sarason, I. G. Sarason, & G. R. Pierce (Eds.), *Social support: An interactional view* (pp. 267–296). New York, NY: John Wiley & Sons, Inc.

Dunne, C. (2011). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology*, *14*(2), 111–124.

Eaton, D., & Pooler, J. (2009). *Vander's renal physiology, 7th Edition* (7th ed.). McGraw-Hill Medical.

Eichhorn, K. C. (2008). Soliciting and providing social support over the Internet: An investigation of online eating disorder support groups. *Journal of Computer-Mediated Communication*, *14*(1), 67–78. http://doi.org/10.1111/j.1083-6101.2008.01431.x

Ekelund, M.-L., & Andersson, S. I. (2010). "I need to lead my own life in any case"—A study of patients in dialysis with or without a partner. *Patient Education and Counseling*, *81*(1), 30–36. http://doi.org/10.1016/j.pec.2009.10.025

Endler, N. S., & Kocovski, N. L. (2001). State and trait anxiety revisited. *Journal of Anxiety Disorders*, *15*(3), 231–245. http://doi.org/10.1016/S0887-6185(01)00060-3

Eysenbach, G. (2005). Patient-to-patient communication: Support groups and virtual communities. In D. Lewis, G. Eysenbach, R. Kukafka, P. Z. Stavri, & H. B. Jimison, *Consumer Health Informatics: Informing consumers and improving healthcare*. New York, NY: Springer-Verlag.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *BMJ*, *328*(7449), 1166. http://doi.org/10.1136/bmj.328.7449.1166

Fan, H., Lederman, R., Smith, S., & Chang, S. (2014). How trust is formed in online health communities: A process perspective. *Communications of the Association for Information Systems*, *34*(1). Retrieved from http://aisel.aisnet.org/cais/vol34/iss1/28

Farley, T. A., Dalal, M. A., Mostashari, F., & Frieden, T. R. (2010). Deaths preventable in the U.S. by improvements in use of clinical preventive services. *American Journal of Preventive Medicine*, *38*(6), 600–609. http://doi.org/10.1016/j.amepre.2010.02.016

Farrokhi, F., Abedi, N., Beyene, J., Kurdyak, P., & Jassal, S. V. (2014). Association between depression and mortality in patients receiving long-term dialysis: A systematic review and meta-analysis. *American Journal of Kidney Diseases*, *63*(4), 623–635. http://doi.org/10.1053/j.ajkd.2013.08.024

Fassett, R. G., Robertson, I. K., Mace, R., Youl, L., Challenor, S., & Bull, R. (2011). Palliative care in end-stage kidney disease. *Nephrology*, *16*(1), 4–12. http://doi.org/10.1111/j.1440-1797.2010.01409.x

Fellner, C. H., & Marshall, J. R. (1968). Twelve kidney donors. *The Journal of the American Medical Association*, *206*(12), 2703 –2707. http://doi.org/10.1001/jama.1968.03150120037007

Ferguson, T., & Kelly, W. J. (1999). E-patients prefer e-groups to doctors for ten of twelve aspects of health care. *Ferguson Report*, *1*, 1–3.

Flanagin, A. J., & Metzger, M. J. (2000). Perceptions of Internet information credibility. *Journalism & Mass Communication Quarterly*, *77*(3), 515–540. http://doi.org/10.1177/107769900007700304

Flanagin, A. J., & Metzger, M. J. (2007). The role of site features, user attributes, and information verification behaviors on the perceived credibility of web-based information. *New Media & Society*, *9*(2), 319–342. http://doi.org/10.1177/1461444807075015

Folkman, S., & Lazarus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, *21*(3), 219–239. http://doi.org/10.2307/2136617

Fortnum, D., Smolonogov, T., Walker, R., Kairaitis, L., & Pugh, D. (2014). “My kidneys, my choice, decision aid”: Supporting shared decision making. *Journal of Renal Care*. http://doi.org/10.1111/jorc.12100

Fox, S. (2011a). *Health topics*. Washington, D.C.: Pew Research Center’s Internet & American Life Project. Retrieved from http://www.pewinternet.org/Reports/2011/HealthTopics.aspx

Fox, S. (2011b). *Peer-to-peer healthcare*. Washington, D.C.: Pew Research Center’s Internet & American Life Project. Retrieved from http://www.pewinternet.org/Reports/2011/P2PHealthcare.aspx

Fox, S. (2011c). *The social life of health information, 2011*. Washington, D.C.: Pew Research Center's Internet & American Life Project. Retrieved from http://www.pewinternet.org/files/old-media//Files/Reports/2011/PIP_Social_Life_of_Health_Info.pdf

Fox, S., & Duggan, M. (2013). *Health online 2013*. Washington, D.C.: Pew Research Center's Internet & American Life Project. Retrieved from http://www.pewinternet.org/files/old-media//Files/Reports/PIP_HealthOnline.pdf

Fox, S., & Jones, S. (2009). The social life of health information. Washington, D.C.: Pew Research Center's Internet & American Life Project. Retrieved from http://www.pewinternet.org/files/old-media/Files/Reports/2009/PIP_Health_2009.pdf

Franklin, P. M., & Crombie, A. K. (2003). Live related renal transplantation: Psychological, social, and cultural issues. *Transplantation*, *76*(8), 1247–1252.

Fraser, S. D., Roderick, P. J., Casey, M., Taal, M. W., Yuen, H. M., & Nutbeam, D. (2013). Prevalence and associations of limited health literacy in chronic kidney disease: A systematic review. *Nephrology Dialysis Transplantation*, *28*(1), 129–137.

Frattaroli, J. (2006). Experimental disclosure and its moderators: A meta-analysis. *Psychological Bulletin*, *132*(6), 823–865. http://doi.org/10.1037/0033-2909.132.6.823

Frazier, P. A., Davis-Ali, S. H., & Dahl, K. E. (1995). Stressors, social support, and adjustment in kidney transplant patients and their spouses. *Social Work in Health Care*, *21*(2), 93–108. http://doi.org/10.1300/J010v21n02_07

Friend, R., Singletary, Y., Mendell, N. R., & Nurse, H. (1986). Group participation and survival among patients with end-stage renal disease. *American Journal of Public Health*, *76*(6), 670.

Frndak, S. E., Kordovski, V. M., Cookfair, D., Rodgers, J. D., Weinstock-Guttman, B., & Benedict, R. H. (2015). Disclosure of disease status among employed multiple sclerosis patients: Association with negative work events and accommodations. *Multiple Sclerosis Journal*, *21*(2), 225–234. http://doi.org/10.1177/1352458514540971

Garg, N., Venkatraman, A., Pandey, A., & Kumar, N. (2015). YouTube as a source of information on dialysis: A content analysis. *Nephrology*, *20*(5), 315–320. http://doi.org/10.1111/nep.12397

Gencoz, T., & Astan, G. (2006). Social support, locus of control, and depressive symptoms in hemodialysis patients. *Scandinavian Journal of Psychology*, *47*(3), 203–208. http://doi.org/10.1111/j.1467-9450.2006.00508.x

Gignac, M. A. M., & Cao, X. (2009). "Should I tell my employer and coworkers I have arthritis?" A longitudinal examination of self-disclosure in the work place. *Arthritis Care & Research*, *61*(12), 1753–1761.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York: NY: Aldine de Gruyter.

Godbold, N. (2010a). An evolving “normal”: Making sense of renal dialysis via online discussion boards. Presented at the Making sense of health, illness and disease conference, Oxford, UK. Retrieved from http://godbold.name/experiencingdialysis/wp-content/uploads/2010/08/paper-hid9-normality-draft2_withconsents-Aug24.pdf

Godbold, N. (2010b). “Come back and post often”: Making sense of renal dialysis via online discussion boards. Presented at the British Sociological Association’s Medical Sociology Group Annual Conference, Durham, UK. Retrieved from http://godbold.name/experiencingdialysis/wp-content/uploads/2010/08/GodboldBSAMedSoc42-v4-draft-with-consent.pdf

Godbold, N. (2012). Usefully messy: How people use rich, complex descriptions to make sense in online renal discussion groups. In *Social Information Research* (Vol. 5, pp. 43–73). Bradford, UK: Emerald Group Publishing Limited.

Godbold, N. (2013a). Listening to bodies and watching machines: Developing health information skills, tools and services for people living with chronic kidney disease. *Australian Academic & Research Libraries*, *44*(1), 14–28. http://doi.org/10.1080/00048623.2013.773859

Godbold, N. (2013b). Tensions in compliance for renal patients: How renal discussion groups conceive knowledge and safe care. *Health Sociology Review*, *22*(1), 52-64.

Goetzmann, L., Saraca, N., Ambühlb, P., Boehlerb, A., Iranib, S., Muellhauptb, B., … Klaghofer, R. (2008). Psychological response and quality of life after transplantation: A comparison between heart, lung, liver and kidney recipients. *Swiss Medical Weekly, 138*(33), 477–483.

Goldade, K., Sidhwani, S., Patel, S., Brendt, L., Vigliaturo, J., Kasiske, B., … Israni, A. K. (2011). Kidney transplant patients’ perceptions, beliefs, and barriers related to regular nephrology outpatient visits. *American Journal of Kidney Diseases*, *57*(1), 11–20. http://doi.org/10.1053/j.ajkd.2010.08.023

Gollop, C. J. (1997). Health information-seeking behavior and older African American women. *Bulletin of the Medical Library Association*, *85*(2), 141-146.

Gottlieb, B. H. (1978). The development and application of a classification scheme of informal helping behaviours. *Canadian Journal of Behavioural Science*, *10*(2), 105–115. http://doi.org/10.1037/h0081539

Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of Psychosomatic Research*, *69*(5), 511–520. http://doi.org/10.1016/j.jpsychores.2009.10.001

Greene, K. (2009). An integrated model of health disclosure decision-making. In In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty and information regulation in interpersonal contexts: Theories and applications* (pp. 226–253). New York, NY: Routledge.

Greene, K., Derlega, V. J., Yep, G. A., & Petronio, S. S. (2003). *Privacy and disclosure of HIV in interpersonal relationships: A sourcebook for researchers and practitioners*. New York, NY: Routledge.

Greene, K., & Magsamen-Conrad, K. (2010). Disclosure decisions in existing relationships online: Exploring motivations for CMC channel choice. In J. R. Park & E. C. Abels (Eds.), *Interpersonal relations and social patterns in communication technologies: Discourse norms, language structures and cultural variables* (pp. 48–76). Hershey, PA: Information Science Publishing.

Greene, K., Magsamen-Conrad, K., Venetis, M. K., Checton, M. G., Bagdasarov, Z., & Banerjee, S. C. (2012). Assessing health diagnosis disclosure decisions in relationships: Testing the disclosure decision-making model. *Health Communication*, *27*(4), 356–368. http://doi.org/10.1080/10410236.2011.586988

Griffiths, K. M., Mackinnon, A. J., Crisp, D. A., Christensen, H., Bennett, K., & Farrer, L. (2012). The effectiveness of an online support group for members of the community with depression: A randomised controlled trial. *PLoS ONE*, *7*(12), e53244. http://doi.org/10.1371/journal.pone.0053244

Griva, K., Stygall, J., Ng, J. H., Davenport, A., Harrison, M. J., & Newman, S. (2011). Prospective changes in health-related quality of life and emotional outcomes in kidney transplantation over 6 years. *Journal of Transplantation*, 1–12. http://doi.org/10.1155/2011/671571

Griva, K., Ziegelmann, J. P., Thompson, D., Jayasena, D., Davenport, A., Harrison, M., & Newman, S. P. (2002). Quality of life and emotional responses in cadaver and living related renal transplant recipients. *Nephrology Dialysis Transplantation*, *17*(12), 2204–2211. http://doi.org/10.1093/ndt/17.12.2204

Groome, P. A., Hutchinson, T. A., & Tousignant, P. (1994). Content of a decision analysis for treatment choice in end-stage renal disease. *Medical Decision Making*, *14*(1), 91–97. http://doi.org/10.1177/0272989X9401400111

Gudex, C. M. (1995). Health-related quality of life in endstage renal failure. *Quality of Life Research*, *4*(4), 359–366. http://doi.org/10.1007/BF01593889

Gulbrandsen, P. al, Østbye, T., Lyna, P., Dolor, R. J., Tulsky, J. A., Alexander, S. C., & Pollak, K. I. (2012). The influence of physician communication style on overweight patients' perceptions of length of encounter and physician being rushed. *Family Medicine*, *44*(3), 183–188.

Hale, T. M., Cotten, S. R., Drentea, P., & Goldner, M. (2010). Rural-urban differences in general and health-related Internet use. *American Behavioral Scientist*, *53*(9), 1304–1325. http://doi.org/10.1177/0002764210361685

Han, J. Y., Hou, J., Kim, E., & Gustafson, D. H. (2014). Lurking as an active participation process: A longitudinal investigation of engagement with an online cancer support group. *Health Communication*, *29*(9), 911–923. http://doi.org/10.1080/10410236.2013.816911

Haque, O. S., & Waytz, A. (2012). Dehumanization in medicine: Causes, solutions, and functions. *Perspectives on Psychological Science*, *7*(2), 176–186. http://doi.org/10.1177/1745691611429706

Hartzler, A. L., McDonald, D. W., Park, A., Huh, J., Weaver, C., & Pratt, W. (2014). Evaluating health interest profiles extracted from patient-generated data. *American Medical Informatics Association Annual Symposium Proceedings*, *2014*, 626–635.

Hartzog, W., & Stutzman, F. D. (2012). The case for online obscurity. *California Law Review, 101*(1). Retrieved from http://papers.ssrn.com/abstract=1597745

Harwood, L., Locking-Cusolito, H., Spittal, J., Wilson, B., & White, S. (2005). Preparing for hemodialysis: Patient stressors and responses. *Nephrology Nursing Journal*, *32*(3), 295–303.

Hawn, C. (2009). Take two aspirin and tweet me in the morning: How twitter, facebook, and other social media are reshaping health care. *Health Affairs*, *28*(2), 361–368. http://doi.org/10.1377/hlthaff.28.2.361

Heaney, C. A., & Israel, B. A. (2008). Social networks and social support. In K. Glanz, B. K. Rimer, & K. Viswanath (Eds.), *Health behavior and health education: Theory, research, and practice* (pp. 189–210). Hoboken, NJ: John Wiley & Sons.

Hedayati, S. S., Yalamanchili, V., & Finkelstein, F. O. (2012). A practical approach to the treatment of depression in patients with chronic kidney disease and end-stage renal disease. *Kidney International*, *81*(3), 247–255. http://doi.org/10.1038/ki.2011.358

Heinström, J. (2003). Five personality dimensions and their influence on information behaviour. *Information Research*, *9*(1), 1–9.

Heinström, J. (2005). Fast surfing, broad scanning and deep diving: The influence of personality and study approach on students' information-seeking behavior. *Journal of Documentation*, *61*(2), 228–247.

Helgeson, V. S. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, *56*(4), 340–347. http://doi.org/10.1001/archpsyc.56.4.340

Helgeson, V. S., & Gottlieb, B. H. (2000). Support groups. In S. E. Cohen, L. G. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 221–245). New York, NY: Oxford University Press.

Higgins, R. (2009). *Vital CKD: Keeping kidneys healthy*. London: Class Publishing.

Hilton, B. A. (1994). The uncertainty stress scale: Its development and psychometric properties. *The Canadian Journal of Nursing*, *26*(3), 15–30.

Hoey, L. M., Ieropoli, S. C., White, V. M., & Jefford, M. (2008). Systematic review of peer-support programs for people with cancer. *Patient Education and Counseling*, *70*(3), 315–337. http://doi.org/10.1016/j.pec.2007.11.016

Hogan, B. E., Linden, W., & Najarian, B. (2002). Social support interventions: Do they work? *Clinical Psychology Review*, *22*(3), 381–440. http://doi.org/10.1016/S0272-7358(01)00102-7

Hogan, T. P., & Palmer, C. L. (2005). "Information work" and chronic illness: Interpreting results from a nationwide survey of people living with HIV/AIDS. In *Proceedings of the American Society for Information Science and Technology*, *42*(1). http://doi.org/10.1002/meet.14504201150/full

Holt, A. (2010). Using the telephone for narrative interviewing: A research note. *Qualitative Research*, *10*(1), 113–121. http://doi.org/10.1177/1468794109348686

House, J. S. (1981). *Work stress and social support*. `Reading, MA: Addison-Wesley.

House, J. S., Kahn, R. L., McLeod, J. D., & Williams, D. (1985). Measures and concepts of social support. In S. E. Cohen & S. L. Syme (Eds.), *Social support and health* (pp. 83–108). Orlando, FL: Academic Press.

Howard, M. C. (2014). An epidemiological assessment of online groups and a test of a typology: What are the (dis)similarities of the online group types? *Computers in Human Behavior*, *31*, 123–133. http://doi.org/10.1016/j.chb.2013.10.021

Iles-Smith, H. (2005). Perceptions and experiences of pre-dialysis patients. *EDTNA/ERCA Journal of Renal Care*, *31*(3), 130–133.

Israni, A. K., Zaun, D. A., Rosendale, J. D., Snyder, J. J., & Kasiske, B. L. (2015). OPTN/SRTR 2013 annual data report: Deceased organ donation. *American Journal of Transplantation*, *15*(S2), 1–13. http://doi.org/10.1111/ajt.13202

Jablonski, A. (2004). The illness trajectory of end-stage renal disease dialysis patients. *Research and Theory for Nursing Practice*, *18*(1), 51–72. http://doi.org/10.1891/rtnp.18.1.51.28053

Jaffery, J. B., & Becker, B. N. (2004). Evaluation of eHealth web sites for patients with chronic kidney disease. *American Journal of Kidney Diseases*, *44*(1), 71–76. http://doi.org/10.1053/j.ajkd.2004.03.025

Jha, V. (2010). Herbal medicines and chronic kidney disease. *Nephrology*, *15*, 10–17. http://doi.org/10.1111/j.1440-1797.2010.01305.x

Jiang, H., Wang, L., Zhang, Q., Liu, D., Ding, J., Lei, Z., … Pan, F. (2014). Family functioning, marital satisfaction and social support in hemodialysis patients and their spouses. *Stress and Health*, 31(2), 166-174. http://doi.org/10.1002/smi.2541

Johnson, J. D. (1997). *Cancer-related information seeking*. New York, NY: Hampton Press.

Johnson, J. D. (2014). Health-related information seeking: Is it worth it? *Information Processing & Management*, *50*(5), 708–717. http://doi.org/10.1016/j.ipm.2014.06.001

Johnson, J. D., & Case, D. O. (2012). *Health information seeking*. New York, NY: Peter Lang Publishing.

Joinson, A. N. (2001). Knowing me, knowing you: reciprocal self-disclosure in internet-based surveys. *CyberPsychology & Behavior*, *4*(5), 587–591. http://doi.org/10.1089/109493101753235179

Jourard, S. M. (1959). Self-disclosure and other-cathexis. *The Journal of Abnormal and Social Psychology*, *59*(3), 428–43.

Jourard, S. M. (1971). *The transparent self*. New York, NY: Van Nostrand Reinhold.

Juhnke, J., & Curtin, R. B. (2000). New study identifies ESRD patient education needs. *Nephrology News & Issues*, *14*(6), 38–39.

Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: Attachment, roles, and social support. *Life-Span Development and Behavior*, *3*, 253–286.

Kalichman, S. C., DiMarco, M., Austin, J., Luke, W., & DiFonzo, K. (2003). Stress, social support, and HIV-status disclosure to family and friends among HIV-positive men and women. *Journal of Behavioral Medicine*, *26*(4), 315–332.

Katz, D. A., McCoy, K., & Sarrazin, M. V. (2014). Does improved continuity of primary care affect clinician-patient communication in VA? *Journal of General Internal Medicine, 29*(2), 682–688. http://doi.org/10.1007/s11606-013-2633-8

Kaushal, A., Naimark, D., & Tangri, N. (2015). Use of the kidney failure risk equation to reduce uncertainty in predicting time to ESRD. *American Journal of Kidney Diseases*, *65*(3), 369–371. http://doi.org/10.1053/j.ajkd.2015.01.002

Khalil, A. A., & Abed, M. A. (2014). Perceived social support is a partial mediator of the relationship between depressive symptoms and quality of life in patients receiving hemodialysis. *Archives of Psychiatric Nursing*, *28*(2), 114–118. http://doi.org/10.1016/j.apnu.2013.11.007

Kierans, C. (2005). Narrating kidney disease: The significance of sensation and time in the emplotment of patient experience. *Culture, Medicine and Psychiatry*, *29*(3), 341–359. http://doi.org/10.1007/s11013-005-9171-8

Kim, S., & Oh, S. (2009). Users' relevance criteria for evaluating answers in a social Q&A site. *Journal of the American Society for Information Science and Technology*, *60*(4), 716–727. http://doi.org/10.1002/asi.21026

Kimmel, P. L. (2000). Psychosocial factors in adult end-stage renal disease patients treated with hemodialysis: Correlates and outcomes. *American Journal of Kidney Diseases*, *35*(4, Supplement), S132–S140. http://doi.org/10.1016/S0272-6386(00)70240-X

Kimmel, P. L., Cukor, D., Cohen, S. D., & Peterson, R. A. (2007). Depression in end-stage renal disease patients: A critical review. *Advances in Chronic Kidney Disease*, *14*(4), 328.

Klang, B., Björvell, H., & Clyne, N. (1999). Predialysis education helps patients choose dialysis modality and increases disease-specific knowledge. *Journal of Advanced Nursing*, *29*(4), 869–876. http://doi.org/10.1046/j.1365-2648.1999.00957.x

Krohne, H. W. (1989). The concept of coping modes: Relating cognitive person variables to actual coping behavior. *Advances in Behaviour Research and Therapy*, *11*(4), 235–248.

Kuhlthau, C. C. (1991). Inside the search process: Information seeking from the user's perspective. *Journal of the American Society for Information Science*, *42*(5), 361–371.

Kuhlthau, C. C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation*, *49*(4), 339–355.

LaCoursiere, S. P. (2001). A theory of online social support. *Advances in Nursing Science*, *24*(1), 60.

Lambert, S. D., & Loiselle, C. G. (2007). Health information seeking behavior. *Qualitative Health Research*, *17*(8), 1006–1019. http://doi.org/10.1177/1049732307305199

Lan, P. G., Johnson, D. W., McDonald, S. P., Boudville, N., Borlace, M., Badve, S. V., … Clayton, P. A. (2014). The association between peritoneal dialysis modality and peritonitis. *Clinical Journal of the American Society of Nephrology*, CJN.09730913. http://doi.org/10.2215/CJN.09730913

Langford, C. P. H., Bowsher, J., Maloney, J. P., & Lillis, P. P. (2008). Social support: A conceptual analysis. *Journal of Advanced Nursing*, *25*(1), 95–100. http://doi.org/10.1046/j.1365-2648.1997.1997025095.x

Lawlor, A., & Kirakowski, J. (2014). Online support groups for mental health: A space for challenging self-stigma or a means of social avoidance? *Computers in Human Behavior*, *32*, 152–161. http://doi.org/10.1016/j.chb.2013.11.015

Leake, R., Friend, R., & Wadhwa, N. (1999). Improving adjustment to chronic illness through strategic self-presentation: An experimental study on a renal dialysis unit. *Health Psychology*, *18*(1), 54–62. http://doi.org/10.1037/0278-6133.18.1.54

Lee, A., Gudex, C., Povlsen, J. V., Bonnevie, B., & Nielsen, C. P. (2008). Patients' views regarding choice of dialysis modality. *Nephrology Dialysis Transplantation*, *23*(12), 3953–3959. http://doi.org/10.1093/ndt/gfn365

Lenz, E. R. (1984). Information seeking: A component of client decisions and health behavior. *Advances in Nursing Science*, *6*(3), 59-72.

Lepore, S. J., Silver, R. C., Wortman, C. B., & Wayment, H. A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of Personality and Social Psychology*, *70*(2), 271.

Leung, D. K. C. (2003). Psychosocial aspects in renal patients. *Peritoneal Dialysis International*, *23*(Supplement 2), S90–S94.

Levey, A. S., Coresh, J., Balk, E., Kausz, A. T., Levin, A., Steffes, M. W., … Eknoyan, G. (2003). National Kidney Foundation practice guidelines for chronic kidney disease: Evaluation, classification, and stratification. *Annals of Internal Medicine*, *139*(2), 137 – 147.

Lewis, A. L., Stabler, K. A., & Welch, J. L. (2010). Perceived informational needs, problems, or concerns among patients with stage 4 chronic kidney disease. *Nephrology Nursing Journal*, *37*(2), 143–149.

Li, N., Orrange, S., Kravitz, R. L., & Bell, R. A. (2014). Reasons for and predictors of patients' online health information seeking following a medical appointment. *Family Practice*, *31*(5), 550–556. http://doi.org/10.1093/fampra/cmu034

Liem, Y. S., & Weimar, W. (2009). Early living-donor kidney transplantation: a review of the associated survival benefit. *Transplantation*, *87*(3), 317–318.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic Inquiry*. Thousand Oaks, CA: Sage Publications, Inc.

Liu, F. X., Ghaffari, A., Dhatt, H., Kumar, V., Balsera, C., Wallace, E., … Guest, S. (2014). Economic evaluation of urgent-start peritoneal dialysis versus urgent-start hemodialysis in the United States: *Medicine*, *93*(28), e293. http://doi.org/10.1097/MD.0000000000000293

Longo, D. R. (2005). Understanding health information, communication, and information seeking of patients and consumers: A comprehensive and integrated model. *Health Expectations*, *8*(3), 189–194. http://doi.org/10.1111/j.1369-7625.2005.00339.x

Lopez-Vargas, P. A., Tong, A., Phoon, R. K., Chadban, S. J., Shen, Y., & Craig, J. C. (2014). Knowledge deficit of patients with stage 1–4 CKD: A focus group study. *Nephrology*, *19*(4), 234–243. http://doi.org/10.1111/nep.12206

Lorber, J. (1975). Good patients and problem patients: Conformity and deviance in a general hospital. *Journal of Health and Social Behavior*, *16*(2), 213–225.

Lunsford, S. L., Simpson, K. S., Chavin, K. D., Hildebrand, L. G., Miles, L. G., Shilling, L. M., … Baliga, P. K. (2006). Racial Differences in Coping With the Need for Kidney Transplantation and Willingness to Ask for Live Organ Donation. *American Journal of Kidney Diseases, 47*(2), 324–331. http://doi.org/10.1053/j.ajkd.2005.10.018

Lutz, E. R., Costello, K. L., Jo, M., Gilet, C. A., Hawley, J. M., Bridgman, J. C., & Song, M.-K. (2014). A systematic evaluation of websites offering information on chronic kidney disease. *Nephrology Nursing Journal*, *41*(4), 355–363.

Madar, H., & Bar-Tal, Y. (2009). The experience of uncertainty among patients having peritoneal dialysis. *Journal of Advanced Nursing*, *65*(8), 1664–1669. http://doi.org/10.1111/j.1365-2648.2009.05013.x

Maglaughlin, K. L., & Sonnenwald, D. H. (2002). User perspectives on relevance criteria: A comparison among relevant, partially relevant, and not-relevant judgments. *Journal of the American Society for Information Science and Technology*, *53*(5), 327–342. http://doi.org/10.1002/asi.10049

Maikranz, J. M., Steele, R. G., Dreyer, M. L., Stratman, A. C., & Bovaird, J. A. (2007). The relationship of hope and illness-related uncertainty to emotional adjustment and adherence among pediatric renal and liver transplant recipients. *Journal of Pediatric Psychology*, *32*(5), 571 –581. http://doi.org/10.1093/jpepsy/jsl046

Major, B., Cozzarelli, C., Sciacchitano, A. M., Cooper, M. L., Testa, M., & Mueller, P. M. (1990). Perceived social support, self-efficacy, and adjustment to abortion. *Journal of Personality and Social Psychology, 59*(3), 452–463.

Makela, K., Kalla, H. K., & Piekkari, R. (2007). Interpersonal similarity as a driver of knowledge sharing within multinational corporations. *International Business Review*, *16*(1), 1–22.

Maloney-Krichmar, D., & Preece, J. (2005). A multilevel analysis of sociability, usability, and community dynamics in an online health community. *ACM Transactions on Computer-Human Interaction*, *12*(2), 201–232. http://doi.org/10.1145/1067860.1067864

Manierre, M. (2015). Examining the relationship between flexible resources and health information channel selection. *Health Communication*, e-publication in advance of print. http://doi.org/10.1080/10410236.2014.930770

Markle, G. L., Attell, B. K., & Treiber, L. A. (2014). Dual, yet dueling illnesses: Multiple chronic illness experience at midlife. *Qualitative Health Research*. Advance online publication. http://doi.org/10.1177/1049732314559948

Marrie, R. A., Salter, A. R., Tyry, T., Fox, R. J., & Cutter, G. R. (2013). Preferred sources of health information in persons with multiple sclerosis: Degree of trust and information sought. *Journal of Medical Internet Research*, *15*(4). http://doi.org/10.2196/jmir.2466

Martin, S. C., Stone, A. M., Scott, A. M., & Brashers, D. E. (2010). Medical, personal, and social forms of uncertainty across the transplantation trajectory. *Qualitative Health Research*, *20*(2), 182 –196. http://doi.org/10.1177/1049732309356284

Marton, C., & Choo, C. W. (2012). A review of theoretical models of health information seeking on the web. *Journal of Documentation, 68*(3), 330–352. http://doi.org/10.1108/00220411211225575

Matas, A. J., Smith, J. M., Skeans, M. A., Thompson, B., Gustafson, S. K., Stewart, D. E., … Kasiske, B. L. (2015). OPTN/SRTR 2013 annual data report: Kidney. *American Journal of Transplantation*, *15*(S2), 1–34. http://doi.org/10.1111/ajt.13195

McAlpine, H., Joubert, L., Martin-Sanchez, F., Merolli, M., & Drummond, K. J. (2015). A systematic review of types and efficacy of online interventions for cancer patients. *Patient Education and Counseling*, *98*(3), 283–295. http://doi.org/10.1016/j.pec.2014.11.002

McCarthy, K. (2014). *Equipping renal patients to make treatment decisions: The use of self-efficacy theory to guide development of a pre-dialysis educational intervention* (PhD). University of Warwick. Retrieved from http://webcat.warwick.ac.uk/record=b2736948~S1

McClellan, W., Stanwyck, D., & Anson, C. (1993). Social support and subsequent mortality among patients with end-stage renal disease. *Journal of the American Society of Nephrology*, *4*(4), 1028 –1034.

McDonagh, J. E. (2005). Growing up and moving on: Transition from pediatric to adult care. *Pediatric Transplantation*, *9*(3), 364–372. http://doi.org/10.1111/j.1399-3046.2004.00287.x

McKenna, K. Y. A., Green, A. S., & Gleason, M. E. J. (2002). Relationship formation on the Internet: What’s the big attraction? *Journal of Social Issues*, *58*(1), 9–31. http://doi.org/10.1111/1540-4560.00246

McKenzie, P. J. (2003). A model of information practices in accounts of everyday-life information seeking. *Journal of Documentation*, *59*(1), 19–40. http://doi.org/10.1108/00220410310457993

McLaughlin, K., Manns, B., Mortis, G., Hons, R., & Taub, K. (2003). Why patients with ESRD do not select self-care dialysis as a treatment option. *American Journal of Kidney Diseases*, *41*(2), 380–385. http://doi.org/10.1053/ajkd.2003.50047

McMullan, M. (2006). Patients using the Internet to obtain health information: How this affects the patient–health professional relationship. *Patient Education and Counseling*, *63*(1–2), 24–28. http://doi.org/10.1016/j.pec.2005.10.006

McMurray, S. D., Johnson, G., Davis, S., & McDougall, K. (2002). Diabetes education and care management significantly improve patient outcomes in the dialysis unit. *American Journal of Kidney Diseases*, *40*(3), 566–575. http://doi.org/10.1053/ajkd.2002.34915

McNeilis, K. S. (2001). Analyzing communication competence in medical consultations. *Health Communication*, *13*(1), 5–18.

Mead, S., Hilton, D., & Curtis, L. (2001). Peer support: A theoretical perspective. *Psychiatric Rehabilitation Journal*, *25*(2), 134–141.

Metzger, M. J., Flanagin, A. J., & Medders, R. B. (2010). Social and heuristic approaches to credibility evaluation online. *Journal of Communication*, *60*(3), 413–439. http://doi.org/10.1111/j.1460-2466.2010.01488.x

Metzger, M. J., Flanagin, A. J., & Zwarun, L. (2003). College student Web use, perceptions of information credibility, and verification behavior. *Computers & Education*, *41*(3), 271–290. http://doi.org/10.1016/S0360-1315(03)00049-6

Miller, L. C. (1990). Intimacy and liking: Mutual influence and the role of unique relationships. *Journal of Personality and Social Psychology*, *59*(1), 50–60.

Miller, L. C., & Read, S. J. (1987). Why am I telling you this?: Self-disclosure in a goal-based model of personality. In V. J. Derlega & J. H. Berg (Eds.), *Self-disclosure: Theory, research, and therapy* (pp. 35–58). New York, NY: Plenum Press.

Miller, S. M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, *52*(2), 345–353. http://doi.org/10.1037/0022-3514.52.2.345

Miller-Matero, L. R., Hyde-Nolan, M. E., Eshelman, A., & Abouljoud, M. (2015). Health literacy in patients referred for transplant: Do patients have the capacity to understand? *Clinical Transplantation*, epub in advance of print. http://doi.org/10.1111/ctr.12519

Mishel, M. H. (1981). The measurement of uncertainty in illness. *Nursing Research*, *30*(5), 258–263.

Mishel, M. H. (1988). Uncertainty in illness. *Image: The Journal of Nursing Scholarship*, *20*, 225–232.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *Journal of Nursing Scholarship*, *22*(4), 256–262. http://doi.org/10.1111/j.1547-5069.1990.tb00225.x

Mishel, M. H. (1999). Uncertainty in chronic illness. *Annual Review of Nursing Research*, *17*(1), 269–294.

Mishel, M. H., & Braden, C. J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research, 37*(2), 98–103.

Mo, P. K. H., & Coulson, N. S. (2013). Online support group use and psychological health for individuals living with HIV/AIDS. *Patient Education and Counseling*, *93*(3), 426–432. http://doi.org/10.1016/j.pec.2013.04.004

Mo, P. K. H., Malik, S. H., & Coulson, N. S. (2009). Gender differences in computer-mediated communication: A systematic literature review of online health-related support groups. *Patient Education and Counseling*, *75*(1), 16–24. http://doi.org/10.1016/j.pec.2008.08.029

Mollicone, D., Pulliam, J., & Lacson Jr, E. (2013). The culture of education in a large dialysis organization: Informing patient-centered decision making on treatment options for renal replacement therapy. *Seminars in Dialysis*, *26*(2), 143–147. http://doi.org/10.1111/sdi.12053

Molzahn, A. E., Bruce, A., & Sheilds, L. (2008). Learning from stories of people with chronic kidney disease. *Nephrology Nursing Journal: Journal of the American Nephrology Nurses' Association*, *35*(1), 13–20.

Morahan-Martin, J. M. (2004). How Internet users find, evaluate, and use online health information: A cross-cultural review. *CyberPsychology & Behavior*, *7*(5), 497–510. http://doi.org/10.1089/cpb.2004.7.497

Muehrer, R. J., & Becker, B. N. (2005). Psychosocial factors in patients with chronic kidney disease: Life after transplantation: New transitions in quality of life and psychological distress. *Seminars in Dialysis*, *18*(2), 124–131. http://doi.org/10.1111/j.1525-139X.2005.18214.x

Muehrer, R. J., Lanuza, D. M., Brown, R. L., & Djamali, A. (2014). Sexual concerns among kidney transplant recipients. *Clinical Transplantation*, *28*(11), 1294–1302. http://doi.org/10.1111/ctr.12454

Nambisan, P. (2011). Information seeking and social support in online health communities: Impact on patients' perceived empathy. *Journal of the American Medical Informatics Association*, *18*(3), 298–304. http://doi.org/10.1136/amiajnl-2010-000058

National Kidney Foundation. (2001). KDOQI clinical practice guidelines for hemodialysis adequacy: Update 2000. *American Journal of Kidney Diseases*, *37*(1 Suppl 1), S7–S64.

Newman, M. W., Lauterbach, D., Munson, S. A., Resnick, P., & Morris, M. E. (2011). It's not that I don't have problems, I'm just not putting them on Facebook: Challenges and opportunities in using online social networks for health. In *Proceedings of the ACM 2011 conference on computer supported cooperative work* (pp. 341–350). New York, NY: Association for Computing Machinery.

Nguyen, M., Bin, Y. S., & Campbell, A. (2012). Comparing online and offline self-disclosure: A systematic review. *Cyberpsychology, Behavior, and Social Networking*, *15*(2), 103–111. http://doi.org/10.1089/cyber.2011.0277

Nicholas, D. B., Picone, G., Vigneux, A., McCormick, K., Mantulak, A., McClure, M., & MacCulloch, R. (2009). Evaluation of an online peer support network for adolescents with chronic kidney disease. *Journal of Technology in Human Services*, *27*(1), 23–33.

Nickerson, R. S. (1998). Confirmation bias: A ubiquitous phenomenon in many guises. *Review of General Psychology*, *2*(2), 175.

Nonnecke, B., Andrews, D., & Preece, J. (2006). Non-public and public online community participation: Needs, attitudes and behavior. *Electronic Commerce Research*, *6*(1), 7–20.

Novick, G. (2008). Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health*, *31*(4), 391–398. http://doi.org/10.1002/nur.20259

Oka, M., & Chaboyer, W. (1999). Dietary behaviors and sources of support in hemodialysis patients. *Clinical Nursing Research*, *8*(4), 302–317. http://doi.org/10.1177/10547739922158322

Olson, K., Camp, C., & Fuller, D. (1984). Curiosity and need for cognition. *Psychological Reports*, *54*(1), 71–74. http://doi.org/10.2466/pr0.1984.54.1.71

Omarzu, J. (2000). A disclosure decision model: Determining how and when individuals will self-disclose. *Personality and Social Psychology Review*, *4*(2), 174–185. http://doi.org/10.1207/S15327957PSPR0402_05

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. *Forum: Qualitative Social Research*, *7*(4). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/175

Organ Procurement and Transplantation Network. (2011). *OPTN/SRTR 2011 Annual data report: Kidney*. Rockville, MD: Department of Health and Human Services, Health Resources and Services Administration, Healthcare Systems Bureau, Division of Transplantation. Retrieved from http://srtr.transplant.hrsa.gov/annual_reports/2011/pdf/01_kidney_12.pdf

Ormandy, P. (2008). Information topics important to chronic kidney disease patients: A systematic review. *Journal of Renal Care*, *34*(1), 19–27.

Orsino, A., Cameron, J. I., Seidl, M., Mendelssohn, D., & Stewart, D. E. (2003). Medical decision-making and information needs in end-stage renal disease patients. *General Hospital Psychiatry*, *25*(5), 324–331.

O'Sullivan, D., & McCarthy, G. (2007). An exploration of the relationship between fatigue and physical functioning in patients with end stage renal disease receiving haemodialysis. *Journal of Clinical Nursing*, *16*(11c), 276–284. http://doi.org/10.1111/j.1365-2702.2007.01965.x

O'Toole, S. M., Fan, S. L., Yaqoob, M. M., & Chowdhury, T. A. (2012). Managing diabetes in dialysis patients. *Postgraduate Medical Journal*, *88*(1037), 160–166. http://doi.org/10.1136/postgradmedj-2011-130354

Park, C. L., Bharadwaj, A. K., & Blank, T. O. (2011). Illness centrality, disclosure, and well-being in younger and middle-aged adult cancer survivors. *British Journal of Health Psychology*, *16*(4), 880–889. http://doi.org/10.1111/j.2044-8287.2011.02024.x

Parrott, R., Duncan, V., & Duggan, A. (2000). Promoting patients' full and honest disclosure during conversations with health caregivers. In S. S. Petronio (Ed.), *Balancing the secrets of private disclosures*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Patel, S. S., Peterson, R. A., & Kimmel, P. L. (2005). Psychosocial factors in patients with chronic kidney disease: The impact of social support on end-stage renal disease. *Seminars in Dialysis*, *18*(1), 98-102. http://doi.org/10.1111/j.1525-139X.2005.18203.x

Paterson, B. L. (2001). The shifting perspectives model of chronic illness. *Journal of Nursing Scholarship*, *33*(1), 21–26. http://doi.org/10.1111/j.1547-5069.2001.00021.x

Pedersen, D. M. (1997). Psychological functions of privacy. *Journal of Environmental Psychology*, *17*(2), 147–156.

Pelletier-Hibbert, M., & Sohi, P. (2001). Sources of uncertainty and coping strategies used by family members of individuals living with end stage renal disease. *Nephrology Nursing Journal*, *28*(4), 411–417.

Pennebaker, J. W. (1997). Writing about emotional experiences as a therapeutic process. *Psychological Science*, *8*(3), 162–166.

Perales-Montilla, C. M., García-León, A., & Reyes-del Paso, G. A. (2012). Psychosocial predictors of the quality of life of chronic renal failure patients undergoing haemodialysis. *Nefrologia*, *32*(5), 622–30.

Perry, E., Swartz, J., Brown, S., Smith, D., Kelly, G., & Swartz, R. (2005). Peer mentoring: A culturally sensitive approach to end-of-life planning for long-term dialysis patients. *American Journal of Kidney Diseases*, *46*(1), 111–119. http://doi.org/10.1053/j.ajkd.2005.03.018

Petronio, S. S. (2002). *Boundaries of privacy: Dialectics of disclosure*. Albany, NY: SUNY Press.

Petrovčič, A., & Petrič, G. (2014). Differences in intrapersonal and interactional empowerment between lurkers and posters in health-related online support communities. *Computers in Human Behavior*, *34*, 39–48. http://doi.org/10.1016/j.chb.2014.01.008

Pettigrew, K. E. (1999). Waiting for chiropody: Contextual results from an ethnographic study of the information behaviour among attendees at community clinics. *Information Processing & Management*, *35*(6), 801–817.

Pfeil, U., & Zaphiris, P. (2007). Patterns of empathy in online communication. In *Proceedings of the SIGCHI conference on human factors in computing systems* (pp. 919–928). New York, NY: Association for Computing Machinery. Retrieved from http://dl.acm.org/citation.cfm?id=1240763

Pickett, C. L., & Brewer, M. B. (2001). Assimilation and differentiation needs as motivational determinants of perceived in-group and out-group homogeneity. *Journal of Experimental Social Psychology*, *37*(4), 341–348. http://doi.org/10.1006/jesp.2000.1469

Piette, J. D., Schillinger, D., Potter, M. B., & Heisler, M. (2003). Dimensions of patient-provider communication and diabetes self-care in an ethnically diverse population. *Journal of General Internal Medicine*, *18*(8), 624–633. http://doi.org/10.1046/j.1525-1497.2003.31968.x

Plantinga, L. C., Fink, N. E., Harrington-Levey, R., Finkelstein, F. O., Hebah, N., Powe, N. R., & Jaar, B. G. (2010). Association of social support with outcomes in incident dialysis patients. *Clinical Journal of the American Society of Nephrology*, *5*(8), 1480–1488. http://doi.org/10.2215/CJN.01240210

Post, T. W., & Rose, B. D. (2012, October 26). Overview of the management of chronic kidney disease in adults. (G. C. Curhan & A. M. Sheridan, Eds.). *UpToDate*, Wolters Kluwer Health.

Preece, J., Nonnecke, B., & Andrews, D. (2004). The top five reasons for lurking: Improving community experiences for everyone. *Computers in Human Behavior*, *20*(2), 201–223. http://doi.org/10.1016/j.chb.2003.10.015

Pulman, A., & Taylor, J. (2012). Munchausen by Internet: Current research and future directions. *Journal of Medical Internet Research*, *14*(4). http://doi.org/10.2196/jmir.2011

Rahman, M., & Smith, M. C. (1998). Chronic renal insufficiency: A diagnostic and therapeutic approach. *Archives of Internal Medicine*, *158*(16), 1743–1752.

Rambod, M., & Rafii, F. (2010). Perceived social support and quality of life in Iranian hemodialysis patients. *Journal of Nursing Scholarship*, *42*(3), 242–249. http://doi.org/10.1111/j.1547-5069.2010.01353.x

Ramos, E., & Klein, C. K. (2012, October 20). Evaluation of the potential renal transplant recipient. (B. Murphy, D. C. Brennan, & A. M. Sheridan, Eds.). *UpToDate*, Wolters Kluwer Health. http://www.uptodate.com/contents/evaluation-of-the-potential-renal-transplant-recipient

Rees, C., & Bath, P. (2001). Information-seeking behaviors of women with breast cancer. *Oncology Nursing Forum*, *28*(5), 899–907.

Rees, M. A., Kopke, J. E., Pelletier, R. P., Segev, D. L., Rutter, M. E., Fabrega, A. J., … Montgomery, R. A. (2009). A nonsimultaneous, extended, altruistic-donor chain. *The New England Journal of Medicine*, *360*(11), 1096–1101. http://doi.org/10.1056/NEJMoa0803645

Reis, H. T., & Collins, N. (2000). Measuring relationship properties and interactions relevant to social support. In S. E. Cohen, L. Underwood, & B. H. Gottlieb (Eds.), *Social support measurement and intervention: A guide for health and social scientists* (pp. 136–192). Oxford, UK: Oxford University Press.

Ren, Y., Harper, F. M., Drenner, S., Terveen, L. G., Kiesler, S. B., Riedl, J., & Kraut, R. E. (2012). Building member attachment in online communities: Applying theories of group identity and interpersonal bonds. *Management Information Systems Quarterly*, *36*(3), 841–864.

Ren, Y., Kraut, R., & Kiesler, S. (2007). Applying common identity and bond theory to design of online communities. *Organization Studies*, *28*(3), 377–408. http://doi.org/10.1177/0170840607076007

Rieh, S. Y. (2002). Judgment of information quality and cognitive authority in the Web. *Journal of the American Society for Information Science and Technology*, *53*(2), 145–161. http://doi.org/10.1002/asi.10017

Rieh, S. Y., & Hilligoss, B. (2008). College students' credibility judgments in the information-seeking process. In M. J. Metzger & A. J. Flanigan (Eds.), *Digital Media, Youth, and Credibility* (pp. 49–72). Cambridge, MA: The MIT Press.

Rogers, E. M. (2003). *Diffusion of innovations, 5th edition*. New York, NY: Simon and Schuster.

Rolland, J. S. (1994). In sickness and in health: The impact of illness on couples' relationships. *Journal of Marital and Family Therapy, 20*(4), 327–347. http://doi.org/10.1111/j.1752-0606.1994.tb00125.x

Rosenfeld, L. B. (2000). Overview of privacy, secrecy, and disclosure. In S. S. Petronio (Ed.), *Balancing the secrets of private disclosures*. Hillsdale, NJ: Lawrence Erlbaum Associates.

Rosenkranz, J., Reichwald-Klugger, E., Oh, J., Turzer, M., Mehls, O., & Schaefer, F. (2005). Psychosocial rehabilitation and satisfaction with life in adults with childhood-onset of end-stage renal disease. *Pediatric Nephrology*, *20*(9), 1288–1294. http://doi.org/10.1007/s00467-005-1952-3

Rosland, A.-M., Heisler, M., & Piette, J. D. (2011). The impact of family behaviors and communication patterns on chronic illness outcomes: A systematic review. *Journal of Behavioral Medicine*, *35*(2), 221–239. http://doi.org/10.1007/s10865-011-9354-4

Rounds, K. A., & Israel, B. A. (1985). Social networks and social support: living with chronic renal disease. *Patient Education and Counseling*, *7*(3), 227–247.

Roy, C. A., & Atcherson, E. (1983). Peer support for renal patients: The patient visitor program. *Health & Social Work, 8*(1), 52-56. http://doi.org/10.1093/hsw/8.1.52

Rubenstein, E. L. (2012). "Things my doctor never told me": Bridging information gaps in an online community. *Proceedings of the American Society for Information Science and Technology*, *49*(1). http://doi.org/10.1002/meet.14504901126

Rubin, Z. (1975). Disclosing oneself to a stranger: Reciprocity and its limits. *Journal of Experimental Social Psychology*, *11*(3), 233–260. http://doi.org/10.1016/S0022-1031(75)80025-4

Russell, C. L., & Brown, K. (2002). The effects of information and support on individuals awaiting cadaveric kidney transplantation. *Progress in Transplantation*, *12*(3), 201–207.

Sampson, R., O'Rourke, J., Hendry, R., Heaney, D., Holden, S., Thain, A., & MacVicar, R. (2013). Sharing control of appointment length with patients in general practice: A qualitative study. *British Journal of General Practice*, *63*(608), e185–e191.

Saracevic, T. (2007). Relevance: A review of the literature and a framework for thinking on the notion in information science. Part III: Behavior and effects of relevance. *Journal of the American Society for Information Science and Technology*, *58*(13), 2126–2144

Sarason, B. R., Sarason, I. G., & Pierce, G. R. (1990). Traditional views of social support and their impact on assessment. In B. R. Sarason, I. G. Sarason, & G. R. Pierce, *Social support: An interactional view.* (pp. 9–25). New York, NY: John Wiley & Sons.

Savolainen, R. (1995). Everyday life information seeking: Approaching information seeking in the context of "way of life." *Library & Information Science Research*, *17*(3), 259–294. http://doi.org/10.1016/0740-8188(95)90048-9

Savolainen, R. (2006). Information use as gap-bridging: The viewpoint of sense-making methodology. *Journal of the American Society for Information Science and Technology*, *57*(8), 1116–1125. http://doi.org/10.1002/asi.20400

Savolainen, R. (2008). *Everyday information practices: A social phenomenological perspective*. Lanham, MD: Scarecrow Press.

Savolainen, R. (2011). Judging the quality and credibility of information in Internet discussion forums. *Journal of the American Society for Information Science and Technology*, *62*(7), 1243–1256. http://doi.org/10.1002/asi.21546

Savolainen, R., & Kari, J. (2004). Placing the Internet in information source horizons: A study of information seeking by Internet users in the context of self-development. *Library & Information Science Research*, *26*(4), 415–433. http://doi.org/10.1016/j.lisr.2004.04.004

Sayegh, M. H., & Chandraker, A. (2011). Transplantation immunobiology. In M. W. Taal, G. M. Chertow, P. A. Marsden, K. Skorecki, A. S. L. Yu, & B. M. Brenner, *Brenner and Rector's the kidney: Expert consult* (9th ed., pp. 2468–2490). Philadelphia, PA: Saunders.

Schaefer, C., Coyne, J. C., & Lazarus, R. S. (1981). The health-related functions of social support. *Journal of Behavioral Medicine*, *4*(4), 381–406.

Schatell, D., Wise, M., Klicko, K., & Becker, B. N. (2006). In-center hemodialysis patients' use of the internet in the united states: A national survey. *American Journal of Kidney Diseases*, *48*(2), 285–291. http://doi.org/10.1053/j.ajkd.2006.04.072

Schell, J. O., Patel, U. D., Steinhauser, K. E., Ammarell, N., & Tulsky, J. A. (2012). Discussions of the kidney disease trajectory by elderly patients and nephrologists: A qualitative study. *American Journal of Kidney Diseases*, *59*(4), 495–503. http://doi.org/10.1053/j.ajkd.2011.11.023

Schmidt, R. J., & Holley, J. L. (1998). Sexual function in patients with end-stage renal disease. *Seminars in Dialysis*, *11*(3), 181–184. http://doi.org/10.1111/j.1525-139X.1998.tb00330.x

Scholz, U., Klaghofer, R., Dux, R., Roellin, M., Boehler, A., Muellhaupt, B., … Goetzmann, L. (2012). Predicting intentions and adherence behavior in the context of organ transplantation: Gender differences of provided social support. *Journal of Psychosomatic Research*, *72*(3), 214–219. http://doi.org/10.1016/j.jpsychores.2011.10.008

Schreiber, R. S., & Stern, P. N. (2001). *Using grounded theory in nursing*. New York, NY: Springer Publishing Company.

Schreiner, G. E. (2000). How end-stage renal disease (ESRD)-Medicare developed. *American Journal of Kidney Diseases*, *35*(4, Supplement), S37–S44. http://doi.org/10.1016/S0272-6386(00)70229-0

Scott, A. M., Martin, S. C., Stone, A. M., & Brashers, D. E. (2011). Managing multiple goals in supportive interactions: Using a normative theoretical approach to explain social support as uncertainty management for organ transplant patients. *Health Communication*, *26*(5), 393–403. http://doi.org/10.1080/10410236.2011.552479

Seto, E., Cafazzo, J. A., Rizo, C., Bonert, M., Fong, E., & Chan, C. T. (2007). Internet use by end-stage renal disease patients. *Hemodialysis International*, *11*(3), 328–332. http://doi.org/10.1111/j.1542-4758.2007.00188.x

Setoyama, Y., Yamazaki, Y., & Namayama, K. (2011). Benefits of peer support in online Japanese breast cancer communities: Differences between lurkers and posters. *Journal of Medical Internet Research*, *13*(4), e122. http://doi.org/10.2196/jmir.1696

Shadish, W. R., Cook, T. D., & Campbell, D. T. (2001). *Experimental and quasi-experimental designs for generalized causal inference* (2nd ed.). Belmont, CA: Wadsworth Publishing.

Shafi, T., & Coresh, J. (2010). Chronic kidney disease: Definition, epidemiology, cost, and outcomes. In J. Himmelfarb & M. H. Sayegh, *Chronic kidney disease, dialysis, and transplantation: A companion to Brenner and Rector's the kidney* (3rd ed.). Philadelphia, PA: Saunders.

Shapiro, R., & Brennan, D. C. (2012, October 20). Benefits and complications of laparoscopic donor nephrectomy. (B. Murphy & A. M. Sheridan, Eds.). UpToDate, Wolters Kluwer Health. Retrieved from http://www.uptodate.com/contents/benefits-and-complications-of-laparoscopic-donor-nephrectomy

Siegal, B. R., Calsyn, R. J., & Cuddihee, R. M. (1987). The relationship of social support to psychological adjustment in end-stage renal disease patients. *Journal of Chronic Diseases*, *40*(4), 337–344. http://doi.org/10.1016/0021-9681(87)90049-X

Simforoosh, N., Gooran, S., Tabibi, A., Bassiri, A., & Ghraati, M. R. (2011). Cadaver transplantation in recent era: Is cadaveric graft survival similar to living kidney transplantation? *International Journal of Organ Transplantation Medicine*, *2*, 167–70.

Skeels, M. M., Unruh, K. T., Powell, C., & Pratt, W. (2010). Catalyzing social support for breast cancer patients. In *Proceedings of the 28th international conference human factors in computing systems* (pp. 173–182). New York, NY: Association for Computing Machinery. http://doi.org/http://doi.acm.org/10.1145/1753326.1753353

Skinta, M. D., Brandrett, B. D., Schenk, W. C., Wells, G., & Dilley, J. W. (2014). Shame, self-acceptance and disclosure in the lives of gay men living with HIV: An interpretative phenomenological analysis approach. *Psychology & Health*, *29*(5), 583–597.

SMF2.0:Search. (2014, February 27). Retrieved February 16, 2015, from http://wiki.simplemachines.org/smf/SMF2.0:Search_(admin)

Smith, E. R., Murphy, J., & Coats, S. (1999). Attachment to groups: Theory and measurement. *Journal of Personality and Social Psychology*, *77*(1), 94–110.

Smyth, J. M., Pennebaker, J. W., & Arigo, D. (2012). What are the health effects of disclosure? In A. Baum, T. A. Revenson, & J. Singer (Eds.), *Handbook of Health Psychology: Second Edition* (pp. 175–191). New York, NY: Psychology Press.

Sonnenwald, D. H. (1999). Evolving perspectives of human information behavior: Contexts, situations, social networks and information horizons. *Exploring the Contexts of Information Behavior: Proceedings of the Second International Conference in*

Information Needs. Retrieved from http://www.informationr.net/isic/ISIC1998/98_Sonnenwald.pdf

Stewart, D. E., Cheung, A. M., Duff, S., Wong, F., McQuestion, M., Cheng, T., … Bunston, T. (2001). Long-term breast cancer survivors: confidentiality, disclosure, effects on work and insurance. *Psycho-Oncology*, *10*(3), 259–263. http://doi.org/10.1002/pon.499

Stiles, W. B. (1987). “I have to talk to somebody”: A fever model of disclosure. In In V. J. Derlega & J. H. Berg (Eds.), *Self-disclosure: Theory, research, and therapy* (pp. 257–282). New York, NY: Plenum Press.

Stoeckle, M. L. (1993). Waiting for a second chance at life: An examination of health-related hardiness, uncertainty, power, and the environment in adults on the kidney transplant waiting list. *Unpublished Doctoral Dissertation, University of Cincinnati: Cincinnati*.

Sturges, J. E., & Hanrahan, K. J. (2004). Comparing telephone and face-to-face qualitative interviewing: A research note. *Qualitative Research*, *4*(1), 107–118. http://doi.org/10.1177/1468794104041110

Stutzman, F. D., Capra, R., & Thompson, J. (2011). Factors mediating disclosure in social network sites. *Computers in Human Behavior*, *27*, 590–598. http://dx.doi.org/10.1016/j.chb.2010.10.017

Stutzman, F. D., Gross, R., & Acquisti, A. (2013). Silent listeners: The evolution of privacy and disclosure on Facebook. *Journal of Privacy and Confidentiality*, *4*(2). Retrieved from http://repository.cmu.edu/jpc/vol4/iss2/2

Suddaby, R. (2006). From the editors: What grounded theory is not. *The Academy of Management Journal ARCHIVE*, *49*(4), 633–642.

Suitor, J. J., Keeton, S., & Pillemer, K. (1995). When experience counts: The effects of experiential and structural similarity on patterns of support and interpersonal stress. *Social Forces*, *73*(4), 1573–1588. http://doi.org/10.1093/sf/73.4.1573

Sullivan, C., Leon, J.B., Sayre, S.S., Marbury, M., Ivers, M., Pencak, J.A., … Sehgal, A.R. (2012). Impact of navigators on completion of steps in the kidney transplant process: A randomized, controlled trial. *Clinical Journal of the American Society of Nephrology*, *7*(10), 1639–1645. http://doi.org/10.2215/CJN.11731111

Swanson, E. A., Jensen, D. P., Specht, J., Johnson, M. L., Maas, M., & Saylor, D. (1997). Caregiving: Concept analysis and outcomes. *Research and Theory for Nursing Practice*, *11*(1), 65–76.

Taal, M. W., Chertow, G. M., Marsden, P. A., Skorecki, K., Yu, A. S. L., & Brenner, B. M. (2011). *Brenner and Rector’s the kidney: Expert consult* (9th ed.). Philadelphia, PA: Saunders.

Tardy, C. H. (1985). Social support measurement. *American Journal of Community Psychology*, *13*(2), 187–202.

Taylor, D. A. (1979). Motivational bases. In Chelune, G. J. (Ed.), *Self-disclosure: Origins, patterns, and implications of openness in interpersonal relationships* (pp. 110–151). San Francisco, CA: Jossey-Bass.

Taylor, R. S. (1962). The process of asking questions. *American Documentation*, *13*(4), 391–396.

The, A., Hak, T., Koeter, G., & van der Wal, G. (2000). Collusion in doctor-patient communication about imminent death: An ethnographic study. *BMJ*, *321*(7273), 1376–1381. http://doi.org/10.1136/bmj.321.7273.1376

Thibaut, J. W., & Kelley, H. H. (1959). *The social psychology of groups.* Oxford, England: John Wiley.

Thomas-Hawkins, C., & Zazworsky, D. (2005). Self-management of chronic kidney disease: Patients shoulder the responsibility for day-to-day management of chronic illness. How can nurses support their autonomy? *The American Journal of Nursing*, *105*(10), 40–48.

Thon, F. M., & Jucks, R. (2014). Regulating privacy in interpersonal online communication: The role of self-disclosure. *Studies in Communication Sciences*, *14*(1), 3–11. http://doi.org/10.1016/j.scoms.2014.03.012

Thong, M. S. Y., Kaptein, A. A., Krediet, R. T., Boeschoten, E. W., & Dekker, F. W. (2007). Social support predicts survival in dialysis patients. *Nephrology Dialysis Transplantation*, *22*(3), 845 –850. http://doi.org/10.1093/ndt/gfl700

Tidwell, L. C., & Walther, J. B. (2002). Computer-mediated communication effects on disclosure, impressions, and interpersonal evaluations: Getting to know one another a bit at a time. *Human Communication Research*, *28*(3), 317–348. http://doi.org/10.1111/j.1468-2958.2002.tb00811.x

Tong, A., Chapman, J. R., Wong, G., & Craig, J. C. (2013). Living kidney donor assessment: Challenges, uncertainties and controversies among transplant nephrologists and surgeons. *American Journal of Transplantation*, *13*(11), 2912–2923.

Tong, A., Lowe, A., Sainsbury, P., & Craig, J. C. (2008). Experiences of parents who have children with chronic kidney disease: A systematic review of qualitative studies. *Pediatrics*, *121*(2), 349 –360. http://doi.org/10.1542/peds.2006-3470

Tong, A., Sainsbury, P., Chadban, S., Walker, R. G., Harris, D. C., Carter, S. M., … Craig, J. C. (2009). Patients' experiences and perspectives of living with CKD. *American Journal of Kidney Diseases*, *53*(4), 689–700. http://doi.org/10.1053/j.ajkd.2008.10.050

Trisolini, M., Roussel, A., Zerhusen, E., Schatell, D., Harris, S., Bandel, K., … Klicko, K. (2004). Activating chronic kidney disease patients and family members through the Internet to promote integration of care. *International Journal of Integrated Care*, *4*, 1–13.

United Network for Organ Sharing, Organ Procurement and Transplantation Network. (2015). *Organ procurement and transplantation network policies*. Richmond, VA. Retrieved from http://optn.transplant.hrsa.gov/ContentDocuments/OPTN_Policies.pdf

United States Renal Data System. (2014). *2014 Annual data report: Epidemiology of kidney disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved from http://www.usrds.org/atlas.aspx

Untas, A., Thumma, J., Rascle, N., Rayner, H., Mapes, D., Lopes, A. A., … Combe, C. (2011). The associations of social support and other psychosocial factors with mortality and quality of life in the dialysis outcomes and practice patterns study. *Clinical Journal of the American Society of Nephrology*, *6*(1), 142–152. http://doi.org/10.2215/CJN.02340310

US Renal Data System. (2014). *2014 Annual data report: Epidemiology of kidney disease in the United States.* Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved from http://www.usrds.org/atlas.aspx

Vangelisti, A., Caughlin, J., & Timmerman, L. (2001). Criteria for revealing family secrets. *Communication Monographs*, *68*(1), 1–27. http://doi.org/10.1080/03637750128052

van Uden-Kraan, C., Drossaert, C., Taal, E., Seydel, E., & van De Laar, M. (2009). Participation in online patient support groups endorses patients’ empowerment. *Patient Education and Counseling*, *74*(1), 61–69.

van Uden-Kraan, C. F., Drossaert, C. H., Taal, E., Seydel, E. R., & van de Laar, M. A. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research*, *10*(2), e18. http://doi.org/10.2196/jmir.992

Varney, S. (2012, May 24). What’s up, doc? When your doctor rushes like the road runner. *All Things Considered*. California: KQED. Retrieved from http://www.npr.org/blogs/health/2012/05/24/153583423/whats-up-doc-when-your-doctor-rushes-like-the-road-runner

Veinot, T. C. (2010). “We have a lot of information to share with each other.” Understanding the value of peer-based health information exchange. *Information Research*, *15*(4). Retrieved from http://www.informationr.net/ir/15-4/paper452.html

Veinot, T.C. Meadowbrooke, C. C., Newman, M. W., Zheng, K., & Perry, E. E. (2010). Routines that ease the pain: The information world of a dialysis clinic. In *Proceedings of the American Society for Information Science and Technology*, *47*(1), 1–4.

Viégas, F. B. (2005). Bloggers' expectations of privacy and accountability: An initial survey. *Journal of Computer-Mediated Communication*, *10*(3). http://doi.org/10.1111/j.1083-6101.2005.tb00260.x

Viseu, A., Clement, A., & Aspinall, J. (2004). Situating privacy online: complex perceptions and everyday practices. *Information, Communication & Society*, *7*(1), 92–114.

Volkman, J. E., Luger, T. M., Harvey, K. L., Hogan, T. P., Shimada, S. L., Amante, D., … Houston, T. K. (2014). The National Cancer Institute's health information national trends survey [HINTS]: A national cross-sectional analysis of talking to your doctor and other healthcare providers for health information. *BMC Family Practice*, *15*(1), 111. http://doi.org/10.1186/1471-2296-15-111

Walther, J. B., Anderson, J. F., & Park, D. W. (1994). Interpersonal effects in computer-mediated interaction: A meta-analysis of social and antisocial communication. *Communication Research*, *21*(4), 460–487. http://doi.org/10.1177/009365094021004002

Warren, E., Footman, K., Tinelli, M., McKee, M., & Knai, C. (2014). Do cancer-specific websites meet patient's information needs? *Patient Education and Counseling*, *95*(1), 126–136. http://doi.org/10.1016/j.pec.2013.12.013

Watson, A. R. (2004). Problems and pitfalls of transition from paediatric to adult renal care. *Pediatric Nephrology*, *20*(2), 113–117. http://doi.org/10.1007/s00467-004-1763-y

Weems, J., & Patterson, E. T. (1989). Coping with uncertainty and ambivalence while awaiting a cadaveric renal transplant. *American Nephrology Nurses' Association Journal*, *16*(1), 27–31.

Weitzman, E. R., Cole, E., Kaci, L., & Mandl, K. D. (2011). Social but safe? Quality and safety of diabetes-related online social networks. *Journal of the American Medical Informatics Association: JAMIA*. http://doi.org/10.1136/jamia.2010.009712

Wellman, B., & Wortley, S. (1990). Different strokes from different folks: Community ties and social support. *American Journal of Sociology*, *96*(3), 558–588.

Wen, K.-Y., McTavish, F., Kreps, G., Wise, M., & Gustafson, D. (2011). From diagnosis to death: A case study of coping with breast cancer as seen through online discussion group messages. *Journal of Computer-Mediated Communication*, *16*(2), 331–361. http://doi.org/10.1111/j.1083-6101.2011.01542.x

Wethington, E., & Kessler, R. C. (1986). Perceived support, received support, and adjustment to stressful life events. *Journal of Health and Social Behavior*, *27*(1), 78–89. http://doi.org/10.2307/2136504

White, M., & Dorman, S. M. (2001). Receiving social support online: Implications for health education. *Health Education Research*, *16*(6), 693–707. http://doi.org/10.1093/her/16.6.693

Wicks, P., Massagli, M., Frost, J., Brownstein, C., Okun, S., Vaughan, T., … Heywood, J. (2010). Sharing health data for better outcomes on PatientsLikeMe. *Journal of Medical Internet Research*, *12*(2). http://doi.org/10.2196/jmir.1549

Wills, T. A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin*, *90*(2), 245.

Wilson, H. S., & Hutchinson, S. A. (1996). Methodologic mistakes in grounded theory. *Nursing Research*, *45*(2), 122–124. http://doi.org/10.1097/00006199-199603000-00012

Wilson, P. (1983). *Second-hand knowledge: An inquiry into cognitive authority*. Westport, CT: Greenwood Press.

Wilson, T. D. (1981). On user studies and information needs. *Journal of Documentation*, *37*(1), 3–15.

Wilson, T. D. (1997). Information behaviour: An interdisciplinary perspective. *Information Processing & Management*, *33*(4), 551–572.

Wilson, T. D. (1999). Models in information behaviour research. *Journal of Documentation*, *55*(3), 249–270. http://doi.org/10.1108/EUM0000000007145

Winkelmayer, W. C. (2010). Kidney disease and medications. In J. Himmelfarb & M. H. Sayegh, *Chronic kidney disease, dialysis, and transplantation: A companion to Brenner and Rector's the kidney* (3rd ed., pp. 208–217). Philadelphia, PA: Saunders.

Winterbottom, A., Bekker, H. L., Conner, M., & Mooney, A. (2012). Choosing dialysis modality: decision making in a chronic illness context. *Health Expectations*, *17*(5), 710–723. http://doi.org/10.1111/j.1369-7625.2012.00798.x

Wojcikowski, K., Wohlmuth, H., Johnson, D. W., Rolfe, M., & Gobe, G. (2009). An in vitro investigation of herbs traditionally used for kidney and urinary system disorders: Potential therapeutic and toxic effects. *Nephrology*, *14*(1), 70–79. http://doi.org/10.1111/j.1440-1797.2008.01017.x

Woudstra, L., & van den Hooff, B. (2008). Inside the source selection process: Selection criteria for human information sources. *Information Processing & Management*, *44*(3), 1267–1278. http://doi.org/10.1016/j.ipm.2007.07.004

Yeun, J. Y., Ornt, D. B., & Depner, T. A. (2011). Hemodialysis. In M. W. Taal, G. M. Chertow, P. A. Marsden, K. Skorecki, A. S. L. Yu, & B. M. Brenner, *Brenner and Rector's the kidney: Expert consult* (9th ed.). Philadelphia, PA: Saunders.

Zheng, K., Newman, M. W., Veinot, T. C., Hanratty, M., Kim, H., Meadowbrooke, C., & Perry, E. E. (2010). Using online peer-mentoring to empower young adults with end-stage renal disease: A feasibility study. *AMIA Annual Symposium Proceedings*, *2010*, 942–946.

Zickuhr, K., & Smith, A. (2013). *Home broadband 2013*. Washington, D.C.: Pew Internet and American Life Project. Retrieved from http://linkidaho.planulus.com/sites/default/files/docs/PIP_Broadband%202013_082613.pdf

Ziegelmann, J. P., Griva, K., Hankins, M., Harrison, M., Davenport, A., Thompson, D., & Newman, S. P. (2002). The Transplant Effects Questionnaire (TxEQ): The development of a questionnaire for assessing the multidimensional outcome of organ transplantation — example of end stage renal disease (ESRD). *British Journal of Health Psychology*, *7*(4), 393–408. http://doi.org/10.1348/135910702320645381